HIV Infection: Solitary Work, Silent Suffering
Beliefs about Responsibility for Health and the
Ability to Impact Disease Progression

Cynthia A. Frank

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Cynthia Frank, PhD

University of Connecticut, 2014

In contemporary Western society, health has become a personal and moral responsibility. People are blamed for their unhealthy or risky behavior and for acquiring certain diseases according to socially and culturally constructed norms. HIV is an infectious disease that is imbued with moral overtones and stigma, often multidimensional, creating an illness in which responsibility (for acquisition, transmission, and viral suppression) is an overarching theme. Thus, it represents a unique vehicle for exploring belief systems related to responsibility for health.

For those with access to medical care and treatment, opportunities exist to slow its progression and improve prognosis. This requires strict adherence to medication regimens, avoiding risky behavior that could lead to reinfection, and engaging in health-enhancing behaviors. Yet these behaviors and choices are mediated by beliefs about the virus and disease causation, the illness experience, treatment, and the associated stigma experienced by many people with HIV infection. For most, this is solitary work; they do not have, or choose not to utilize, their social networks. The stigma, social isolation, often co-morbid mental illness, and fear of disclosure surrounding HIV cause significant suffering that affects and constrains everyday lives, opportunities, and social
relationships. Biomedicine has focused on curing the physical disease, but the social
disease and suffering persist.

To address these issues, I utilized a mixed-methods approach to research the
meaning-centered understandings and the contemporary lived experience of HIV
infection among U.S. Veterans that encompasses their belief systems about responsibility
for both disease management and health optimization, and their agency with respect to
managing HIV now that treatment is available. I explored how the relabeling and
reconstruction of HIV infection from “acute” disease to “chronic” affects how people
understand and experience their illness and their responsibility for health and disease
management.

I suggest that these insights into the lived experience of HIV infection can inform
biomedicine and society about the need to take a new direction in treating people with
HIV infection from one that treats just the physical body to one that reduces the multiple
physical, psychological, and social suffering and restores dignity to the person who is ill.
HIV Infection: Solitary Work, Silent Suffering
Beliefs about Responsibility for Health
and the Ability to Impact Disease Progression

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B.S.N., State University of New York, Albany, 1976
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Submitted in Partial Fulfillment of the
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at the
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APPROVAL PAGE

Doctor of Philosophy Dissertation

Solitary Work, Silent Suffering
Beliefs about Responsibility for Health
and the Ability to Impact Disease Progression

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2014
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Writing a dissertation has been solitary work but the process of becoming an anthropologist has been in great part due to the mentorship, guidance, and support of many people who have been by my side, at times pulling me forward, or pushing me ahead.

I am so grateful to the men at the Infectious Disease Clinic at the VA Connecticut Healthcare System in West Haven who so graciously shared their time, their thoughts and feelings, and their stories. I hope that my attempt to give them a voice has done them justice so that others can bear witness to their suffering. Change will come.

I am indebted to my committee, Pamela Erickson Dr.PH, PhD, Merrill Singer, PhD, and Barbara Grace Sullivan, PhD. for their mentorship and guidance and the knowledge that they have shared. They understand that life intervenes, shifting and disrupting the path, and they granted me the flexibility and support that I needed to accomplish this goal. Grace has been a role model for melding my life’s work in healthcare with my dream of being an anthropologist. Merrill has pushed me forward, encouraging me to question and think. He is a ceaseless inspiration. It is to Pam that I am most grateful. She has been the quintessential mentor. She has provided guidance and support but let me find my own way as an anthropologist, researcher, educator, and writer. Her integrity, empathy, and deep understanding about people and life are an enduring inspiration. I hope to do good work and make them proud.

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There are people in my personal life who have given me the love and support that is so necessary when the road is long and hard. With them, my suffering was not silent. Ruthanne Marcus, PhD
is both a colleague and a best friend. We shared a dream of being medical anthropologists and I honestly could not have achieved this without her. She is one of the people who was beside me, pushing and pulling when necessary. I am eternally grateful to her, and for her. I am proud of both of us for persevering in this endeavor while working full time and caring for our families.

I am grateful for Jody Peterson Haddock, a best friend since our early days as nurses, for her enduring and unconditional friendship and support. Although she lives far away, she is with me in spirit and is an integral part of this achievement.

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Last but not least, I am indebted to my daughter, Alexa Frank, who has sacrificed, supported and inspired me through this educational journey and in life as well. I hope that I have shown her that hard work and perseverance are the keys to accomplishing her dreams and aspirations. She inspires me every day to be a better person and a better woman.
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 Relevant Definitions

**HIV infection:** For the purposes of this research, I will use the term “**HIV infection**” rather than AIDS (Acquired Immunodeficiency Syndrome) or HIV/AIDS. HIV infection represents the primary disease whereas AIDS is a progression of the HIV infection that is represented by specific opportunistic infections or cancers and/or a severely compromised immune system. Not everyone who acquires HIV infection develops AIDS and this is particularly true since the advent of effective treatment.

**HIV viral load:** The term will be used throughout this thesis and represents the amount of HIV (i.e., copies of virus per milliliter) that can be detected in the blood or other bodily fluids (e.g., cerebrospinal fluid; semen) through a laboratory test. The primary test for monitoring HIV disease progression is a HIV Viral Load (also known as HIV RNA PCR) measuring the amount of HIV in the blood. Viral load assays have become increasingly sensitive. When they were first developed, the lowest limit the test could measure was 400 copies per milliliter (ml). The most recent viral load assay can measure as little as 20 copies per ml.

**HIV viral suppression:** A viral load result that is less than 20 copies per ml or “non-detectable” is desirable because it represents **HIV viral suppression**. This does not mean that the person does not have HIV in their blood but that the amount of the virus is so low that the most sensitive test cannot measure it.

**Antiretroviral medications:** This is the term for drugs that are used to treat HIV infection. They are typically abbreviated as ARVs. People with HIV infection are
prescribed more than one of these medications. HIV treatment will be discussed in more
detail in the background section of this dissertation.

**Disease and Illness:** I will also use the terms “disease” and “illness” which represent
different explanations of human experience. For the purposes of this thesis, disease is the
biomedical interpretation and labeling of physiological malfunctions and biological
disruptions while illness is the deeply personal and subjective experience and
understanding of ill health and the related distress and suffering. These concepts will be
discussed in more detail in the background chapter of this thesis (Kleinman, 1998;
Erickson, 2008). Discussion of HIV infection, HIV viral load and suppression, and
treatment will pertain to disease. How people infected with HIV understand, give
meaning to, and experience a “disease” will relate to illness.
### Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>AIDS:</td>
<td>Acquired Immunodeficiency Syndrome</td>
</tr>
<tr>
<td>ART:</td>
<td>Antiretroviral Therapy</td>
</tr>
<tr>
<td>ARV:</td>
<td>Antiretroviral medications</td>
</tr>
<tr>
<td>HIV:</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>HLOC:</td>
<td>Health Locus of Control</td>
</tr>
<tr>
<td>ID:</td>
<td>Infectious Diseases</td>
</tr>
<tr>
<td>LOC:</td>
<td>Locus of Control</td>
</tr>
<tr>
<td>MHLC:</td>
<td>Multidimensional Health Locus of Control</td>
</tr>
<tr>
<td>PTSD:</td>
<td>Post-traumatic stress disorder</td>
</tr>
<tr>
<td>VA:</td>
<td>Veterans Administration</td>
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<tr>
<td>VHA:</td>
<td>Veterans Health Administration</td>
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<tr>
<td>VACHS:</td>
<td>Veterans Administration Connecticut Healthcare System</td>
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Chapter 1  Introduction

Overview of Research

Much has been studied and written about Human Immunodeficiency Virus (HIV) infection since it was first detected three decades ago. It is a disease that has been responsible for significant morbidity and mortality globally. From the beginning the epidemic has affected the lives of much of humankind in some way; those who were infected with the virus, those who cared for the ill, and those who were fearful of transmission.

HIV is an infectious disease that has been imbued with moral overtones and stigma, often multidimensional, creating an illness where responsibility is an overarching theme. The original stigma related to route of infection. Sexual intercourse among gay men and injection drug use (IDU) emerged early as the major routes of infection in the early years of the epidemic, and people were blamed for their behavioral roles in acquiring the infection (e.g., homosexuality, IDU). As the epidemic wore on, however, it became clear that there were also "blameless" individuals who, in the view of other societal members, acquired the infection through no "fault" of their own -- through maternal-child transmission, infected blood transfusions, and heterosexual intercourse. The latter was highly stigmatized for sex workers and those with multiple partners, but less so for the unsuspecting wives or partners of infected persons. This early separation of the "guilty" who were held responsible for their disease and the "innocent victims," who were not was a widespread and damaging social construction of the epidemic. Worse,
during this phase of epidemic there was no cure and no treatment for HIV/AIDS, which contributed to the fear of the disease and the people who had acquired it. Thus, since the inception of the epidemic, HIV has invoked feelings of hopelessness and powerlessness among those afflicted and among medical professionals.

Since the 1980s, great strides have been made in developing medications that can suppress the virus. The availability of effective treatment has considerably lengthened the lives of people infected with HIV, and this has led to its current status as a chronic condition rather than one that is acute and imminently fatal. The treatment regimen, however, requires strict medication adherence and ongoing health care and disease progression monitoring which places the onus of responsibility for maintaining viral suppression on the person who is ill, creating a second layer of stigma for those who are non-adherent. Complicating this picture is the fact that while treatment is effective for many of those who are adherent, viral mutations can develop independently despite rigorous adherence creating resistance to the medications, and non-adherence can also lead to failure of viral suppression and to disease progression. Thus, treatment regimens demand a high level of adherence and "self-policing", failure at which can lead to disease progression and further stigmatization of persons living with HIV. In sum, HIV is still an incurable disease that is not completely controllable even with strict medication adherence and health-enhancing behaviors and stigmatization now surrounds both acquisition of the virus and failure to adhere to treatment regimens.

This doubly stigmatized illness can take a great toll on the health and well-being of those infected. HIV infection is a unique vehicle for studying patient beliefs about the ability to impact the course of the disease and personal responsibility for its management
and health optimization. Strict adherence to HIV medication regimens is directly related to viral suppression and improved health outcomes but is notoriously difficult for patients to maintain. In order to optimize care and adherence, it is important to understand how people infected with HIV conceptualize their illness, their beliefs about personal responsibility for health and whether they believe they can impact the course of their disease. My research addressed these meaning-centered understandings and provides insight into the illness experience and the connections between conceptualization of illness, adherence to antiretroviral medications, health care visits, and health-enhancing lifestyle behaviors, and beliefs about disease management and the construct of responsibility.

In this dissertation, I explore how the relabeling and reconstruction of HIV infection from an “acute” disease to one that is “chronic” affects how U.S. veterans infected with HIV come to understand and experience their illness and their role in disease management. I discuss how beliefs about responsibility for health and the ability to impact disease progression are based on how people conceptualize and experience their illness. It is my hope that illuminating how people infected with HIV think about their illness will contribute to gaining further insight into the contemporary lived experience of HIV infection that encompasses beliefs about responsibility, both for the disease and for health optimization, and the agency of the patient to impact the disease course now that treatment is available. A nuanced understanding of these issues will enhance theory building and practical applications regarding disease management. It will also inform health care practitioners of the illness experience of people with HIV.
infection and the importance of holistic healing and treating the social body along with
the physical body.

**Relevant Professional Background**

I have been a nurse for 38 years and have had the opportunity, and the privilege,
to participate in the healthcare of countless people. For the past 22 years, I have worked
in infectious diseases clinical research primarily working with people with HIV infection.
My previous work was in a large emergency department in Los Angeles where I provided
emergency care to people in the early days of the epidemic. My cumulative research
experience has included both retrospective and prospective studies through which I have
followed patients from enrollment throughout the study period. Many of these studies
lasted for multiple years because of the need for long-term follow-up, which is part of the
FDA approval process for new drugs. Clinical research requires a relationship of trust
between the person participating in the research and those who are conducting the
research. This is particularly true for people with HIV infection who have often been
desperate for access to medications to treat their disease as the virus often became
resistant to the treatment. While they were willing to participate in research to get newly
developed medications that could control the virus, they were still concerned with being
involved in ethical research that was as concerned about their well-being as the collective
good. As a result of my work experience I have seen how the trajectory of the disease has
changed since the early days of the epidemic and have had the opportunity to listen to the
stories of people with this illness.
When I began working in HIV clinical research in 1992, there was only one approved drug to treat the disease; AZT, which was toxic and not efficacious as a single therapy. There was desperation among those who were afflicted, their health care providers, and biomedicine to find a way to stem the morbidity and mortality caused by this virus. The fear and suffering was palpable. Twenty years later, there are over thirty antiretroviral medications that are available to treat the disease, which is now controllable for some people. The fear and suffering still exist but they are quieter, less palpable. HIV receded from the mainstream discourse once it became known that treatment was available and that life with the disease was prolonged. The activism that was the hallmark of the first two decades of the epidemic diminished. But treatment is not available to everyone, and even those who do have access have difficulty controlling the disease despite strict adherence to medication regimens. The virus has demonstrated its ability to develop resistance to all of the medications that have been discovered thus far. People living with HIV now have hope of living a longer life span, but it is a life that is constrained on many levels. I have listened to the stories about the stigmatization that they experience, from employers, health care providers, and their personal and the wider social network as a result of this disease. It constrains their lives, their relationships, their employment, and shapes how they view themselves. They have shared their fears, their distress, and the self-blame that is a pervasive theme among those who are afflicted with this disease. While my work experience may create a bias in terms of interpretation of this research, it also has provided a close lens for viewing this epidemic since its inception. I have also had the privilege of access to people with HIV infection who were willing to tell me their stories and talk about their disease.
In this dissertation, I seek to illuminate sufferer meaning-centered understandings of their illness and the construct of responsibility as it relates to health optimization as well as their beliefs about their ability to impact the course of their disease. By giving a voice to their stories, I hope to enhance our understanding of the illness experience of people living with HIV infection.

**Preview of Chapters**

In this first chapter I present a brief description of the background for my research. Furthering the understanding of the illness experience of this extraordinary and devastating disease will hopefully inform both health care and the wider social network.

In Chapter 2, I address the theoretical and conceptual underpinnings of my research by providing a brief overview of HIV infection, the course of the epidemic, and available treatment. Now that people infected with HIV are living longer, other co-morbidities that impact physical and social health as well as the accelerated aging that has been identified in those with HIV infection have become significant factors affecting quality of life. A discussion of these factors illuminates how they intensify the distress and disruption caused by HIV infection. The concepts of personal responsibility for health and health locus of control (HLOC) are also explored in order to frame the construct of responsibility for this research as it relates to health optimization. Kleinman’s explanatory model is also discussed to help frame the narratives presented as part of the findings of the research. Finally, I describe the Veterans Health Administration, an integrated health system that provides medical care and treatment for veterans.
Chapter 3 addresses some of the interconnected factors and social forces that impact the health of U.S. veterans that will help to situate this research on beliefs about responsibility for disease management and health optimization. It is important to have an understanding of how gender impacts health and how masculinity is shaped by military culture all of which influence health over the life course. The reframing of HIV as a chronic illness has had significant ramifications for people living with the disease. In this discussion, I address the validity of the acute-chronic labels that are applied by biomedicine and the impact of this dichotomy on both the emic and etic perspectives of HIV infection. Finally, I present a discussion of stigma, which will advance an understanding of the roots of the social burden of HIV infection.

In Chapter 4, I discuss my research site (VA Connecticut Health Care System at West Haven, CT), the design of my study and the research methods used, and provide a description of my study sample. Chapter 5 presents narratives obtained through semi-structured interviews related to how people infected with HIV conceptualize their illness and their beliefs about disease causation, responsibility, stigma, and the trajectory of their illness.

Chapter 6 presents the research findings from both qualitative and quantitative data to explore beliefs about disease management, health optimization, and the ability to impact disease progression. In Chapter 7, I provide an integrated analysis of the all of the data obtained through the research and situate it within the context of the social construction of illness and the resulting social suffering. I also present some final thoughts and implications for the research.
Chapter 2  Underpinnings of the Research

HIV Infection

Much has been experienced, studied, and written about HIV/AIDS since it was first detected over three decades ago. HIV has been identified as the pathogen that weakens, and often overtaxes, the body’s immune system potentially resulting in constellations of medical conditions and diseases known as Acquired Immunodeficiency Syndrome (AIDS).

HIV/AIDS represents a microcosm in which to explore how people understand a disease, how this information is shared, and the role of biomedicine in the construction of this understanding (Bolognone, 1986). Since its identification in the early 1980s, HIV infection has been steeped in symbolic meaning in no small part due to its association with bodily fluids (especially blood and sexual fluids) and lifestyle choices (e.g., intravenous drug use; sexual orientation) that are viewed by some as deviant and/or immoral (Schoef, 2001). The disease has been viewed as a punishment for these behaviors and attributes, and those who acquire the infection are often “blamed” for their disease (Castro, 2005). HIV/AIDS is one in a long line of epidemics, which include tuberculosis and leprosy, that have created an environment of stigma, discrimination, and physical and social suffering (Herek, 1996). Beyond its stigmatizing effects, HIV/AIDS also impacts society on a macro level affecting biomedicine, the health care system, and the pharmaceutical industry (Herek, 1996). From a micro perspective, AIDS-related stigma affects the health of those infected with the virus (e.g., increased stress; deleterious effects on the immune system), access to health care (e.g., decreased access;
delayed testing and diagnosis) and quality of life (e.g., guilt and self-blame for acquiring the infection; social rejection and isolation; feelings of fear, hopelessness, and powerlessness) (Herek 1996; Fife and Wright 2000).

Initially little was known about the causal agent of HIV/AIDS and modes of transmission resulting in a lack of treatment options. What was apparent was that the prognosis was poor. There was much fear experienced by those who had acquired the disease as well as those who were concerned about transmission. An overwhelming aura of powerlessness and hopelessness was felt by those who were ill with the disease, the health care professionals who were trying to treat them, and the general public. The tide turned in the mid-1990s when combinations of antiretroviral medications (ARVs), which became known as highly active antiretroviral therapy (HAART), became available. Although elimination of the virus is still not possible, these medications, if taken as prescribed, can often suppress the virus. Viral suppression, along with decreasing the probability of developing opportunistic infections, decreases an individual’s likelihood of transmitting the virus to others, thus preventing further spread of the disease.

Yet, despite these advances, the sense of powerlessness surrounding the disease has not significantly diminished because of the emergence of the virus’ ability to mutate and become resistant to these medications. The availability of numerous medications to treat HIV infection over the last two decades has provided more treatment options, infusing hope and stimulating the transition of the disease from an “acute” fatal disease to a “chronic” manageable disease for those who have access to medical care and ARVs. For those with such access, the ability to treat the disease, slow its progression, and improve prognosis creates opportunities to impact the course of their disease. This can be
accomplished by strict adherence to their medication regimen, avoiding risky behavior that could lead to reinfection (e.g. unprotected sex, IDU), and doing what is necessary to keep the immune system as strong as possible through healthy lifestyle choices (e.g., diet; exercise). Yet these behaviors and choices are mediated by beliefs about the virus and disease causation, the illness and its treatment, and the associated stigma experienced by many people living with HIV infection.

**HIV Epidemic and Antiretroviral Treatment (ART)**

Although much progress has been made in the last three decades in diagnosing and treating HIV and AIDS, the epidemic has endured and remains responsible for significant morbidity and mortality and for much human suffering. In 2010 it was estimated that the number of people globally with HIV infection was 34 million with 2.7 million annual new HIV infections (World Health Organization Progress Report 2011). Incidence of HIV has been decreasing globally since 2001; the number of new infections in 2011 was 20% lower compared to 2001. However, infections have begun to climb again in Eastern Europe, Central Asia, the Middle East, and North Africa (UNAIDS 2012). In 2011, there were 1.7 million deaths globally related to AIDS compared to 2.3 million in 2005 representing a 24% decrease (UNAIDS 2012). According to the CDC, in the U.S., people ages 45 to 54 years have the highest prevalence of HIV infection (CDC, 2012) and by 2015, half of the people with HIV infection in the U.S. be will over age 50 (CDC, 2014). The largest percentage of new infections (31%) in 2010 occurred among people aged 25-34 (31%), followed by those aged 13-24 (26 %) and those aged 35-44 (24 %). Among older Americans, new infections occurred in 15% of people aged 45-54 and
5% of those aged 55 and over (CDC Fact Sheet New HIV Infections, 2012). What is equally significant is that the CDC estimates that 25% of people who have HIV infection are unaware and represent more than 50% of new infections (CDC Fact Sheet Estimates of New HIV Infections in the United States).

As I discuss the HIV epidemic it is important to remember that it involves more than the biologic process of viral transmission. As Schoepf expresses so well,

“Disease epidemics are social processes: Spread of infectious agents is shaped by political economy, social relations, and culture. A disease of modernity and global population movement, AIDS has struck with particular severity in communities struggling under the burdens of poverty, inequality, economic crisis, and war. Many people who know about the danger of sexual transmission, especially many girls and women, cannot avoid becoming infected because they cannot control the relations of power that put their lives at risk (2001:336).

The HIV epidemic has illuminated the health disparities that exist for many people in the U.S., and globally, constructing increased risk for acquiring HIV and impacting access to health care and treatment. Men who have sex with men (MSM) represent over half (63%) of the new HIV infections followed by those who acquire the virus by heterosexual sex among whom there is a higher proportion of African American women (25%), and those who engage in intravenous drug use (12%) (CDC Today’s HIV/AIDS Epidemic, 2013). In the U.S. these disparities affect African Americans and Latinos disproportionately. As of 2012, African Americans comprised 14% of the population but represented 44% of both new infections and those living with HIV infection (CDC HIV Surveillance Report, 2013; CDC Estimated HIV incidence, 2012). Those who identified themselves as Latinos, although comprising only 16% of the population, represented 21% of all new HIV infections and 19% of HIV infections. There
are numerous social, political, and economic factors that contribute to these disparities including poverty, lack of health insurance, homophobia, and stigmatization, incarceration rates, and immigration issues, all of which can increase risk and impact access to testing and treatment (CDC Today’s HIV/AIDS Epidemic, 2013).

The availability of ARVs to treat HIV infection has made a significant impact on disease suppression. As of 2012, more than 9.7 million people living with HIV were receiving ART in low- and middle-income countries (WHO 2013). The first ARV became available in 1990 and aggressive clinical research over the past two decades has resulted in the current cadre of over 30 medications that can be used in various combinations to treat HIV infection. Treatment has evolved from multiple medications prescribed multiple times a day to the recent advent of single-tablet regimens (STRs). These once a day tablets contain multiple medications and may revolutionize HIV treatment due to the ease of adherence in taking only one pill.

The amount of HIV found in the body, most often tested in the blood, is known as a viral load. ART medications work by suppressing the HIV viral load. Lack of suppression is not guaranteed, however, and has been attributed to medication intolerance, toxicity, drug interactions, the presence of resistant virus, and most commonly to non-adherence. (Conway et al., 2007; Mannheimer et al., 2002; Liu et al., 2006; Paterson et al., 2000). Althoff et al. (2014) found that 22% of people with HIV infection in the U.S. did not have HIV viral load suppression with higher proportions found in women, young adults, non-whites, and those engaged in injection drug use (IDU). Although HIV viral suppression has contributed to improved clinical conditions and decreased mortality, research has found that the virus remains latent in reservoirs in
the body (e.g., brain, lymphoid tissue, genital fluids), and this makes eradication of the
virus, and hence a cure, very difficult (Schrager et al., 1998; Chun, 1997, 2010; Finzi,
1997).

The need for strict medication adherence to maximize therapeutic benefit is
evidenced by extensive research that has been conducted since the inception of ART
(Conway et al., 2007; Mannheimer et al., 2002; Liu et al., 2006; Paterson et al., 2000).
Adherence behavior has been well studied and is influenced by multiple factors including
patient beliefs about treatment, disease and medication education, patient-health care
provider relationship, social support, and the medications themselves (Friedland, 2006;
Horne et al., 1999; Mostashari et al., 1998). Gao et al. (2000) found that a person’s
experience with the disease and its treatment impacts adherence. The more symptomatic
the individual’s illness, the more they are able to connect disease progression and
adherence to their treatment. Research has also shown a statistically significant
relationship between patients’ beliefs about ART efficacy and adherence to ART (Smith
et al., 1997; Mostashari et al., 1998; Stone et al., 1998; Horne et al., 1998; Altice et al.,
2001).

A recent study by Moore et al. (2012) conducted between 1995 and 2010,
followed 6,366 patients infected with HIV, 87% of who were taking ARVs. The findings
demonstrated an estimated life expectancy of 73 years (Moore et al., 2012). The North
American AIDS Cohort Collaboration on Research and Design (NA-ACCORD) group
concluded that "a 20-year-old HIV-positive individual on ART in the U.S. or Canada is
expected to live into their early 70s, a life expectancy approaching that in the general
population." Life expectancy was lower for people with a history of IDU, non-whites,
and those with lower CD4+ cell counts (i.e., less than 350) (Samji et al., 2013:e81355). HIV infection has, thus, been reframed as a “chronic” illness in the developed world and in the developing world where antiretroviral medication and medical care are available, but this does not necessarily translate into disease suppression. HIV treatment has been notoriously difficult due to complex regimens with often intolerable side effects, and it is also affected by other negative mediating factors that affect adherence such as mental illness, co-morbidities, and social conditions such as homelessness.

**Co-Morbidities**

As effective treatment has become available for HIV infection, people are living longer and are experiencing comorbid conditions that are also common in an aging general population. There has also been a shift in the causes of death for people with HIV/AIDS from opportunistic infections to non-AIDS medical conditions (Sackoff et al., 2006; Martinez et al., 2007; Palella et al., 2006; Smit et al., 2006). These comorbid conditions include cardiovascular disease, renal and liver disease, osteoporosis and osteopenia, metabolic diseases such as diabetes, and cancer (Goulet et al., 2007; Onen et al., 2010; Hasse et al., 2011; Young et al., 2011). Approximately 75% of people living with HIV infection in the U.S. are over the age of 40 years and research on co-morbidity prevalence has shown that people with HIV infection have more co-morbidities and are prescribed more non-HIV medications than their counterparts of the same age that do not have HIV infection (Koram et al., 2013). The most prevalent co-morbid conditions include diabetes, neurocognitive impairment, chronic obstructive pulmonary disease (COPD), hypertension, osteoporosis, cardiovascular disease, and cancer. (Kilbourne et
al., 2001; Hasse et al., 2011; Rodriguez-Penney et al., 2013). People with HIV infection are experiencing higher cardiovascular disease rates than their counterparts who do not have HIV infection at time when the prevalence is decreasing in the general population (Silverberg, Hurley, and Prassad, 2013).

Deeks discusses accelerated aging in people with HIV infection who are taking antiretroviral medications. He outlines three contributory factors: infectious process and associated inflammation; consequences of antiretroviral medications; and what he terms as “host-related” factors that include other co-infections such as Hepatitis C and lifestyle behaviors such as alcohol use and smoking (Deeks, 2009). Goulet et al., (2007) in their work with The Veterans Aging Cohort Study (VACS), found that people with HIV infection who were over age 50 had a higher prevalence of hypertension, diabetes, vascular and pulmonary disease, and renal disease but were less likely to have substance abuse or a psychiatric diagnosis. They also found that HIV infection-associated comorbidities are typically medical or mental health conditions or related to substance abuse. They also noted that HIV progression had an exacerbating effect on some comorbidities.

According to the VA State of Care 2011, the most common co-morbidities found in people living with HIV infections and receiving care at the VHA include: depression (55%), hypertension (high blood pressure) (53%), dyslipidemias (high cholesterol; high triglycerides) (50%), anemia (30%), anxiety disorders (30%), Hepatitis C infection (26%), esophageal disease (25%), and diabetes (18%). Other important clinical conditions affecting HIV care included PTSD (16%), COPD (chronic obstructive pulmonary disease) (13%), heart disease (12%), and chronic renal failure (11%).
**Contributions of Medical Anthropology**

Anthropologists have made significant contributions to illuminating the individual, social, and cultural understandings of HIV infection and AIDS as well as the other factors that have shaped the spread of the disease and its resultant human suffering. It is in part, through their work that epidemics have come to be fully understood as social processes whose spread is shaped by social, cultural, political, and economic forces rather than just biological (Singer 1994; Schoepf, 2001; Castro and Farmer, 2005). The initial identification of risk groups for HIV infection by epidemiologists constructed the social groups that have been marginalized and stigmatized and created misperceptions of risk by the wider social world (Farmer, 1988; Bolton, 1992; Singer, 1994; Schiller et al., 1994; Herek et al., 1996; Link and Phelan, 2001). This public health strategy focused on individual agency ultimately placing responsibility on the afflicted person for their illness and ignoring the social, political, and economic forces that have framed and promoted the epidemic (Schoepf, 2001). Singer (1994) writes about the social dimensions of AIDS including its construction, transmission, and location as well as its disproportionate spread, “In the U.S. especially, AIDS is disproportionately a disease of the dispossessed, a disease of the socially condemned and denigrated, a disease of social outcasts and a disease of the poor” (Singer, 1994:944). Indeed, this is not just the case in the U.S., but globally. The critical medical anthropological perspective has contextualized the disease and illness by bringing into focus the social, political, and economic forces that have shaped the lives of those afflicted with HIV infection and the course of the
epidemic. Castro and Farmer (2004) conceptualized “structural violence” as a means of understanding the historical and structural factors that have shaped the suffering and stigma related to HIV and AIDS.

Anthropology also has helped to expose biomedicine’s role in constructing infectious disease as primarily biological in nature, an issue of pathogens, vectors or other transmission mechanisms, hosts, and immune systems (Bolognone and Johnson, 1986; Farmer and Kleinman, 1988; Farmer, 1994; Farmer and Good, 1991; Taylor, 2007). Through the use of ethnography and other qualitative research methods, anthropologists have illuminated the actual on-the-ground behaviors, local contexts, meaning-centered understandings and lived experience of HIV/AIDS and the importance of these insights in framing responses to the epidemic (Parker, 1987; Parker and Ehrhardt, 2001; Castro and Farmer, 2004; Mosack et al., 2005; Singer, 2013). Medical anthropology, along with other social science disciplines, has delved deeply into the roots, conceptualization, and psychological and physiological effects of stigma and discrimination related to HIV infection (Rhodes et al., 1995; Herek, 1999; Parker and Aggleton, 2003; Golub, 2003). Stigma has been identified as a major driver of the personal and social suffering that is associated with living with HIV infection. My research will build on this foundation of knowledge about HIV-related stigma and social suffering and provide insight into the contemporary lived experience of this illness (Kleinman, Das, and Lock, 1997; Singer, 2006). Although many anthropologists have contributed to this knowledge base, the epidemic, the cultural meanings and social construction of the illness and disease, and the structural and institutional forces that shape and impact it are dynamic
entities that have evolved over the last three decades. It is important to remember the dynamic nature of culture and structural forces and continue to describe the evolution of how people conceptualize, experience, and suffer from, this socially and biologically complex and devastating illness.

**Theoretical Perspectives**

In this research I used two different theoretical perspectives to understand the lived experience of veterans with HIV and their ability to adhere to treatment. The first is a psychological model of behavior related to locus of control (LOC) that has long been used in health research. The second comes from medical anthropology, Kleinman's ideas about explanatory models of disease. Each is discussed below.

**Health Locus of Control**

“The experience of illness in and of itself challenges a belief in control over one’s health” (Wallston and Smith, 1994)

Much work in understanding health behavior has been done using the idea of locus of control (LOC), a psychological concept that refers to beliefs about whether life events can be impacted by an individual’s actions (i.e., internal locus of control), by forces outside human control (i.e., external locus of control), or by a combination of both (Rotter, 1966; Wallston and Wallston, 1981; Christensen et al., 1991). The basic tenet of locus of control, which is based on social learning theory (SLT), is that a person’s behavior in a particular situation will be related to what s/he expects will happen based that behavior and how much s/he values that outcome (Rotter, 1966). Rotter conceptualized LOC as an expectancy construct in that people will expect that their behaviors will have a certain outcome. Wallston and his colleagues (1992) ultimately
modified SLT for the health domain theorizing that to predict health-enhancing behaviors, a person must value health, believe that they can impact it, and believe that they are able to engage in these behaviors. This health value construct is thought be the mediator between beliefs about control over health and behavior (Wallston, 1992).

Self-efficacy has been found by some to be a more effective predictor of behavior than locus of control. It is a similar construct that refers to the belief in one’s ability to engage in a specific behavior whereas locus of control relates to outcomes (Bandura, 1977; 1982). This difference is the basis for the use of locus of control for my research. Wallston et al. (1987) came to believe that LOC was not as effective a predictor of health behaviors as a solitary construct because multiple factors influenced these behaviors. They believed that the value that is placed on health is important to consider and should be included when studying locus of control. Wallston modified Rotter’s SLT to study his belief that perceived control is a broader and more encompassing way to look at behavior than LOC (Wallston et al., 1987). Thus, it was important to understand both dimensions – feelings of responsibility health behavior and perceiving whether or not they can control their health. They theorized that control and responsibility represent different concepts, with the latter as beliefs about what should be done compared to control, which relates to what can be done (Wallston et al., 1987).

Wallston and Wallston utilized the LOC framework to study beliefs as they relate to health-related behaviors (Wallston and Wallston, 1981) through the development of the Multidimensional Health Locus of Control (MHLC) survey. It is a validated tool with 18 items and utilizes a 6-point Likert scale for responses. There are four subscales within this survey which have been labeled Internality, which is unidimensional and the
subscales of Chance, Doctors, and Powerful Other People which comprise the Externality scale, which is multi-dimensional (Wallston, Stein, and Smith, 1994).

- Internal health locus of control (Internal HLOC) is the belief that a person’s actions and behavior determine their health

- External dimension is composed of three subscales:
  - Chance represents the beliefs that one’s health status is due to chance or fate
  - Doctor is the belief that one’s health is controlled by doctors
  - Others is the beliefs that one’s health is due to others such as social support system or God

(Wallston et al., 1987)

Individuals who assume personal responsibility for their health would be expected to engage in behaviors that would enhance their health such as adhering to medication regimens and attending medical appointments (Marshall, 1991). Although these dimensions were thought to be a continuum, research has shown that they are independent and that a person may have multiple beliefs about control. Wallston felt that the belief that control is possible was more significant than the locus of control (Wallston, 1992).

However, just because a person believes that they can impact the course of their disease doesn’t mean that they are able to do what is necessary to do so. In order for LOC to be relevant, people must value health, believe that their behavior can impact their health, and believe that they are able to engage in the behaviors that are necessary to maximize health (Wallston, 2005; Christensen, et al., 1991). It must also be considered
that even though a person engages in strict treatment adherence and healthy behaviors, s/he may still not be able to impact the course of their disease. There are many factors, both structural and personal, that can mediate the ability to prevent disease progression despite the belief that control over health is possible. In addition, beliefs are socially constructed and dynamic and they will transform over time particularly when related to health and disease.

Wallston reviewed health LOC research thoroughly and found that research on different diseases yielded different results regarding LOC. Research on diabetes and LOC has been indeterminate with some studies showing that a high internal LOC is associated with better adherence to treatment while others show no relationship. Studies of smoking indicate that people with a high internal LOC tend to be non-smokers while LOC does not appear to impact weight loss. A study of college students found that those who used birth control were twice as likely to have a high internal LOC (Wallston and Wallston, 1978). Early work on the relationship between medication adherence in a number of diseases and locus of control was indeterminate (Wallston and Wallston, 1978). Research on health locus of control (HLOC) and chronic illness showed that those patients with a high internal HLOC had “higher level of adaptation to their illness when control was possible but adjustment was poor if personal control was hindered by circumstances” (Christensen et al., 1991). Burish (1984) noted that the health LOC for people living with a chronic illness is dynamic and may trend over time toward an external LOC. They relate this to feeling distress about the ability to control their health and that transferring some of the control to others (i.e., significant others) may help adjustment to the illness. Evans et al., (2000) found that belief that control over health is related to chance or luck
was associated with depression, hopelessness, and stress. Most of the studies, however, are not longitudinal and do not consider the dynamic nature of beliefs.

Ubbiali et al. (2008) utilized the MHLC Form C with people infected with HIV to explore how they think about their disease and their beliefs about health. They found that people with HIV infection tended to have high Internal HLOC and low Chance HLOC scores. Their interpretation of the results was that people with HIV believe that they are able to impact their disease course. They also found that the Doctor HLOC scores were relatively high and the Others HLOC scores were low indicating a reliance on their doctors for controlling their health rather than their social network. Some more recent studies have utilized HLOC when looking at clinical outcomes. Burker et al. (2005) studied the relationship between HLOC and survival using the MHLC Form A in people with lung transplants. They found that those with a high Internal LOC lived longer post-transplant. O’hea et al. (2005) conducted research on HLOC and adherence to medications for diabetes and recognized the importance of the external dimensions related to adherence and subsequent HbA1c levels.

These more recent studies demonstrate the continued utility of the HLOC construct for at least some health domains, and I use it here to determine if beliefs about control over health exist for this population and where it is situated.
**Explanatory Model**

Belief systems, based on cultural, social, and psychological factors, along with lived experience provide the lens through which people view disease, its manifestations, and its treatment. Kleinman’s explanatory model of illness narratives is useful in eliciting how people think about, give meaning to, and experience their illness: how they live with it on a daily basis, how it affects their lives and the lives of those around them, and how they make decisions about treatment. It also provides a framework for understanding the concept of illness, the factors that impact the illness experience, and the associated suffering (Kleinman, 1988). He writes of chronic illness,

“The trajectory of chronic illness assimilates to a life course contributing so intimately to the development of a particular life that illness becomes inseparable from life history” (Kleinman, 1988).

Although there are common understandings between people who are diagnosed with the same disease because of the social construction of illness, each person’s schema for thinking about, and experiencing, illness is ultimately individualized because it is subjective and deeply personal.

With HIV infection, many people feel no symptoms but because they have been told that their body is harboring a virus that can be fatal without treatment, they still experience the illness and suffer because of the uncertainty that they must live with in anticipation of morbidity and mortality as well as the stigma that is associated with this disease (Mosack et al., 2005).

“Suffering becomes a process of social mediation and transformation. It is experienced within nested contexts of embodiment: collective, intersubjective, individual. It absorbs into the body-self the moral world’s contradictory obligations/rights and the norms/contestations of the body politic.” (Kleinman et al., 1997:xix)
The personal and social suffering that many with HIV infection experience, and their understandings about their illness and the meanings that they assign, are socially and culturally constructed by the prevailing social, cultural, political, and economic forces that are at play (i.e., stigma, substance abuse, homelessness, military service). HIV infection is what Singer (2004) terms an ‘oppression illness’ which relates to the long term effects of stigmatization and the internalization of blame. He takes illness beyond the physiological realm and situates it additionally as a social phenomenon that significantly affects health. I situate my research within the perspective that recognizes that health, disease, and illness are biological and social, and are affected by other forces all of which contribute to the social construction of illness.

Responsibility for Health

The construct of responsibility for health has been present in the U.S. since at least the early 19th century and has its basis in the American cultural values of “individual rights and responsibilities” (Leichter, 2003). Its evolution accelerated in the 1970’s in response to, as Minkler writes, “A growing disillusionment with the limits of medicine, pressures to contain health care costs, and a social and political climate emphasizing self-help and individual control over health” (Minkler, 1999).

Most of the historical research on responsibility for health has had a public health perspective focusing on prevention of disease (Minkler, 1999). As more understanding has been gained about the ability to mediate risk factors, more onus has been placed on the individual for acquiring his/her disease (Gunderman, 2000; Brownell, 1991). Gunderson cites examples of substance abuse, smoking, sedentariness, and unprotected
sex as risk factors that are viewed as within the control of the individual. Those who don’t engage in health-enhancing behaviors are viewed as lazy and lacking both responsibility and control that creates a milieu where disease can be viewed as a personal and in some cases a moral failure (Brownell, 1991).

Yet this ability to avoid risk factors and enhance health may not be feasible given the social, political, cultural, economic, and biological factors that may impede or prevent the lifestyle choices and behaviors necessary to avoid or mitigate disease (e.g., food deserts in urban areas). Using the example of obesity and the impact of social, cultural, and economic factors, Brownell writes, “humans gain weight when their environment promotes highly palatable food, rising portion sizes, increasing amount of sugar in foods and beverages” (Brownell, 2010). It is clear that the factors that are in play at both macro and micro levels must be taken into consideration in the discussion about personal responsibility for health (Chan and Reidpath, 2003). Some diseases are not avoidable or controllable and considering the other factors at play, it might be said that no disease is preventable for everyone.

The focus on control creates an atmosphere in which individuals are responsible for their health- to themselves, their family, their employer, and to the nation as a whole. When individuals do not meet the implied responsibilities, they are blamed and are assumed to have negative personal characteristics. (Brownell, 1991:308)

Health has become a personal and moral responsibility under which people are blamed for their unhealthy behavior according to norms that have been socially and culturally constructed (Becker 1986; Marantz 1990). Minkler writes that for Americans, being in control is an “important cultural and ideological underpinning of American health promotion efforts, which have in turn helped to shape their uniquely individual
focus” (Minkler, 1989:21). Yet the political and economic factors that affect health cannot be minimized. Syme (1997) found that people with higher economic means have an increased ability to engage in health-enhancing behaviors compared to those in lower socioeconomic categories who have less control over the social and economic factors that affect health.

For those who have acquired a disease, especially one that is chronic, the concept of responsibility for health may have a different connotation because the focus is often on disease management and preventing or limiting disability. People with chronic diseases are expected to engage in health-enhancing behaviors that can include diet, exercise, treatment adherence, adequate rest, and smoking cessation.

**Veterans and the Veterans Health Administration**

The Veterans Health Administration (VHA), which is part of the Department of Veteran’s Affairs, provides health care for 8.3 million veterans annually at its 1,700 plus facilities that include medical centers, outpatient clinics, and extended care facilities. It is recognized as the major integrated health care system in the U.S. (Department of Veterans Affairs 2011). In addition to medical care, the VHA also provides programs and domiciles for substance abuse as well as programs for mental illnesses including PTSD, housing, and transportation among others. The VA motto, “To care for him who shall have borne the battle and for his widow, and his orphan,” established in 1959, is based on words from President Abraham Lincoln’s second inaugural address in 1865.

There are approximately 22.3 million Veterans in the U.S. as of 2012 (Department of Veterans Affairs Statistics at a Glance 2013). The VHA is recognized as
the major integrated health care system in the U.S. (Department of Veterans Affairs 2011) which means that Veterans who are enrolled in the VA health care system may receive care at any VA facility at any time. The VHA also utilizes an electronic medical record system that allows VHA facilities around the country to access a patient’s medical record optimizing continuity of care. In additional to medical care, the VHA also provides many support services including programs and domiciles for substance abuse and mental illness including PTSD, as well as housing and transportation. Veterans are not prohibited from seeking health care from both the VHA and private health care providers. In an effort to optimize access to care, the VHA is now focusing on an outpatient system for care rather than the hospital-based system it has utilized historically (Department of Veterans Affairs State Summary 2010).

Not all veterans are eligible to receive health care without cost. Eligibility for health care is related to what the VHA defines as a service-connected rating which is based on whether the Veteran has an illness or disability that is directly related to their military service. According to the VA Health Care Overview website, veterans may be eligible for health care and medications for little, if any, cost based on criteria that include, but are not limited to, the following: Purple Heart recipient status, prisoner of war status, catastrophic disability, and an income below the income threshold. There are eight priority enrollment groups with Groups 1 and 2 having the highest priority for cost-free health care and groups 7 and 8 consisting of those whose income are above the defined VA national income thresholds. Many veterans have some financial responsibility for their health care in the form of co-pays (VA Health Care Benefits Overview 2012).
The majority of living veterans alive today have served during periods of major warfare, while only approximately a quarter served during peacetime (U.S. Census Bureau 2010). As of 2011, Vietnam veterans represent 35% of current veterans, along with 22% from the Gulf Wars, and 19% from World War II and the Korean War with the rest being peacetime veterans (Profile of Veterans, 2013). According to the Profile of Veterans 2011 based on data from the 2011 American Community Survey, male veterans are older, more likely to be White non-Hispanic and married, less likely to be uninsured and live below the poverty line, and to have higher income levels than their non-veteran counterparts (2013:19). The survey also found that the median age for male veterans was 64 years compared to 41 years for non-veterans (Profile of Veterans, 2013).

Veterans represent 13% of people in the U.S. who are receiving care for HIV infection. Statistics show that 40% of these veterans receive their care for HIV at VHA facilities making it the largest provider of HIV care in the U.S. (Department of Veterans Affairs 2011). In 2009, about 1 of every 250 veterans receiving health care at a VHA facility was infected with HIV (Department of Veterans Affairs 2011). Of the veteran population receiving care at a VHA facility who are infected with HIV, 68% are between the ages of 40 and 59 and 20% are over the age of 60. (U.S. Department of Veterans Affairs, HIV/AIDS website 2013). According to the CDC, the proportion of HIV infected veterans in care at a VHA facility who are over the age of 50 (64%) is more than double the estimated percentage for the HIV positive population in the U.S. (27%) (CDC HIV/AIDS Surveillance Report, 2005).

According to the Department of Veterans Affairs National HIV/AIDS Strategy Operational Plan 2011, 91% of HIV infected veterans in health care were on
antiretroviral therapy and 96% of newly identified HIV positive Veterans were linked to health care. All antiretroviral medications approved by the Food and Drug Administration are available on the VHA formulary. In 2009, 84% of HIV positive veterans on antiretroviral medications had a viral load less than 400 copies/ml, which was considered non-detectable (Department of Veterans Affairs 2011).

Goulet et al. (2007), in their work with The Veterans Aging Cohort Study (VACS) provide some comparison between veterans living with HIV infection and their non-veteran counterparts. They found that the similarities include being non-white, having a lower socio-economic status, and acquiring HIV infection through IDU or heterosexual sex.

The VA Connecticut Healthcare System, where this research took place, serves veterans in southern New England and is part of the VA New England Healthcare System. The VA Connecticut Healthcare System (VACHS) is comprised of the medical center in West Haven, an ambulatory care center in Newington, and six community-based primary care centers in Danbury, New London, Stamford, Waterbury, Winsted, and Windham (U.S. Department of Veterans Affairs VA Connecticut Healthcare System 2013)

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Summary

This chapter has provided information about HIV as a disease and an epidemic as well as a demographic and clinical profile of contemporary U.S. veterans. I have also discussed some of the theoretical perspectives that underpin the research. In the following chapter I explore other social forces that shape the illness experience of veterans to enhance our understanding of how they think about and experience HIV infection.
Chapter 3  Interconnections

Overview

There are many issues that underpin research about HIV infection and beliefs about responsibility. In this chapter I provide a brief overview of some of the interconnected factors and social forces that impact the health of U.S. veterans that will help to situate this research on beliefs about responsibility for health optimization and disease management. These factors include socioeconomic status, masculinity and gendered health, military culture and service experience, illness chronicity, and stigma. The fact that military veterans comprise the participant population gives rise to questions about the impact of masculinity gender norms and military service on health. In this chapter, I provide a brief overview of Western masculinity norms and military culture and service to understand how they shape beliefs about health and illness and health-seeking behavior and feed into each other in the social construction of masculinity over the life course in order to contextualize my study population as veterans.

I also address the issues of chronicity and stigma attached to HIV because these are important aspects of the social construction and experience of HIV/AIDS. With the advent of effective treatment, HIV infection has been reframed by biomedicine as a chronic illness. The concept of chronicity has many ramifications for both the person living with HIV infection and the global community, and has significantly impacted the burden of illness. A major contributor to this burden is the stigma that has been a hallmark of this disease since its emergence.
Masculinity and Gendered Health

Given the gender homogeneity of the study population, it is important to have some understanding of the role of masculinity as it relates to the domain of health. This discussion provides a brief overview of the research and theory regarding the relationship between gender and health.

Gender has been identified as an influential factor in health risks and health care seeking behavior and how men experience illness (Sabo, 2000). In 2011, the life expectancy for men was 76.3 years compared to 81.1 years for women in the United States (CDC National Vital Statistics Reports in October 2012). Along with a shorter life expectancy, men also have increased mortality due to heart disease, cancer, diabetes, and unintentional injuries (CDC Men’s Health, 2010). Studies of men’s health care seeking behavior have shown that men are less likely than women to seek medical care, including help for substance abuse and depression, are also less apt to report psychosocial issues (Galdas et al., 2005) and have a tendency to ignore symptoms of ill health (Sharpe and Arnold, 1998).

Research on gender and health has shown that there is a high consensus in Western society about what constitutes masculine and feminine characteristics (Courtenay, 2000; Williams and Best, 1990; Street et al., 1995). Specifically, Western masculinity norms include the achievement of success and status, emotional control, risk-taking, violence, dominance (particularly over women), virility, avoidance of “feminine behaviors”, and self-reliance (Mahalik et al., 2003; Addis and Mahalik, 2003; Good et al., 1989). Gender stereotypes for men include the following attributes: independence, inexpressive, aggressive, ambitious, analytical, assertive, competitive, dominant, athletic,
and invulnerable, among others (Edley and Wetheral, 1995; Kilmartin, 1994; Courtenay, 2000). Feminine stereotypes include characteristics such as: emotional, gentle, loyal, sensitive, understanding, yielding, and gullible. Traditional Western masculinity norms include high risk behaviors such as smoking, unprotected sexual activity, and substance abuse (Courtenay, 2000). These norms, for both men and women, constitute, in part, the construction of gender which impact health in that illness “can reduce a man's status in masculine hierarchies, shift his power relations with women, and raise his self-doubts about masculinity” (Charmaz, 1995:268).

Sabo (2000) traces the trajectory of theories regarding men’s health over the last three decades of the 20th century beginning in the 1970’s when the gender exploration began. The initial work sought to understand the role of conforming to traditional masculinity norms (i.e. toughness, self-reliance, stoicism) on the determination of health outcomes. The following decade did little to advance the understanding of gender and illness beliefs, and experience. During this time period, the sex-role theory was predominant, focusing on the impact of gender expectations of traditional masculinity on morbidity and mortality. This was also a time of emerging activism for gay rights and the beginning of the HIV epidemic. The 1990s brought gender identity to the forefront, which Sabo defines as the “individual manifestations of masculine or feminine traits and cultural practices that are better understood as expressions of wider institutional processes” (Sabo, 2000:135). Feminist ideology was instrumental in the inclusion of other factors such as class, race, ethnicity and the power differentials that exist at multiple levels.
In the United States men construe and construct masculinity by avoiding healthy behaviors such as not utilizing sick time at work, dangerous driving habits, and participation in sports that are prone to injury and disability (Courtenay, 2000; Mahalik et al., 2003). Men are also less apt to get health care for depression and substance abuse, among other health conditions (Galdas et al., 2005). Traditional masculinity is related to reduced utilization of preventative health care and health care seeking for medical and mental health issues as well as aggressive and violent behavior (Mahalik et al., 2003).

“By dismissing their health needs and taking risks, men legitimize themselves as the “stronger” sex. In this way, men’s use of unhealthy beliefs and behaviors helps to sustain and reproduce social inequality and the social structures that, in turn, reinforce and reward men’s poor health habits” (Courtenay, 2000:1397).

Moynihan’s (1998) work with young men who had been “cured” of testicular cancer found that few were experiencing depression or anxiety and none had sought mental health care. She found that while they felt a need to demonstrate “self-control” in public, many admitted to allowing themselves to experience in private, the emotions associated with a life-threatening disease (Moynihan, 1998). “By successfully using unhealthy beliefs and behaviors to demonstrate idealized forms of masculinity, men are able to assume positions of power -- relative to women and less powerful men -- in a patriarchal society that rewards this accomplishment” (Courtenay, 2000:1397). Courtenay also notes that some men construct different forms of masculinity by adopting health-enhancing choices but that this is not the dominant behavior.

It is not gender alone that affects how and when men seek care for health problems but socioeconomic status, occupational factors, and lifestyle “choices” may be more influential (Galdas et al., 2005; Lee and Owens, 2002). These authors noted that while the significance of the beliefs about, and socialization into, what constitutes
masculinity is an emerging research theme, these definitions are variable and that most of the research to date has been based in Western belief systems.

What has been omitted from most discussions about gender and health are the social, economic, and political forces that contribute to the construction of gender and illness. For veterans, these structural factors have a significant impact on health, particularly regarding the military institution, culture, and service.

Military Culture and Service: Impact on Health

The U.S. military is an institution that has been shown to significantly impact health, social networks, life trajectory, and other socioeconomic factors for veterans (Modell & Haggerty, 1991; MacLean & Elder, 2007; Wilmoth et al., 2010). Both military culture and military service shape and reinforce gender roles and serve as contributing factors to veterans’ health trajectory.

Military Culture

The United States Armed Forces is comprised of the Army, Navy, Marine Corps, Air Force, Coast Guard, and the National Guard, the latter being a reserve military force. Veterans from the last two decades are from military conflicts named Operation Enduring Freedom (OEF), which began in Afghanistan in 2001, and Operation Iraqi Freedom (OIF), which was initiated in 2003 and became known as Operation New Dawn in 2010. Those who served in these conflicts are referred to as OEF/OIF veterans, a term often heard at VHA facilities in the last decade.

Enculturation into the military occurs on many levels (e.g., individual, community, and institutional) and requires, according to military ideology, the
relinquishment of individual agency for the collective good. Smith and True call the military a, “total institution’’ with high levels of social integration, regimentation, and social control.” (Smith and True 2014:6). Titunik writes that, “Because war requires such a high degree of cohesiveness among members of a military unit, this most violent and aggressive of enterprises ironically requires qualities of submissiveness, obedience, and fidelity to one’s fellow comrades in arms” (2000:236). Those who join the military become part of a community, albeit one that is hierarchical. Authority is “depersonalized” in the military in that respect is given to those higher in rank rather than based upon personal attributes (Titunik, 2000).

It is during basic training (i.e., boot camp) that the socialization and enculturation process is initiated. Basic training, which typically lasts 8 to 12 weeks, is the military’s main source of socialization and it represents “the intentional disruption of civilian patterns of adjustment, replacement of individual gratifications with group goals, inculcation of unquestioning acceptance of authority and development of conformity to official attitudes and conduct” (Arkin and Dobrofsky, 1978:158). Basic values, such as tradition, ‘esprit de corps’, unity and community, are instilled during boot camp (Goertzel and Hengst, 1971). While each branch of the military has its own code of values, the overarching ones are honor, courage, loyalty, respect, selflessness, service, and integrity (Kuehner, 2013). For example, the Army values include loyalty, duty, respect, selfless service, honor, integrity, and personal courage (U.S. ARMY, 2014), whereas the Navy embodies honor, courage, and commitment (Navy, 2014). These values are in juxtaposition to the pervasive incidence of sexual assault that occurs in the U.S. military for women and to a lesser degree, men. The reported rates in the military are comparable
to, and are potentially higher, than for civilians (Turchik and Wilson, 2010). While there are many factors that may contribute to this behavior (e.g., substance use; historical sexual abuse), military culture plays a role in that it promotes the acceptance of violent and sexist behavior (Morris, 1995). Honor is represented, in part, by taking responsibility for one’s actions, and commitment is exemplified by obeying orders. The hierarchal structure of the military has perpetuated sexual assault because of the power differentials that exist, primarily for women but for men as well, creating “male-dominated and loyalist environments in which women are both the minority and desired sexual objects for men” (Turchik and Wilson, 2010:271) (Henry, Ward, and Hirshberg, 2004).

Along with the norms and values that are instilled, basic training entails learning the rituals of military life, the language, and the discipline. These rituals are how the military fosters social control (Burk, 1999; Hauser, 1973). Hierarchy, rituals, and language are also learned through the socialization process in boot camp (Dunivin, 1994). The emphasis on inspections and drills fosters conformity to discipline and to authority, which are also reinforced by uniformity in dress and other activities (e.g., salutes) (Hauser, 1973). Discipline is the hallmark of the military social system and demands “the total individual’s conformity to a prescribed role, including one’s behavior, attitudes, beliefs, values, and definitions” (Arkin and Dobrofsky, 1978:158).

The other significant impact of the military aside from its enculturation is the masculine warrior image that is the face of the military and represents its goal of preparing for and conducting the activities of war. The military creates a “cult of masculinity” (with accompanying masculine norms, values, and lifestyles)” that values dominance, achievement, and power (Dunivin, 1994:534). At its core is the belief that
soldiering is a masculine role with accompanying norms, values, and lifestyle. This “masculine mystique” of the independent, competitive, aggressive and virile man is promoted during boot camp (Dunivin, 1994:536). The military, and war, are typically viewed as “men’s work”. “Through relative physical isolation, community insulation, and behavior modification, the traditional prototype of masculinity is molded by the military in the belief that war and military are masculine domains” (Arkin and Dobrofsky, 1978:166). While this model is slowly evolving as a result of more women entering the military in combat roles and some increased tolerance of homosexual soldiers, most of the participants in this study represent an older generation of veterans and are a product of the traditional military model that stresses the dominant masculine male (Segal et al., 1993; Bicknell, 2000). This underscores the beliefs in hierarchy and obedience, which can be considered part of the patient-physician relationship, one that is hierarchical and requires adherence to orders.

Exploring the social structural factors related to military service, the effect of the military on life trajectory is based on whether a person enlists during war or peace time and whether enlistment is voluntary or mandatory (MacLean and Elder, 2007). During peacetime, racial inequalities among veterans are reduced because “it appears that military service improved the life chances of African Americans, while eroding the life chances of whites” (MacLean and Elder, 2007:177). Vietnam veterans were more likely than their non-veteran counterparts to have a college degree and report increased marijuana and alcohol use during and after military service. (Robins et al., 1974; Robins, Helzer, and Davis, 1975; MacLean and Elder, 2007; Mazur, 1995).
In 1990, African-Americans were underrepresented in the military but that had changed by 2000 when they were overrepresented as compared to the general population (Lutz, 2008). Non-whites were also underrepresented in the Vietnam War (Mazur, 1995). Lutz, in her research on who joins the military, demonstrated that,

“… among race, socioeconomic status, and immigration status, socioeconomic status is the only significant predictor of having ever served in the military. Class differences in military enlistment likely reflect differences in the non-military occupational opportunity, structured along class lines. This research shows that the all-volunteer force continues to see over-representation of the working and middle classes, with fewer incentives for upper class participation” (Lutz, 2008:185).

Another important predictor of military service in the general population is family income; people from lower socioeconomic means are more likely to enlist in the “all volunteer” military forces (Seeborg, 1994; Lutz, 2008). According to Defense.gov (2014) in their report on “Who is Volunteering for Today’s Military?” 90% of those who enlisted in the military through 2005, had a high school diploma compared to those not in the military and more were from the middle rather than lower socioeconomic classes.

**Veterans Health**

“Military veterans’ culture transcends ethnicity. Their work as soldiers shapes their health practices and their susceptibility to particular mental and physical health risks.” (Hobbs, 2008:340)

As noted previously, as of 2011, Vietnam veterans represented 35% of current veterans, along with 22% from the Gulf Wars, and 19% from World War II and the Korean War with the rest being peacetime veterans (Profile of Veterans, 2011). Military service can affect health by increasing the prevalence of smoking and the physical and psychological stress related to combat duty (Dobkin and Shabani, 2009). Vietnam veterans are in much worse health than non-veterans and this disparity increases with age.
Veterans, in general, have much higher rates of depression and anxiety than non-veterans and that disparity also increases with age (Dobkin and Shabani, 2009). Wilmoth et al. found that,

“Overall veterans seem to experience better health relative to nonveterans around retirement age [66], but decline more rapidly over time, such that veterans have poorer health than nonveterans among the oldest old. These trends are particularly noticeable among veterans with wartime service overall and veterans from WWII and Korea in particular (Wilmoth et al., 2010:753).

Older veterans, aged 45 to 64, tend to report more than two chronic medical conditions (diabetes, hypertension, heart disease, cancer [excluding non-melanoma skin cancer], stroke, chronic bronchitis, emphysema, asthma, and kidney disease), being in fair or poor health, and more serious psychological distress compared to their non-veteran counterparts (Kramarow and Pastor, 2012).

From 2006 to 2010, those who received mental health care at VHA facilities represented 38% of OEF/OIF veterans and 28% of all other veterans indicating that mental health issues for veterans are on the rise (United States Government Accountability Office, 2011). The most common mental illness diagnoses in 2010 for these veterans included adjustment reaction, depressive disorder, episodic mood disorder, neurotic disorder, and substance abuse disorder (United States Government Accountability Office, 2011).

According to the Substance Abuse and Mental Health Services Administration (SAMHSA), three-quarters of Vietnam veterans have both PTSD and a substance abuse disorder (SAMHSA, 2014) and 20% of veterans from the current wars in Iraq and Afghanistan have major depression or PTSD (Kramarov and Pastor, 2012). Mental health issues continue to rise. According to the VA Quality Enhancement Research Initiative,
the percent of Gulf War veterans being treated for mental health conditions increased from 21% in 2003 to 37% in 2013 (Quality Enhancement Research Initiative Fact Sheet Mental Health, 2013).

Mental illness among veterans is further complicated by a diagnosis of HIV infection. Approximately 63% of veterans living with HIV infection have at least one mental health diagnosis (Nurutdinova et al., 2012). Justice et al. (2004) conducted a comparative study of psychiatric and neurocognitive disorders between HIV infected and non-infected veterans and found that veterans who are living with HIV infection are more likely to have symptoms of depression and current substance abuse. Alcohol abuse has equal prevalence in those with HIV infection and without it but along with depression, and substance abuse, the prevalence increases with age.

In sum, military culture and service contribute to the construction of masculinity along traditional lines and affect the life course and health of those who serve. The health of veterans is affected on many levels both physically and psychologically, and there is a greater prevalence of alcohol abuse and substance use. These effects, in synergy with HIV infection, the co-morbidities of aging, and other social structural constraints place a disproportionate health burden on veterans. An additional contributor to this burden is the reframing of HIV infection as a chronic illness.

**Chronicity**

There has been much discussion about the evolution of HIV from an “acute” illness with high mortality to one that is considered “chronic”. Chronic illnesses can be defined as those that persist for more than three months and are “not self-limiting” (Von
Korff et al., 1997:1097) or as Allotey et al. write “serial acute episodes with multiple interactions with the health care system” (2011:450). HIV infection is a chronic disease in that it has an “uncertain course, a prescribed treatment regimen, requirement for self-care, some degree of stigma, changes in roles and relationships, and psychological distress” (Swendeman, 2009:1322).

Chronic illness requires a significant amount of self-care since most of the disease management is done on a daily basis rather than periodically in the formal health care setting (Siegal and Lekas, 2002; Corbin and Strauss, 1995). The self-care that is part of managing a chronic illness, which some label self-management, is composed of health-enhancing behaviors, treatment adherence, self-monitoring, disease and symptom management, and the effects of the illness itself, which are related to impacting the course of the disease (Von Korff et al., 1997; Emlet et al., 2011)

Corbin and Strauss (1995) talk about three different types of work that comprise self-care in chronicity: 1) “illness work” that entails treatment adherence, symptom management, and prevention of acute illness; 2) “everyday life work” that relates to the continuation of activities of daily living; and 3) “biographical work” that refers to the reconstruction of life, which can be required because of the consequence of the illness (e.g., limitations; outcomes). Ferzacca (2010) writes about the suffering of those diagnosed with diabetes and their “work” to control their disease such that “This willingness to work operated symbolically as the mark of a useful, disciplined, and productive self. Such work, indexed by the obtainment of “control” measured biochemically in blood glucose levels, is rewarded as a practical, rational, mental, and moral achievement” (2010:160). Bury writes about disruptions in biography caused by
chronic illness referring particularly to the effects on social relationships and the work entailed to maintain them (Bury, 1982). This “work” is not often recognized as such even though it represents individual agency in impacting the course of disease (Conrad, 1990). It is invisible work for most people only recognized within their personal social network and by their health care providers.

Several researchers recommend similar behavior change goals that can be used for all chronic illnesses, including adoption of a healthy lifestyle (e.g., sufficient sleep, moderation in use of alcohol, good nutrition, weight control, smoking cessation, exercise, and regular health care); adherence to treatment protocols, particularly medications; stress, anger, and depression management; and effective communication with health professionals (Swendeman, 2009; Barlow and Wright, 2009; Lorig et al., 2001). Those who are ill are expected to adapt to this work despite disability, uncertainty, and barriers to adherence and health-enhancing behaviors (Sigel and Lekas, 2002). Thorne and Paterson (1998) discuss the shift from the sick person as patient to partner in the health care relationship but write that not everyone who is ill with a chronic illness is capable or desirous of taking on disease management.

HIV was labeled as a chronic disease in the late 1980’s once the initial drugs became available for treatment (Colvin, 2011) but it was not generally accepted as such until more effective treatment became available in the mid-1990’s when HAART became available (Siegal and Lekas, 2002). In truth, HIV infection was never easily defined as an acute illness. It is most often characterized by a long asymptomatic period, often years, during which the immune system is being weakened and ultimately overwhelmed if treatment is not efficacious or not available. For those living with HIV infection, the self-
care required includes enhancing immune systems, controlling symptoms and minimizing disease progression (Siegal and Lekas, 2002). As the quote below suggests, although chronic and manageable, HIV is experienced as a series of acute episodes as in many chronic diseases.

“HIV continues to be experienced by many, through intermittent acute episodes of symptoms of disease with underlying worry about disease progression and worry about perpetuity and life-threatening nature of the illness, rather than a relatively low-level, long-lived condition ‘under control’” (Kendall and Hill, 2010:175)

Colvin writes, “…treatment narratives that celebrate HIV’s long-awaited arrival as a chronic condition mask the persistence of the local and global structural conditions that produced vulnerability and infection in the past and continued suffering and poor therapeutic adherence in the present” (Colvin, 2011:4). He talks about the inadequacy of the acute and chronic dichotomy in that it doesn’t address the often acute phases of chronic illness. For those with HIV, the effects of a weakened immune system and side effects from medications can cause periods of ill health. This labeling not only affects how the person living with a “chronic” illness experiences their illness but also the political and economic forces that shape funding and activism (Colvin, 2011).

The inadequacy of the acute-chronic dichotomy is also discussed by Manderson and Smith-Morris (2010) in their work on chronicity and the illness experience. They write that this categorization is effective for biomedicine and for discourse about disease, but that it discounts the significance of the subjective illness experience. They advance a nuanced understanding of the political-economic and hegemonic forces that construct and influence this chronic-acute dichotomy that contributes to the “invisibility of suffering” (2010:11). The self-care model of chronic illness that shifts the burden to the person who
is ill discounts the inherent suffering, disruption, and uncertainty that must be endured. In relation to HIV, they say that, “the very presence of categories of experience that inhabit both chronic and acute categories, infectious and yet long-term, demonstrate the declining explanatory power of the chronic-acute paradigm (and its variations)” (Manderson and Smith-Morris, 2010:12). The distress and uncertainty still persist even for those with HIV viral load suppression even though they have been told by biomedicine that their disease is chronic and that death is not imminent (Siegal and Lekas, 2002). “The underlying embodiment of AIDS, especially through its symptomatic ups and downs, is truly chronic” (Kendall and Hill, 2010:176). As Bury notes, chronic disease engenders chronic worries and disruptions that don't show up as medical issues:

Chronic illness involves a recognition of the worlds of pain and suffering, possibly even of death, which are normally only seen as distant possibilities or the plight of others. In addition, it brings individuals, their families, and wider social networks face to face with the character of their relationships in stark form, disrupting normal rules of reciprocity and mutual support. (Bury, 1982:169)

This aspect of chronicity speaks to the importance of the illness experience and meaning-centered understandings that people use to make sense of their lives and determine how to live with their illness. Biomedicine's labeling of acute and chronic disease does not take into consideration how people experience their illness and intensifies their burden on all levels. This construction of HIV infection by biomedicine as a chronic illness and the perpetuation of this distinction by those with disproportionate political and economic power contribute to the burden of those living with HIV infection. A significant contributor to this suffering is the stigma that affects those living with HIV infection.
Stigma

“Throughout history, the stigma attached to epidemic illnesses and the social groups linked to them has often hampered treatment and prevention, and has inflicted additional suffering on sick individuals and their loved ones.” (Herek et al., 1996:2).

As the quote above shows, stigma adds to the suffering that is a significant aspect of the lived experience of many individuals who are infected with HIV. It is experienced on an individual level, but it is a socially constructed phenomenon. Understanding this phenomenon of stigma can provide insight into how the social suffering of people with HIV infection comes into being.

Much effort has been made to conceptualize stigma but it has proven difficult. Often the literature addressing stigma begins with Goffman’s definition, an “…attribute that is deeply "discrediting”, “tainted”, “discounted” (Goffman 1963:3). Discussions of stigma generally center on stereotypes and negative attributes, as in Goffman’s conceptualization, rather than the power relations that create and perpetuate stigma.

“What is most poignant about Goffman’s description of stigma is that it suggests that all human differences are potentially stigmatizable. As we move out of one social context where a difference is desired into another context where the difference is undesired, we begin to feel the effects of stigma. This conceptualization of stigma also indicates that those possessing power, the dominant group, can determine which human differences are desired and undesired (Coleman, 1986: 212)

Goffman did seminal work on stigma in the 1960’s, writing that it was related to values and social norms; those who don’t conform are perceived as different or deviant (i.e., sex workers, drug addicts). He identified three characteristics that connote difference: 1) blemishes of individual character for which he uses homosexuality as an example, 2) abomination of body represented by physical deformity, and 3) tribal stigma
of race, nation, or religion (Goffman, 1963) such that “Perceptually, stigma becomes the master status, the attribute that colors the perception of the entire person.” (Goffman 1963: 219).

The definition of stigma has evolved since Goffman’s work. Jones et al. (1984) identified six “dimensions of stigma” that affect the stigmatizing process: 1) the degree to which the condition can be concealed; 2) the course and appearance of the condition; 3) its disruptiveness (defined as its effect on social interaction); 4) whether the afflicted person is responsible for acquiring the condition; 5) whether it is unattractive or repulsive in nature; and 6) if it is a threat to others (Jones et al., 1984). The work of other social scientists such as Stafford and Scott defined stigma as a “characteristic of persons that is contrary to a norm of a social unit” did little to advance the conceptualization of stigma (Stafford and Scott 1986:80). Crocker and Lutsky mirrored Goffman in their definition of stigma as an “attribute, or characteristic, that conveys a social identity that is devalued in a particular social context” (Crocker and Lutsky, 1986:505). The historical contributions to a conceptualization and theory of stigma reveal the difficult evolution of defining a ubiquitous but slippery social force.

Link and Phelan (2001) wrote one of the first works that recognized that power differentials are inherent when stigma is viewed in the context of social, political, and economic forces (Link and Phelan, 2001). From this perspective, people distinguish and label the differences in others and associate these differences with undesirable or negative attributes resulting in a separation into “them” and “us”. This power differential between the dominant group who label and those that suffer from the stereotyping is what allows stigmatization to lead to discrimination and inequity (Link and Phelan, 2001). People
with HIV infection have been labeled as “different” and stereotyped with negative attributes (i.e. deviant; immoral; uncooperative, non-adherent, and responsible for their illness) and have been categorized as an “out-group”. Stigmatization allows dominant groups to legitimately create power inequities for marginalized groups on many levels (i.e. social; economic; political; health care treatment and access). Prior to Link and Phelan’s work, the conceptualization of stigma focused on the individual or groups being stigmatized and those who stigmatize. This focus has largely ignored the social, economic, and political forces that create and contextualize who is stigmatized. Parker and Aggleton (2003) moved conceptualization forward by advocating for the need to “reframe our understandings of stigmatization and discrimination to conceptualize them as social processes that can only be understood in relation to power and domination” (Parker and Aggleton, 2003:16). This work has advanced the understanding of stigma in terms of its origin, function, and the forces that create and perpetuate it.

Much research has been done to understand the various shapes and forms of stigma. Stigma that impacts an individual has been defined as primary while that which affects those close to the individual such as family, friends, and significant others is termed secondary stigma (Herek, 1999). Bond et al. (2002) have described three types of stigma; self-stigmatization which is related to feelings of blame and shame; perceived stigma which is often driven by fear of disclosure of a stigmatized condition; and enacted stigma which is the resulting status loss and discrimination. Others refer to self-stigmatization as internalized or “felt stigma” (Green, 1995; Siegel and Lekas, 2002; Herek, 1999). Internalization of stigma can lead to self-doubt, lower self-esteem, depression, immunosuppression, and even premature death (Fife and Wright, 2000).
Other effects of stigma include depression and anxiety, social isolation and fractured social and familial relationships, as well as loss of employment and decreased access to health care (Varas-Diaz, 2005; Herek, 1999). Institutional discrimination relates to the stigma that is associated with access to health care, employment, and social interactions that occur at the levels of the local social support system and the wider social world (Herek, 1999).

**HIV Related Stigma**

“Throughout history, the stigma attached to epidemic illnesses and the social groups linked to them has often hampered treatment and prevention, and has inflicted additional suffering on sick individuals and their loved ones.” (Herek et al., 1996:2)

As the opening quote for this section suggests, the impact of the AIDS epidemic has been enormous for both the individuals who are infected with HIV infection, the wider social community, and those in the healthcare field. It is a disease that is associated with death, fear, uncertainty, stigmatization and discrimination. It has brought marginalized populations, such as intravenous drug users and homosexuals, to the forefront of society’s awareness creating an additional layer of stigma and resulting in health care inequities. “Vast majority of AIDS patients would often be stigmatized in a negative manner even if they were healthy” (Kelly et al., 1987:789). Familial and social networks have disintegrated for people infected with HIV affecting their ability to cope with a long-term illness with an uncertain outcome. Stigma is an important issue in this epidemic because it increases the suffering of people who are infected with HIV, ultimately affecting their quality of life and access to diagnosis and treatment.
Because HIV infection has historically been viewed as primarily affecting people who are considered to be “abnormal” or “deviant” and are violating the norms of society (i.e. intravenous drug users; homosexuals; sex workers), this results in isolation, rejection, and discrimination and the extension of the same stigma to other sufferers who do not share these attributes. The creation of risk groups by epidemiologists since the advent of the epidemic, while epidemiologically logical and useful for understanding the disease, had the unfortunate consequence of fostering the social concept of “in-groups” (non-infected, non-deviant people) and “out-groups” (infected deviant people), creating a distinct line between “us” and “them” (Herek et al., 1996; Link and Phelan, 2001). HIV emerged primarily in stigmatized populations such as homosexuals, intravenous drug users, and immigrants, and the initial response of screening those individuals who were thought to be at risk, were discriminatory and set up the non-traditional way that HIV is handled as opposed to other infectious diseases (Frieden and Douglas, 2005).

Although most individuals with HIV/AIDS cannot be identified by their appearance, there are some physical manifestations that people have come to associate with the disease. Early in the epidemic, Karposi’s Sarcoma, a medical condition that was manifested by purple lesions, became a hallmark of the disease and a means of identifying people who were infected. Although this condition has become rare in people with HIV/AIDS due to the use of antiretroviral medications, the current association of lipoatrophy (loss of fat in the face and extremities) and lipodystrophy (i.e. abnormal fat distribution) with the disease has become the new "mark” of the disease as Goffman would term it. Lipoatrophy is manifested by facial and extremity fat tissue wasting which results in an emaciated look. With lipodystrophy, fat is often redistributed to the back of
the neck (i.e., buffalo hump) or abdominal area which makes the person look physically disproportionate and in ill health

Stigma related to HIV/AIDS is not only imposed by society and other social, economic, and political forces but self-imposed as well (i.e., internalized stigma). Disclosure of HIV infection often also results in disclosure about lifestyle choices, sexual orientation, or substance abuse. Lack of knowledge, fear, contagion and other factors contributed to the stigmatization of people infected with HIV and those believed to be at risk for contracting the disease. Due to the fact that the early cases of HIV infection were identified in homosexual men, the disease quickly became associated with this marginalized population. As it became apparent that the disease is transmitted through bodily fluids, sexual activity and sharing needles during intravenous drug use became primary risk factors for infection. This contributed to the identification of groups who were already marginalized within society as different or abnormal. There were also some who believed that these people deserved HIV infection as punishment for violating the norms of society. Interestingly, people infected with HIV are stigmatized to a greater or lesser degree based on how they acquired the disease. Hemophiliacs and other people who require blood transfusions as well as children are viewed as innocent victims who do not deserve HIV infection because they did not participate in lifestyles that are considered immoral or illegal. While homosexual sex and intravenous drug use remain the major routes of transmission, heterosexual sex has become a more prevalent mode of transmission. Taking a critical anthropology perspective, Paul Farmer writes, “the variability of AIDS lies not in its modes of spread nor in the mechanisms by which the virus saps the host. It lies, rather, in its clinical course, which varies according to the
patient’s social condition, and according to society’s ways of responding to a deadly pathogen.” (Farmer, 1997:525). Stigma has been a barrier to people seeking HIV testing and accessing health care. The literature provides evidence of people with HIV/AIDS who feel that the stigma they experience is worse than the disease (Mosack et al., 2005). Singer (2004) discusses ‘oppression illness’ which refers to long-term effects of experiencing stigma (and the internalization process that often results in self-blame). The synergism of experiencing the social trauma of stigma and discrimination (e.g., racism, sexism, sexual orientation), which is often layered and multidimensional, and internalizing guilt, blame, and self-hatred ultimately affects the course of the disease (Baer, Singer, and Susser, 2013).

Historically in the U.S., AIDS has been associated with negative attitudes, stigma, and discrimination.

“AIDS stigma represents a set of shared values, attitudes, and beliefs that can be conceptualized at both the cultural and individual levels. At the cultural level, AIDS stigma is manifested in laws, policies, popular discourse, everyday social practices, and the social conditions of persons with HIV (PWHIVs) and those at risk for infection. At the individual level, it takes the form of behaviors, thoughts and feelings that express prejudice against persons infected with HIV” (Herek et al., 1996:2).

Given society’s fear of transmission and lack of knowledge, many people with HIV/AIDS live in varying degrees of social isolation. Some do not tell anyone, not even friends or family, that they are infected with the virus for fear of discrimination and rejection. Others disclose their HIV infection with deleterious results. Many live in fear of exposure which results in the lack of social support that many with this disease experience. To what degree it is self-imposed is questionable, but it is clear that many
people who have discussed being infected with HIV have been stigmatized as a result of their declaration.

Jonathan Mann wrote eloquently about the political economy of HIV and the health disparities it created:

“... as the HIV epidemic matures and evolves within each community and country, it focuses inexorably on those groups who, before HIV/AIDS arrived, were already discriminated against, marginalized, and stigmatized within each society. Thus, in the United States the brunt of the epidemic today is among racial and ethnic minority populations, inner city poor, injection drug users, and especially women in these communities” (Mann, 1997:11)

Stigma is socially and culturally constructed and it is contextualized. Jones et al., write,

“Designations of stigma have histories, and the public definition of deviant behavior is itself changeable. Interpretations of stigma… are open to reversals of political power, twists of public opinion, moral crusades, and the impact of social movements” (Jones et al., 1984: 44).

Stigma is what some people think about and do to other people and it is contingent on power differentials based on social, political, and economic forces. Singer (2004) makes the point that HIV/AIDS is not only a biological entity but also a social process that has influenced who has become infected with HIV and how they are treated within their personal and the wider social network. Much work remains to further the understanding of this phenomenon in terms of how it is created and perpetuated and the impact of structural factors on the experience of stigma in the epidemic. There is a need for the development of a bio-social theory of stigma that is grounded in critical medical anthropology in order to incorporate the individual, social, cultural, economic, and political dimensions of this phenomenon. Interventions to impact stigma must be multi-faceted and multi-level and address the individual, community, and structural factors
particularly in terms of the power differentials that contribute to its creation and persistence. Parker and Aggleton suggest that the goal of research should be help mitigate the suffering related to stigma of not only those who are living with HIV infection but to those who are at risk of contracting the virus. (Parker and Aggleton, 2003)

HIV/AIDS will not be the last epidemic nor will it be the last disease to generate stigma and create health inequities. Early research on the SARS epidemic has shown that there are similar patterns of stigmatization based on high morbidity and association with groups that have been labeled as different (i.e. homosexuals and intravenous drug users for AIDS and Asians for SARS) even though the modes of transmission are different (Des Jarlais et al., 2006:563). Gaining insight into what creates and perpetuates the stigma associated with HIV infection will help to impact the social suffering from it and inform interventions to combat this obstacle to equitable and effective health care for all.

The information in this chapter provides a foundation for understanding some of the social forces that impact the health of veterans, with a particular focus on HIV infection, as well as other co-morbidities (e.g., mental illness, substance abuse). The next chapter presents the research methods used in this study and my study sample for the research into the lived experience of HIV among veterans.
Chapter 4 Research Methods

In this chapter, I provide a description of the research and its objectives, an overview of the main study, a description of the research setting, sample design, participant characteristics, data collection methodology, and the analyses of the quantitative and qualitative data.

Overview

My dissertation research was a substudy of a larger project conducted at the VA Connecticut Healthcare System in West Haven, CT. It was embedded in a pilot feasibility study of an incentive system designed to reward people infected with HIV for viral load suppression (Farber et al., 2013). The main study, which utilized monetary incentives to reward patients for HIV viral load suppression, provided an opportunity to explore beliefs about responsibility related to health and disease management. I used a mixed-methods study design to elicit information about how people infected with HIV conceptualize the virus, their illness, and their beliefs about their responsibility for management of their disease and their perceived ability to impact its course. Data were collected from people who were currently prescribed antiretroviral medication for HIV treatment. Quantitative data were collected through the utilization of the Multidimensional Health Locus of Control (MHLC) Form C, which was customized for HIV infection. Patients were asked to complete the MHLC Form C survey as well as participate in an optional semi-structured interview in order to describe how patients understand and experience their illness and their beliefs regarding their ability to affect their own health. Medical record review was done to obtain descriptive statistics and the
outcome data that included incentive study visit attendance and HIV viral load data. Patient attendance at the incentive study visits (i.e., main study), which corresponded with routine HIV health care visits during the year on study, served as a marker for responsibility for health and HIV viral load suppression data were used as a measure of the ability to impact the course of the disease. All of the patients who enrolled in the incentive study were asked to participate in the research that comprises this thesis. Analysis focused on determining how these meaning-centered understandings relate to the quantitative measurement of health locus of control (HLOC) and outcome data (HIV Health Care Visit Attendance; HIV Viral Load Suppression) in order to provide insight into the connections between conceptualization of illness, responsibility for health, and beliefs about the ability to impact the course of disease from an emic perspective. The study was approved by the IRBs at the VA Connecticut Healthcare System in West Haven, CT and the University of Connecticut.

**Research Objectives:**

- To gain insight into how people infected with HIV conceptualize the disease and their schema for thinking about it.

- To utilize the theoretical framework of Locus of Control (LOC) utilizing the Multidimensional Health Locus of Control (MHLC) survey customized for HIV and semi-structured interviews to gain insight into the construct of responsibility for health and how people infected with HIV understand and experience their illness.

- To better understand the social construction of illness and the construct of responsibility as it relates to health.
To understand the connection between conceptualization of illness, responsibility for health, and beliefs about the ability to impact disease progression to determine if these beliefs translate to agency and positive health outcomes.

The research was conducted with U.S. military veterans at the VA Connecticut Healthcare System (VACHS) in West Haven, CT. This site provided a distinct environment in which to study the concept of personal responsibility for health. The veterans who participate in the VA health care system, an integrated medical system, have access to medical care, medications, diagnostics and treatment, and other support services (e.g., substance abuse treatment programs; transportation; housing) with little, if any, financial responsibility. This represents a system where many of the barriers to adherence and disease management are greatly diminished, or eliminated, providing opportunities to optimize health.

**Hypothesis**

To date research on responsibility for health and medication adherence has used psychological models, including health locus of control (HLOC) that assesses the extent to which individuals believe that health is impacted by their own actions rather than other forces outside their control. Individuals who believe that their own behaviors and actions determine their health (high Internal HLOC) are expected to participate in health-enhancing behaviors, including adherence to medication regimens, to optimize therapeutic benefit resulting in HIV viral load suppression.
Description of the Main Study

“A Study of Financial Incentives to Reduce Plasma HIV RNA Among Patients in Care”

The main study in which this research was embedded was a small one-site pilot feasibility study to determine if monetary incentives could improve HIV viral load control. The research was conducted at the Infectious Diseases Clinic at the VA Connecticut Healthcare System in West Haven, CT. It was designed to reward patients for viral load suppression and collaterally for attending routine HIV care visits and to improve communication between patients and their health care providers regarding symptoms that the patients experience that might impact adherence and quality of life (Justice, AC et al., 1999; Kilbourne et al., 2001; Johnson et al., 2003; Cunningham et al., 1998). Suppression of, or improvement in, HIV viral load was chosen as the target for the incentive because it does not have the same potential for “gaming” as adherence, which can be “gamed” because pill counts can be manipulated (Farber et al., 2013).

The study design involved four study visits over the course of a year at three-month intervals and a symptom survey that was administered at the first and final study visits. The timing of the study visits was designed to coincide with the typical HIV care visit schedule. HIV health care providers typically order HIV viral load tests every three months in order to monitor disease progression. The amount of the incentive, $400 per-person per-year, was calculated based on the annual amount of money that the “health care system” would save if a person infected with HIV suppressed the virus. This viral suppression translates to reduced HIV infectiousness and transmissibility (Farber et al.,
2013). The incentive program was designed to reward improvement in HIV viral load control as well as achievement of viral suppression.

All veterans who participate in the ID clinic for their HIV care were eligible for the study. Those who consented to the study were asked to attend their quarterly routine HIV care visits and have a HIV viral load test done prior to the visit. The participant would meet with their health care provider for a routine care visit to review the HIV viral load test result and would then meet with a member of the research team for an incentive study visit. The participant was eligible for a $100 incentive at each of four visits (i.e., a potential total of $400 over the course of the study year) if the HIV viral load test showed viral suppression or if it was lower than any previous viral load result over the previous year.

In order to be eligible for the incentive, the participant had to have their blood drawn for a HIV viral load assessment prior to the visit in order for the results to be available and they had to attend their scheduled clinic visit. Having blood drawn for routine testing prior to the visit is a common practice in the ID clinic so that the health care provider can discuss the results with the patients during their appointment and make adjustments to medications as necessary. If participants were eligible for an incentive payment they were given a voucher that they could take to the cashier to receive cash. The voucher could be cashed in at any time but a cashier was always available during the time the clinic was in session so that the ability to get cash was immediate.

Participants were informed by the research staff associated with the study that they could help to suppress their HIV viral load by taking all of their anti-HIV medications as directed and communicating with their health care provider regarding any
symptoms that might affect their adherence so that changes could be made to their regimens if necessary to optimize therapeutic benefit.

The study was conducted from January 2010 through July 2011. There were 78 male Veterans who consented to participate in the study but one was found to be ineligible. During the course of the study, three participants died, three relocated, and two were lost to follow up.

For analyses, the HIV viral load results for the year in which each patient was enrolled in the study was compared to the results from the year prior to study enrollment. Given that the study was a small feasibility study, it was not powered to identify significant differences in the outcome measure of HIV viral load. The results showed that the incentives were potentially responsible for a 12% increase (i.e., from 57 to 69 %) in suppressed HIV viral loads. (Farber et al., 2013) There were limitations to the study that included potential regression to the mean and the small sample size. The results of the study were published in AIDS and Behavior in 2013 (Farber et al., 2013).

I was a member of the research team for this the main study. I was not involved with the study at its onset but joined the team as a Research Coordinator around April of 2010. My responsibilities included conducting the study visits, determining if participants were eligible for an incentive payment, providing the incentive voucher if appropriate, and counseling the participants who were not eligible for an incentive payment. I was also involved in the medical record review, data collection and maintenance, assuring that the regulatory requirements were met, and was an author on the paper. During my work on the main study, I was approached by the Principal Investigator who asked if I was willing to design and conduct a qualitative research component for the study to elicit...
information about how the study participants viewed incentivizing viral load suppression. I was also given the opportunity to study additional relevant constructs and domains. The design of the main study provided an opportunity to explore beliefs about responsibility for health and disease management and gain insight into whether the study participants believed they could impact the course of their disease.

Enrollment in the main study began in January 2010. Once this substudy received IRB approval, all of the patients in the main study were approached at their next study visit and asked if they were willing to participate in this research. For those who expressed willingness to participate, the process of informed consent was conducted and the participants were asked to sign an amended informed consent form that included information about the MHLC survey and the semi-structured interview. By signing the amended informed consent form, the participants acknowledged their willingness to complete the MHLC survey. There was a separate section embedded in the amended informed consent form that provided an opportunity to consent to the optional semi-structured interview.

**Research Setting**

**The Infectious Diseases Clinic at the VA Connecticut Healthcare System at West Haven, Connecticut**

The VA Connecticut Healthcare System (VACHS), often called VA Connecticut, offers primary and specialty care to Veterans in southern New England and is part of the VA New England Healthcare System. VA Connecticut is comprised of the main medical center in West Haven, an ambulatory care center in Newington, and six community-based
primary care centers, in six cities: Danbury, New London, Stamford, Waterbury, Winsted, and Windham (U.S. Department of Veterans Affairs VA Connecticut Healthcare System 2013). The main medical center in West Haven, where this research was conducted, is a Clinical Referral Level 1 Facility with 230 beds that provides “primary, acute, tertiary, and long-term care”. For the fiscal year 2009 there were approximately 5500 hospital admissions and over 600,000 outpatient visits in the VA Connecticut Healthcare System. 

http://www.va.gov/opa/publications/factsheets/ss_connecticut.pdf)

It is a teaching hospital with academic affiliations with the Yale University School of Medicine and the University of Connecticut Medical and Dental Schools. (vaww.visn1.va.gov). There are also affiliations with numerous other educational programs including nursing, pharmacy, social work, physical therapy, and occupational therapy (http://www.connecticut.va.gov/about/index.asp). Research is a primary focus of the VHA and the VACHS conducts local research in various disciplines (e.g., psychiatry; medicine; surgery; and neurology) as well as participation in national research programs including the National Laboratory for Tuberculosis and Other Mycobacterial Diseases, the Mental Illness Research, Education and Clinical Center (MIRECC), the National Center for PTSD, the National Center for Research in Alcoholism and Substance Abuse, and the Clinical Epidemiology Center.

The Infectious Disease (ID) Department at the VACHS provides primary and specialty care for veterans with HIV and other infectious diseases. At the time of the study there were approximately 150 veterans who utilized the Infectious Diseases Department for their HIV care. The primary clinic for both HIV care and general
Infectious Diseases is conducted weekly on Friday mornings. Due to the high volume there is a small overflow clinic session on Monday afternoons that is dedicated to general infectious diseases and not HIV care.

The Department of ID consists of the following personnel: the Chief of ID who is the physician who oversees the administrative and clinical functions of the department; several Attending Physicians; a Physician’s Assistant (PA-C) who is certified as an American Academy of HIV Medicine Specialist who assists the Chief with clinical care; an Administrative Assistant; a physician who directs the infection control program; and a number of Infectious Disease Fellows that changes yearly. A fellowship provides an opportunity for a physician to pursue an education in a specialty area and usually lasts for two to three years. The physicians, with the exception of the Fellows, are all board-certified in ID. I fulfill the role of the Infectious Disease Research Coordinator as part of my full time work for the Yale University HIV Clinical Research Program along with a Research Assistant.

During the HIV clinic sessions, patients are seen by their HIV health care provider by appointment and are offered HIV care with the option of receiving Primary Care services as well. Typically there are three to four ID Fellows and the PA-C who see patients during the Friday morning clinic sessions with two to three attending physicians who provide supervision. The ID clinic is conducted in the Specialty Care Clinic, an area which consists of many examinations rooms that are utilized by multiple specialties during a given clinic session. The nursing staff sees all of the patients before their appointment which enhances continuity of care as they are a stable presence in the Specialty Care Clinic and come to know the patients well. There is a large waiting area
that is utilized by all of the veterans who have an appointment with any of the specialty clinics being conducted.

When clinic is not in session, much of the communication regarding HIV care occurs between the patients and the PA-C whose responsibilities include triaging patients by phone or in person when medical problems arise, prescribing medications and refills, and arranging any support services that are necessary (e.g., programs for substance or alcohol abuse; housing; transportation). There are many social and economic issues that impact a person’s health and this is particularly true for the veteran population and those who are infected with HIV (e.g., lack of social support; homelessness; lack of transportation; and PTSD). The Infectious Disease physicians and PA-C at the VACHS who provide care to the veterans with HIV infection are very responsive to the social and economic needs and constraints of their patients.

The main study and this embedded substudy were conducted primarily during the Friday morning clinic sessions although several patients were seen during the Monday afternoon clinic session. I assisted with the implementation and data collection of the main study and conducted the data collection for the substudy. The MHLC surveys and the semi-structured interviews were administered in either an exam room in the Specialty Care Clinic that was dedicated to ID Research or in a private office located in the Department of ID. Patients who could not participate in the survey and/or interview on Friday mornings were seen at their convenience in a private office in the Department of ID.
Sample Design

All HIV+ patients participating in healthcare in the Infectious Disease clinic at the VA Connecticut Healthcare System in West Haven, CT who had been prescribed HIV combination therapies for at least one year and were participating in the main incentive feasibility study were eligible to participate in the survey and the semi-structured interview that comprise this research. There were 78 male participants who enrolled in the main study.

Survey

All of the 77 participants who enrolled in the main study were asked to participate in the survey component of the research. There were 78 participants who consented to the main study but one was found to not be eligible. Participation in the survey was optional and participants were informed that refusal would not impact their participation in the main study.

Semi-structured Interview

All of the participants who completed the survey were invited to participate in the semi-structured interview. Participation was optional and participants were informed that refusal would not impact their participation in the main study.

Participant Characteristics

The study population reflected the patients who received health care for their HIV infection in the Infectious Disease clinic at the VA Connecticut Healthcare System in West Haven, CT. At the time this research was conducted, there were approximately 150 veterans with HIV infection who participated in this clinic; only two of who were female.
There were 78 participants who enrolled in the main study and 69 of those individuals consented to complete a MHLC survey. The number of participants who completed a survey and subsequently consented to an interview was 57. A comparison of the demographic and other relevant characteristics for all three groups is presented in Table 4.1. This comparison was conducted to show the differences and similarities of the groups and to assure that no selection bias existed for the survey and interview groups.
<table>
<thead>
<tr>
<th>Participant Characteristics</th>
<th>Main Study (n=78) Number (%)</th>
<th>MHLC Survey (n=69) Number (%)</th>
<th>Interview (n=57) Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>78 (100)</td>
<td>69 (100)</td>
<td>57 (100)</td>
</tr>
<tr>
<td>Female</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Age, years</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>59.4</td>
<td>60</td>
<td>60</td>
</tr>
<tr>
<td>Range</td>
<td>25-79</td>
<td>25-79</td>
<td>25-79</td>
</tr>
<tr>
<td>Years of HIV (+) diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>14.9</td>
<td>14.8</td>
<td>14.3</td>
</tr>
<tr>
<td>Range</td>
<td>3-28</td>
<td>3-28</td>
<td>3-27</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic</td>
<td>70 (90)</td>
<td>61 (88)</td>
<td>49 (86)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>6 (7.5)</td>
<td>5 (7)</td>
<td>5 (9)</td>
</tr>
<tr>
<td>Unknown</td>
<td>2 (2.5)</td>
<td>3 (5)</td>
<td>5 (9)</td>
</tr>
<tr>
<td>Self-reported Race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black/African American</td>
<td>42 (54)</td>
<td>36 (52)</td>
<td>28 (49)</td>
</tr>
<tr>
<td>White</td>
<td>29 (37)</td>
<td>26 (38)</td>
<td>23 (40)</td>
</tr>
<tr>
<td>Unknown</td>
<td>7 (9)</td>
<td>7 (10)</td>
<td>6 (11)</td>
</tr>
<tr>
<td>Level of Education, highest completed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elementary School</td>
<td>1 (1)</td>
<td>1 (1)</td>
<td>1 (2)</td>
</tr>
<tr>
<td>9th Grade</td>
<td>5 (6)</td>
<td>3 (4)</td>
<td>2 (3)</td>
</tr>
<tr>
<td>High School/GED</td>
<td>23 (30)</td>
<td>23 (33)</td>
<td>20 (35)</td>
</tr>
<tr>
<td>College</td>
<td>5 (6)</td>
<td>5 (7)</td>
<td>5 (9)</td>
</tr>
<tr>
<td>Unknown</td>
<td>44 (56)</td>
<td>37 (54)</td>
<td>29 (51)</td>
</tr>
<tr>
<td>IDU</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>History</td>
<td>40 (51)</td>
<td>35 (51)</td>
<td>27 (47)</td>
</tr>
<tr>
<td>No history</td>
<td>31 (40)</td>
<td>27 (39)</td>
<td>23 (40)</td>
</tr>
<tr>
<td>Unknown</td>
<td>7 (9)</td>
<td>7 (10)</td>
<td>7 (12)</td>
</tr>
<tr>
<td>Alcohol Abuse</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current</td>
<td>4 (5)</td>
<td>4 (6)</td>
<td>4 (7)</td>
</tr>
<tr>
<td>History</td>
<td>38 (49)</td>
<td>33 (48)</td>
<td>27 (47)</td>
</tr>
<tr>
<td>No history</td>
<td>29 (37)</td>
<td>25 (36)</td>
<td>19 (33)</td>
</tr>
<tr>
<td>Unknown</td>
<td>7 (9)</td>
<td>7 (10)</td>
<td>7 (12)</td>
</tr>
<tr>
<td>Mental Illness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>30 (39)</td>
<td>26 (38)</td>
<td>19 (33)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>12 (15)</td>
<td>12 (17)</td>
<td>11 (19)</td>
</tr>
<tr>
<td>PTSD</td>
<td>9 (10)</td>
<td>6 (8)</td>
<td>5 (9)</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>3 (4)</td>
<td>3 (4)</td>
<td>3 (5)</td>
</tr>
<tr>
<td>Bi-polar disease</td>
<td>1 (1)</td>
<td>1 (1)</td>
<td>1 (2)</td>
</tr>
<tr>
<td>1 or more psychiatric</td>
<td>39 (50)</td>
<td>33 (48)</td>
<td>26 (46)</td>
</tr>
</tbody>
</table>
The analysis of the participant characteristics of the MHLC survey participants (n=69) is presented here because they are the focus of my research and the interview participants (n=57) are included within this group. Data from the interview participants (n=57) were used for my qualitative analysis. These participants are a subset of the MHLC survey participant group and do not differ from the overall group in any significant characteristics.

The study population was homogeneous in terms of gender; all of the participants were men. There were only two women who participated in the Infectious Diseases Clinic for their HIV care at the time of the study but did not attend an HIV health care appointment during the main study enrollment. Women represent only 0.01% of the Infectious Diseases Clinic patient population. The average age of the participants was 60 years with a range of 25 to 79 years. The interquartile range was 50 to 64, which reflects an aging population living with HIV. The CDC has noted that 31% of those with HIV infection are over age 50 (Department of Health and Human Services Administration on Aging).

In terms of substance abuse, 51% of the participants have a history of IDU although none report current use. Current alcohol abuse was reported by only 6% of the participants but approximately half noted historical abuse. Data on substance abuse was collected in part because of the potential negative effects these conditions can have on

<table>
<thead>
<tr>
<th>diagnoses</th>
<th>66 (85)</th>
<th>58 (84)</th>
<th>47 (83)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Religious Affiliation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hepatitis C</td>
<td>41 (53)</td>
<td>35 (51)</td>
<td>28 (49)</td>
</tr>
<tr>
<td>Homelessness</td>
<td>3 (4)</td>
<td>3 (4)</td>
<td>2 (4)</td>
</tr>
</tbody>
</table>

• Percentages may not equal 100 due to rounding.
immune health, adherence to medication regimens, and other health issues. Co-morbidities such as Hepatitis C infection and mental illness can have a detrimental effect on HIV infection that is often multiplicative.

Almost half (48%) of the participants have more than one psychiatric diagnosis with depression being the most prevalent at 38%. This data was collected through medical record review indicating that there was a medical diagnosis. The incidence of serious mental illness is only 4% in the general U.S. population according to the National Institute on Mental Health. According to the U.S. Government Accountability Office, from 2006 through 2010, 38% of veterans of the most recent wars in Afghanistan and Iraq while 28% of all other veterans accessed mental health care at the VHA (U.S. GAO, 2011).

An additional co-morbidity that affects immune health is Hepatitis C, which was diagnosed in 51% of the study participants. In terms of structural issues, 4% of the men had issues with housing. According to the 2013 Annual Homeless Assessment Report (AHAR) to Congress, veterans comprise 12% of the homeless population in the U.S. (U.S. Department of Housing and Urban Development, 2013).

**Informed Consent**

All patients enrolled in the study were asked to sign a consent form prior to the conduct of any of the study procedures. The consent form discussed the main study as well as the MHLC survey and the interview, both of which were optional. Patients could choose not to consent to the survey or the interview, which did not affect their participation in the main study. Patients who consented to participate in the interview
were also asked to sign the Department of Veterans Affairs Consent for Use of Picture and/or Voice Patients Form 10-3203.

**Data Collection Methodology**

**Quantitative Method**

**Multidimensional Health Locus of Control (MHLC) Form C**

All patients enrolled in the main study were asked to complete the Multidimensional Health Locus of Control (MHLC) Form C (Appendix A), which was customized for use with patients who are infected with HIV (Wallston and Wallston 1978). This survey provides insight into whether people believe they are responsible for their health, whether health is under the control of others (e.g., physicians; powerful others such as God), or due to external forces such as fate or chance. Form C of the MHLC survey was designed to study people with chronic illnesses such as HIV infection and can be customized to reflect the disease being studied. It is a validated tool with 18 questions with response options based on a 6-point Likert scale. The scale has been determined to be moderately reliable based on Cronbach alphas in the .60-.75 range (Wallston 1993).

There are four subscales within this survey, which are encompassed within two dimensions:

**Internality**, which is unidimensional, is the belief that one’s health status is affected by one’s actions and behaviors (e.g., I am directly responsible for my HIV getting better or worse)
Externality, which is multidimensional, and is comprised of the following subscales:

**Chance** – the belief one’s health status is affected by chance, luck, or fate. (e.g., If my HIV worsens, it’s a matter of fate)

**Doctors** – the belief that doctors determine one’s health. (e.g., Following my doctor’s orders to the letter is the best way to keep my HIV from getting any worse)

**Others** is the belief that powerful others affect one’s health (e.g., friends, family, God) (e.g., Other people play a big role in whether my condition improves, stays the same, or gets worse)

(Wallston, Stein, and Smith, 1994).

For the purposes of this research, these constructs will be referred to as Internal HLOC, Chance HLOC, Doctor HLOC, and Others HLOC.

The MHLC survey was administered from January to July 2011. Of the 78 patients who enrolled in the main study, 69 completed the survey. I administered the MHLC surveys with occasional assistance from the PA-C who was another member of the research team. The following table (4.2) provides information regarding the number of participants and the reasons for lack of participation.
Table 4.2. Overview of Participation in MHLC Survey

<table>
<thead>
<tr>
<th>Main Study Participants</th>
<th>n = 78</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of participants who completed a survey</td>
<td>69</td>
</tr>
<tr>
<td>Number of participants who did not complete a survey</td>
<td>9</td>
</tr>
</tbody>
</table>

Reasons for lack of participation

<table>
<thead>
<tr>
<th>Reason</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Passed away during study</td>
<td>3</td>
</tr>
<tr>
<td>Relocation</td>
<td>3</td>
</tr>
<tr>
<td>Lost to Follow Up</td>
<td>1</td>
</tr>
<tr>
<td>Unable to offer participation due to missed study visits</td>
<td>1</td>
</tr>
<tr>
<td>Ineligible</td>
<td>1</td>
</tr>
</tbody>
</table>

Qualitative Method

Semi-Structured Interviews

All patients who enrolled in the main study and consented to complete the MHLC survey were invited to participate in a semi-structured interview. The interviews allowed me to gain insight into the emic perspective of being infected with HIV and the concept of control of and responsibility for disease progression and overall health. The interview questions were developed to elicit information regarding the following constructs:

- conceptualization of HIV (i.e., how do they think about it)
- how do they think about and experience their illness
- beliefs about responsibility for HIV infection
- beliefs about responsibility for health
- beliefs about responsibility for disease progression (i.e., viral suppression)
beliefs about ability to impact the course of the disease (i.e., affecting the amount of virus; efficacy of antiretroviral medications; suppression of HIV without medication).

An interview guide (Appendix B) was developed to provide consistency of data collection during the interviews. The interviews were approximately 30-60 minutes in duration and took place in a private room in either the Specialty Care Clinic or a private office in the Department of ID at the patient’s convenience. A VA-approved recording device was utilized to audiotape the interview with the written consent of the participants and interview field notes were taken to augment the audiotape.

I conducted all of the semi-structured interviews, which occurred between December 2010 and July 2011. Of the 78 patients who consented to the survey, 69 completed it. I planned to conduct at least 30 interviews in order to achieve cultural saturation and gain insight into the shared beliefs of the population and the range of variability of these beliefs (Trotter et al., 2001). Over the course of conducting the interviews, it became apparent that the participants wanted the opportunity to talk about their illness, their beliefs, and their suffering. For many, their HIV infection was a secret that they only spoke with their health care providers about. They rarely talked to their providers about their illness and they seemed to savor the opportunity to talk to someone without fear. I decided early on to conduct interviews with all of the participants that consented to the interview. It hopefully was beneficial to the participants but it was definitely valuable for the research. Their stories, their lived experiences, and their schemas for thinking about their illness were very distinct.

The following table provides information regarding the number of participants and the reasons for lack of participation.
Table 4.3. Overview of Participation in the Semi-Structured Interview

<table>
<thead>
<tr>
<th>Main Study Participants</th>
<th>n = 78</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number who participated in the interview</td>
<td>57</td>
</tr>
<tr>
<td>Number who did not participate in the interview</td>
<td>21</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Reasons for lack of participation</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Passed away during study</td>
<td>3</td>
</tr>
<tr>
<td>Relocation</td>
<td>3</td>
</tr>
<tr>
<td>Lost to follow up</td>
<td>1</td>
</tr>
<tr>
<td>Unable to offer participation due to missed study visits</td>
<td>2</td>
</tr>
<tr>
<td>Declined participation</td>
<td>7</td>
</tr>
<tr>
<td>Consented but not able to schedule before end of study closure</td>
<td>4</td>
</tr>
<tr>
<td>Ineligible</td>
<td>1</td>
</tr>
</tbody>
</table>

It is important to note that the participants completed the survey, and frequently the interview as part of their study visit. Given that they typically waited for a period of time prior to their appointment with their HIV health care provider and then had their study visit, it was a considerable request to then ask them to review, discuss, and sign an informed consent form, then complete a survey, and potentially participate in an interview. It was a significant investment of time for which they received no compensation aside from the incentive payment for which they may have been eligible. They were always offered the opportunity to schedule the interview at a time that was more convenient and while some took advantage of this opportunity, many stayed and completed both study components.
Medical Record Review

I also collected data through medical record review for each participant for characteristics that would provide descriptive information about the study participants in addition to insight into co-morbidities that impact the quality of life and create additional suffering of those infected with HIV. Information regarding the following variables was collected:

- age
- gender
- self-reported race and ethnicity
- number of years of HIV infection
- diagnoses of mental illness
  - Number of diagnoses
  - Schizophrenia
  - Bipolar Disorder
  - Depression
  - Anxiety
  - Post-Traumatic Stress Disorder (PTSD)
- Level of education
- Hepatitis C infection
- Current or history of intravenous drug use (IDU)
- Current or history of alcohol abuse
- Current or history of homelessness
- Self-reported religious affiliation
Data collected as part of the main study, which were used as outcome data for this research included:

- the number of monetary incentives the participant received over the course of the main study which served as the marker for viral suppression. This was the outcome measure for the ability to impact the course of their disease.

- the number of study visits the participant attended over the course of the main study which corresponded to incentive care visits with their health care provider. This active participation in their health care served as a measure of responsibility for health.

**Analyses**

**Overview**

The mixed method analysis integrated data from ethnographic interviews and surveys assessing Health Locus of Control (HLOC) to describe how patients understand their illness, their beliefs about responsibility for health, and their perceived ability to affect their own health. The data from the MHLC survey was analyzed to gain insight into HLOC and perceived responsibility for disease management and progression. The analysis of the qualitative data from the semi-structured interviews complemented the survey data by providing rich textual information to illuminate beliefs about illness, responsibility for disease management and health maintenance, and the perceived ability to impact the course of disease progression. Viral load data for the year of study was
utilized to analyze whether HLOC, and beliefs about responsibility and agency translate into HIV viral suppression, which impacts disease.

**Quantitative Analyses**

All analyses were performed using SAS software v9.2 (SAS Institute, Inc.). An alpha level of 0.05 was used to assess statistical significance.

Data collected on the following variables were used in the analysis:

- **Patient characteristics**
  - age
  - gender
  - self-reported race/ethnicity
  - years of HIV infection
  - level of education
  - diagnoses of mental illness
  - Hepatitis C infection
  - current or history of intravenous drug use (IDU)
  - current or history of alcohol abuse
  - current or history of homelessness

- **MHLC dimensions**
  - Internal HLOC
  - Chance HLOC
  - Doctors HLOC
  - Others HLOC
**Outcome Variables**

- Incentives received (i.e., HIV Viral Load Suppression): the number of monetary incentives the participant received over the course of the main study which represented viral suppression and served as the proxy measure of the ability to impact disease progression. For the analysis we dichotomized this outcome variable into those who always had viral suppression at all time points during the study year and those who did not always achieve viral suppression.

- Visits attended (e.g., HIV Health Care Visits): the number of HIV Health Care Visits the participant attended over the course of the main study which corresponded to routine care visits with their health care provider. This served as a proxy for individual responsibility for one's own health. For the analysis we dichotomized this outcome variable into those who always attended their HIV Health Care Visits and those who did not always attend all of their visits.

The outcome data was available from the main study. I determined that the HIV viral load data would be an effective measure of impacting the course of the disease for this purposes of this research. This is based on the fact that the main indicator of disease progression for HIV infection is viral load suppression. The choice of HIV Health Care Visits as a measure of responsibility is based on the importance of routine health care visits for monitoring disease progression. At the Infectious Diseases Clinic, patients are
expected to attend routine health care visits as determined by their health care provider. For the main study, patients were scheduled to see their health care provider every three months and to have a HIV viral load drawn prior to the visit so that the results would be available for the visit. Those individuals who assume responsibility for their health would be expected to attend these visits, which made them an effective marker for responsibility for the purpose of this research.

A data dictionary was developed that defines the values for the variables (see Appendix C).

The MHLC Form C was scored so that the HLOC data could be analyzed on both an individual and aggregate level. The median was used to determine the value that constituted a ‘high’ HLOC for each dimension (Wallston et al., 1994). Values above the median were considered a high HLOC for that dimension. Descriptive analysis was performed including frequency and measures of variability. Based on these findings, further analysis was performed utilizing multivariate analysis.

Chi Square analysis was conducted to determine if there was an association between the MHLC dimensions (Internal, Chance, Doctors, Others) and the outcome variables (i.e., All HIV Health Care Visits Attended/Not all Visits Attended; Always HIV Viral Load Suppression during the study year /Not Always HIV Viral Load Suppression during the study year).

Univariate analysis was conducted to compare the relationship between the MHLC dimension variables (Internal HLOC, Chance HLOC, Doctor HLOC, Others HLOC) and the participant characteristics with the outcome variables. Odds Ratios and 95% Confidence Intervals were calculated for the MHLC dimension variables and
participant characteristics to predict the outcomes of interest. The variables that were identified as significant (alpha=0.2) in the Univariate analysis were then utilized in a stepwise logistic regression analysis to identify what variables were independently associated with the outcomes variables. This multivariate logistic regression analysis was used to identify what variables predicted whether the participants:

- received all of the incentives or missed at least one incentive
- attended all of the incentive visits or missed at least one.

**Qualitative Analyses**

The qualitative data obtained in the semi-structured interviews allowed me to tap into the emic perspective of people living with HIV infection and gain insight into beliefs about responsibility for health and the perceived ability to impact the course of the disease. I conducted all of the interviews and took interview notes in conjunction with audiotaping the interviews. I listened to the voice files repeatedly and read my interview notes to ground myself in the data. Relying on listening to the interviews rather than reading transcripts to do coding, allowed me to maintain a more human and subjective sense of the data. The voice inflections, the pain that was often evident in their voices, made the data more animate.

In order to identify relevant themes and constructs, I created a matrix on an Excel spreadsheet that included, among other variables, responses to key interview questions and the descriptive characteristics obtained through medical record review. I was able to visualize the data through color-coding which facilitated in the identification of themes.
and connections. The matrix was created to integrate the analysis of the qualitative and quantitative data and included the following variables:

- responses to the key interview questions
- the descriptive characteristics obtained through medical record review
- the MHLC scores for the four dimensions (i.e., Internal HLOC; Chance HLOC; Doctors HLOC; Others HLOC)
- the number of monetary incentives the participant received over the course of the main study which served as the marker for viral suppression
- the number of incentive study visits the participant attended over the course of the main study which corresponded to routine care visits with their health care provider. This served as a marker for responsibility for health.

**Integrated Analysis of Qualitative and Quantitative Data**

The intent of the analysis was to determine if beliefs about responsibility for health and the ability to impact disease progression translate to positive outcomes (i.e.; HIV viral load suppression; active participation in health care). The quantitative data from the MHLC survey and the rich data from the semi-structured interviews provided information about how people infected with HIV think about their illness and the two constructs that are the foundation of this research. The MHLC data and the participant characteristic data were analyzed to determine if any of the variables impacted these outcome variables. It is the availability of outcome data that lends uniqueness to this research.
Chapter 5  Conceptualization – How do people with HIV infection think about HIV?

In order to understand whether people infected with HIV believe they can impact their disease progression and what they believe about their own responsibility for their health, it is helpful to gain insight into how they conceptualize and experience their illness. How do they think about it? Do they think about it as anything other than a disease or a virus? Who or what do they believe is responsible for their acquisition of the virus? I asked these questions of HIV-infected patients during semi-structured interviews, and my questions prompted narratives about their beliefs about disease causation, responsibility, stigma, and the trajectory of their illness.

Thinking about HIV

In this section I discuss how people infected with HIV think about their illness and why some “don’t think about it”.

"I don’t think about it."

Surprisingly, approximately one-third of the participants said that they don’t think about their HIV infection, but this response had many layers of meaning. For some it related to beliefs about the disease being controllable and its contemporary characterization as a “chronic” disease. In addition, with the increase in life expectancy for HIV infection, people are living relatively normal life spans and have begun to experience the co-morbidities and symptomology that come with aging. Thus, for many older HIV infected people, other medical conditions, including cardiovascular disease and diabetes, may have more immediate impact and sometimes overshadow the illness experience of those with pharmaceutically controlled HIV infection. Nevertheless, the
stigma and marginalization of HIV disease throughout the epidemic has constructed an environment where HIV infection remains a “hidden thing” that can adversely affect health and quality of life and intensify the suffering that is part of the entirety of the illness experience.

"It’s controllable".

[I] Don’t think about it. It’s controllable. At this stage it’s a positive thing that’s controllable. It’s up to me to do everything I need. Don’t think about HIV. Only focus on having meds and taking them.

(African-American man in his 50s with HIV diagnosis for almost 20 years)

Some participants said that they don’t think about HIV because they think about their disease as being “under control” or “controllable”. Yet there are many nuances to beliefs about HIV infection being “controllable”. Most viewed “control” as a result of taking antiretroviral medications. They talked about the level of virus in the body decreasing or becoming non-detectable when taking antiretroviral medications and the importance of adherence. Suppression of their HIV viral load by adhering to treatment provided them evidence that their disease was controlled and that perhaps it was not important to worry about it. As this participant, who is one of the oldest patients and has been living with HIV infection for almost 20 years noted:

Medical science has prolonged life if you do what you’re told to do.

In contrast to the earlier years of the HIV epidemic, medication regimens are now less complex (lower pill burden) and more tolerable (fewer side effects) so they are easier to work into a daily routine. There are now single tablet regimens that consist of one pill that contains multiple antiretroviral medications. For those who are fortunate enough to have access to these medications and can tolerate them, HIV treatment is far less
cumbersome than it was a decade ago. Many who are infected with HIV are no longer living their lives around the disease. The prevalence of HIV-related symptoms and opportunistic infections has decreased to the extent that many patients are asymptomatic, which is expressed in the lived experience of not feeling sick and feeling like they can live a “normal life” as this man who is in his mid 60s with a 20 year history of HIV infection noted:

People [are] dying every day, you know, from something. It [HIV] might be a death sentence but people with HIV are living longer than people that are healthy.

Some participants talked about knowing people who died because they hadn’t taken antiretroviral medications, had poor adherence, or had not changed risky behaviors or lifestyle choices (e.g., IDU; unprotected sex). This “survivor” perspective also contributes to the perception of the controllability of the disease, as noted by this survivor:

So many people refuse treatment. They just ignore risky behavior and didn’t have opportunity to see death like I have.

Many patients recognize that “doing what I’m told to do” has allowed their disease to transition to a chronic state, at least biologically. As the participant quoted above suggests, older HIV patients have seen the horror of death in the early phase of the epidemic before effective drugs were available and may have greater adherence to their treatment because of this.
"I'm living with it."

I really don’t think about it. I’ve had it for so long that I don’t give it any weight at all.
(Caucasian man in his late 50s who has been diagnosed with HIV infection for almost 20 years)

I had it so long, it is what it is. I’m living with it. I’m alive at least.
(Younger participant who has had HIV infection for at least five years)

HIV as a Chronic Condition

The evolution of HIV infection within biomedicine and especially in developed countries from a deadly acute illness to one that is chronic is a shift from the old rhetoric that characterized the past decade. It has significantly reframed the disease for people infected with the virus as well as for the broader society. In the early days of the epidemic, HIV infection was viewed as a fatal illness although there was often a long period of latency during which most carriers were asymptomatic. Many of my participants talked about the disease as chronic, which for them had the connotation of manageability rather than fatality. People with HIV infection now talk about being able to live a normal life span.

This is also how HIV health care providers now talk about the disease with their patients, and this has encouraged those with access to HIV care and treatment to think differently about the disease. The participants used phrases such as “it’s no longer a death sentence” and as a disease that may be “someday curable”. One man in his 60s who has been diagnosed for over 10 years said that he thinks about it “less now because taking meds has been helping all these years.” This transition to thinking about the disease as chronic in the minds of those infected is also influenced by the length of time the individual has been infected with HIV. For the participants who consented to do the
interview component of the study, the average length of HIV infection was 14 years. This illuminates the extended illness experience that characterizes chronicity that the study participants have endured and helps us understand how they have integrated their illness into their lives to the extent that they don't need to think much about it. As one of the younger participants who has had a diagnosis of HIV infection for only a few years said:

Now it’s basically a part of me so there are days I wake up and forget I even have it.

"It's a medical condition."

Some participants talked about HIV as a medical condition like diabetes, hypertension, or other “chronic” diseases. They talked about it as a “challenge” in terms of controlling viral loads and as something that they needed to learn to accept since it is not yet curable. This is the essence of chronic disease – it is not curable but is often controllable – and the affected must make the effort to control it. Thus, participants didn’t discuss or acknowledge distress or suffering due to HIV, but rather spoke about it as just another disease that they have integrated into their lives, but one that demands vigilance to control. As this participant notes, HIV is no longer experienced as a moral failing. It is a chronic disease:

I have to live with it on a daily basis; have to accept it. It’s part of me. A challenge. It’s part of my life. I have to live with it. It’s a condition like diabetes or high blood pressure… something you have to live with and accept. I don’t think about it, it’s the cards dealt to you. (Caucasian man in his late 40s who has been diagnosed for over 10 years)

"I have so many other things that now I forgot about this [HIV]."

Part of the chronicity component of long-term HIV infection is the presence of co-morbidities such as diabetes and hypertension. In the U.S., the population with HIV
infection is aging due to the availability and efficacy of antiretroviral therapy that has resulted in longer life expectancy. With this prolonged life span comes the risk of acquiring other conditions that are prevalent in non-HIV-infected, aging populations. Recent research has shown that people infected with HIV have higher levels of cardiovascular disease and liver disease, which is primarily related to comorbid Hepatitis C infection. The interesting twist in the history of HIV is that for those whose HIV infection is under control, non-AIDS related co-morbidities often become more worrisome than HIV, an idea that was unthinkable in the early phase of the epidemic. The comments below attest to this;

I don’t even think I have the virus anymore. I have old age problems.
(Caucasian man in his late 60s who has been diagnosed for a few years)

I got everything. COPD (chronic obstructive pulmonary disease). I got heart trouble. I got leukemia. Have prostate cancer. So many other things that now I forgot about this.
(Caucasian man over 60 years of age who has been diagnosed for almost 20 years)

Got so many things wrong with me. Diabetes. Too preoccupied with body pain to think about it.”
(Hispanic man in his mid 50s who has had HIV infection for over 10 years)

“It’s a hidden thing.”

It’s [having HIV] a hidden thing. I’m ashamed of it.
(African-American man in his 60s who has been living with HIV infection for almost 15 years)

HIV Stigma: Rejection and Isolation

Silence, secrecy, and isolation characterize the lives of many living with HIV infection. For many diseases (even with cancer, that was once as stigmatized as is HIV), it is expected and acceptable for people to talk about their illness as a means of dealing
with the stress of being ill. Talking about HIV, however, is not part of the acceptable discourse within society because of the enduring if somewhat irrational fears of contagion and the morality issues that hold people responsible for acquiring their disease. This constrains people from talking about their illness and sharing their fears and distress, ultimately increasing their suffering.

The social isolation and stigma of living with HIV infection is still an overarching theme for most of the participants and shaped their conceptualization of the disease. The need to hide or minimize the impact of HIV infection compared to other chronic comorbidities played a significant role in why they often don’t think about it and in how they think about it when they do. Many participants talked about how the social construction of the meaning of HIV contributed to how they viewed themselves as “dirty” and their appropriate interactions with others as though they were “untouchables.”

Given society’s still tangible fear of HIV transmission, continuing lack of knowledge, and moral judgments about those who are HIV-infected, many people with HIV/AIDS live in varying degrees of social isolation. Some do not tell anyone that they are infected with the virus, not even friends or family, for fear of rejection. Others who have disclosed their HIV infection, experienced rejection and decided to keep their disease a secret in the future. Many live in fear of exposure, which often results in the withdrawal of social support from family and friends that many with this disease still experience. The issue of stigma is still important in this epidemic because it increases the suffering of people who are infected and ultimately affects their quality of life. This perceived stigma results in feelings of social isolation and a need to keep HIV secret from others, including friends and family. This stigma and secrecy is ultimately internalized.
Stigma: Social Networks

"People still have stigma on it. They have no idea that I'm one of them people."

Am I really that bad off where I really worry about people accepting or rejecting me. You know am I really that bad?

(African-American man in his mid 50s who has been living with HIV infection for almost 20 years)

The feelings of being ‘untouchable” and “dirty” and the fear of disclosure, affected the lives of most of the participants. Those who said that they had not disclosed their illness to anyone spoke about the need to isolate themselves. Most had not felt actual rejection or stigma but rather lived in fear of it. They have accepted the now dated societal view of the disease and those who have acquired it – that they are untouchables to be avoided and cast out. As this participant who has had HIV infection for eight years noted:

People still have stigma on it. They still think that if you touch them then you catch it. If you kiss me you catch it. People are naïve about what HIV is.

The participants were aware of the stigma of HIV. They referred to it. They internalized it. They lived in fear that people would find out they were “positive” (for HIV).

[I] Don’t usually talk about it… It would ostracize [me from other] people. People I know would avoid me and talk about me. Family doesn’t know. From time to time it bothers me but don’t let it get me depressed. Meds received from the VA are helping me.

I’ve learned I have to manage my own health. I can’t rely on anyone in this regard. Isolate myself. Don't tell people I have HIV.

(Caucasian man in his 60s who has only had HIV infection for a few years)

Many of the participants I interviewed had experienced telling a friend about their illness and then been distanced or rejected. Others had heard friends talking negatively and with a lack of compassion about people who were known to have HIV infection.
These experiences were a strong deterrent to disclosing their illness as this man in his mid 50s with a diagnosis of less than 10 years noted:

Been around friends who have talked about it negative. Wouldn’t socialize with people like that and they deserve what they get and all this other stuff. They have no idea that I’m one of them people.

One of the older participants who has been living with HIV infection for almost 20 years shared,

I had this HIV for the longest, all these years you know, and that’s a terrible disease and I got through it alright. You know, can’t tell anybody, ya know. You know if people find out they’ll be scared to come near you.

Many don’t even tell their families or partners for fear of rejection or disappointing them, as this man, who was diagnosed with HIV infection a few years ago, noted:

I think about people I hurt. My family by getting involved with drugs.

This fear of disclosure affected their social support system, often narrowing it to only the closest confidants as indicated by this participant:

People think bad about it. My wife and family know about it. No one talks about it.

One participant said that he will only talk to people who are also infected. He has not disclosed his illness to his family but has a group of friends who have HIV infection. They support each other emotionally and make sure that each of them takes their medications and attends their health care appointments. He has created his own support system that only includes people that he identifies with and with whom he is comfortable.

Some don’t tell their family or friends because they’re concerned about further
disclosure to a wider social network, as this man in his 60s with a seven-year history of known HIV infection shared:

Mother and sis don't know. Two of three kids know and someone at work. Don't talk about it. If I told my sis everyone would know. If people knew they would treat me different… wouldn't believe how I got it.

One of the more significant themes in the participants' stories was that even though some had disclosed their illness to family members it did not create an environment of support. I asked why they didn’t talk about it with the people who did know, and most said that their family members didn’t bring it up in conversation, didn’t ask them about their illness or how they were feeling. One said that his mother would occasionally ask if he was taking his medications but there was no other discussion. They perceived this as discomfort and disapproval. It’s hard to conceive of having a serious illness, one that is often fatal, and not feel comfortable talking about it to those who are closest to you -- your family, significant others, and friends -- or have them ask you how you are feeling, simply showing concern. They were not able to articulate why they didn’t initiate conversations about their illness. Was it because they didn’t want to make their family or friends feel uncomfortable? Were they concerned about being rejected or judged? Most said it was because they didn’t think about the HIV. This denial is a significant component of “I don’t think about it”. It weakens patients' support systems, which ultimately increases their suffering, but they suffer silently.
Stigma: Sexual and Romantic Relationships

"It was so devastating to tell her I was HIV positive. It ended the relationship."

The rejection participants faced from others is intensified in the context of romantic relationships. This is exacerbated by the perception that they may have potentially infected a partner or that a partner infected them. Because HIV transmission is related to bodily fluids, it constrains sexual interactions that ultimately affect romantic relationships. In particular, some are inhibited about or simply reject engaging in intimate and romantic relationships. At the very least they are constrained in the expression of sexual and romantic needs, as this man who is in his 50s and was diagnosed with HIV infection almost 10 years ago said:

When I first got it I thought I was a disgusting human being. I thought I was pretty repulsive. I happened to be going out with the woman who I loved and I, I really loved her and she is one of the most beautiful women that I have ever met and I got tested because of her, because of my love for her and it was so devastating to tell her I was HIV positive. Uh, it kinda ended the relationship. We both cried and I told her not to worry about it. I felt pretty disgusting as a human being.

This is not an unusual scenario. The majority of the participants talked about their relationships or the lack thereof, as this African-American man in his 50s said:

I’m not in a relationship. Have to tell [HIV status] someone you’re intimate with. Worries me because if you have a fall-out with that person what’s private isn’t private anymore.

Many participants talked about constraining their romantic relationships or avoiding them altogether. The majority referred to relationships with women, only a few discussed relationships with other men. One man said that he only allows relationships with women to continue until the woman wants to move forward to a sexual relationship.
He ends the relationship at that point. He worries that if he discloses his HIV infection, and the relationship ends, that the woman will divulge the information to others, especially if she is angry or hurt. He said that most of his relationships are short-lived. Another man said that he doesn’t allow his relationships with women to become romantic. He tries to maintain a friendship with them, which he admits, is hard and the women eventually move on. He talked about holding hands with women but not letting it go further physically. Both of these men said that they were continually worried that the women would become suspicious when they didn’t initiate a sexual relationship. Other men had sexual relationships with women and talked about always using protection. The few that were in long-term relationships had told their partners about their infection. Others had protected sex with women but did not disclosure their infection. None of the men talked about having unprotected sex with women. They talked about protected sex being necessary not only to protect their partners but also to protect themselves from reinfection.

Figure 5.1 summarizes the factors that contribute to the concept of “I don’t think about it”.

Figure 5.1. “I don’t think about it.” Contributing Factors
For many of the participants, “I don’t think about it” also means “I don’t talk about it”. While it seems that some of the participants did not think about HIV much because they believed their disease was under control, others had no one to talk to about their disease so they put it out of their minds. For most of the participants, the only person that they talked to about their illness was their HIV health care provider and other members of the health team as these patients noted:

When I see Dr. X, it’s the only time I get to talk to someone about it. It’s a privacy thing. I know people who are open about it. “How do you do it?” Where do they get the courage?

(African-American man in his mid 50s who has lived with HIV infection for almost 20 years. He also suffers with depression and anxiety.)

No one outside the medical profession knows I have this. I’ve not told anyone in my family including my wife.

(Caucasian man who is well over 60 years of age who has been diagnosed for less than 10 years)

This fear of disclosure not only weakens participants' social support systems but also increases their reliance on their health care providers to whom they look not only for disease management but for someone, in some cases the only one, who accepts them without judgment.

**HIV as a Serious, Life-shortening Health Problem**

While some participants seemed matter-of-fact about not thinking about their disease, a few said that they tried not to think about it. Thoughts of HIV brought on feelings of fear, anxiety, and stress. It’s a “death sentence”, a “slow kill”, a “deadly serious disease”, a “dangerous disease.” They also talked about the infection being controllable, which mitigated some of their fear and anxiety, but the beliefs about the
virus being a death sentence or shortening one’s life span were ever-present, as this man noted:

> When I think about it [HIV] I think about how I got it, I think about how it would shorten my life span.  
> (*African-American man in his late 50s who has been diagnosed for almost 20 years*)

Another participant, who is in his early 50s and has been diagnosed with HIV for over 20 years, said that he thinks about HIV every day. He looks back and thinks about how he could have avoided acquiring the virus and thinks ahead about how to get things done before he becomes incapacitated. Another man said:

> I try not to think about it. It can kill me. It scares me.  
> (*African-American man in his late 40s who has had a diagnosis of HIV infection for almost 15 years*)

Many participants, however, manage their anxiety about HIV by focusing on taking the medications rather than thinking about the disease.

This dual belief among participants about HIV/AIDS as both an imminently fatal disease and a chronic disease that, when controlled, allows the ability to live a normal lifespan is an interesting aspect of the epidemic. Both are ultimately true. Sometimes individual patients express both ideas; other times patients adhere to one or the other belief. This shifting in perception is likely due to many things – how long the person has been infected, their age, how well the viral load is controlled, and what other comorbidities are present as well as the symptoms that are produced. Ultimately, HIV will contribute many participants’ deaths. At the same time, however, successfully controlling viral load allows sufferers not to really think about it. This may also be the case with other chronic diseases like diabetes and heart disease, where life can be
prolonged, but eventually the disease or the interaction with, or exacerbation of, other comorbidities of aging will eventually cause death.

**HIV as a Consequence of Behavior**

"Certain consequences of your actions you will pay for the rest of your life."

When asked how they think about HIV, some participants told me that it was a consequence of their personal behavior or “bad” choices. Although they knew HIV was a disease, they believed that they somehow deserved their illness. Although no one explicitly called HIV a punishment, self-blame and personal responsibility were prevalent for those who talked about having had “wicked ways” or not doing what they were “supposed to do” as these men said:

Paying for my ways, the wicked ways in the past, ya know, I can’t blame anybody else but myself so who do I blame? I did some bad things and this is my payment, my suffering. It’s a cross I have to bear. It most likely won’t kill me but it’s gonna make me hurt and that I have to deal with that.  
*drink*  
*(African-American man in his early 40s who has been diagnosed for approximately 15 years)*

They talked about sharing needles for IDU and unprotected sex with multiple partners. Alcohol lowered their inhibitions and affected their behaviors and the choices they made about drug use and unprotected sex. Drugs, alcohol, and unprotected sex were their “wicked ways”. One participant said that it was a disease brought on by carelessness. Another man said that he got it because he was irresponsible; he “slept with lot of women, did a lot of drugs”. For those who talked about HIV as a consequence, personal responsibility for their behavior and choices was evident in how they articulated their illness, as these two men noted that for them HIV is:
What you get when you do things you’re not supposed to do.
(*African-American man in his fifties who has been diagnosed for approximately 5 years*)

Something I did to myself. Have to live with it.
(*Caucasian man in his 50’s who has been diagnosed for almost 20 years*)

While the majority of the participants acquired the virus through IDU and/or risky sexual behavior, some took responsibility for their choices that shaped how they thought about their illness. This is not to say that for those men who believe that HIV is a consequence, that all of their choices were consciously made (i.e., risky sexual behavior under the influence of drugs and/or alcohol) or that they deserved to acquire the virus because of their choices. As these men said:

I made bad choices in my youth…experimenting with drugs. It's my consequence

I think about it as a poor choice in my life.
(*Caucasian man well over 60 years of age who has been diagnosed for less than 10 years*)

This self blame is also a consequence as well but of a different sort – the result of our social construction of the epidemic that frames sufferers as worthy of blame or blameless depending on their route of infection. Thus, these men's beliefs reflect the dominant social construction of this disease. The men assumed responsibility for acquiring the infection because of the moral overtones that surround this disease. People who are infected with HIV are thought to deserve their illness because of their behavior and choices and they embody these beliefs by blaming themselves.
Misfortune “A Bad Thing”

In contrast to those who thought about HIV as a consequence of their “bad” behavior, were those participants who talked about HIV as a misfortune that happened to them: “It happened for a reason.” or as one of the oldest participants shared,

That’s the cards that were dealt to you. That’s all when I first got it in (mid-1990s). I thought I was gonna die anyway, didn’t think I’d make a year, but I didn’t care then, the hell with it.

These beliefs have a connotation of fate and may be related to a personalistic explanation of disease causation rather than a naturalistic one. Participants who thought HIV was a misfortune also tended to say that they thought about HIV often. For some it’s a “daily disease” or one that they are aware of all the time. When asked how they think about HIV they called it a “plague”, a “road block” or a “life sentence”. Others viewed it as a “bad disease” or an “uncurable disease” and thought that they “will die sooner” because of it.

Spiritual Beliefs

[HIV is] Something God put there cuz I was messing up. Hey, you gotta slow down.
(An African-American man in his late-50s who has been living with HIV infection for less than 10 years)

For some participants spiritual beliefs shaped how they experienced their illness. Consistent with the Western religious beliefs they held or had been raised with, these participants referenced “God” or their “higher power”. They did not believe that HIV was a punishment from a higher power, but rather that there was a spiritual influence on their
illness. When they think about HIV, they feel that much of the power over their disease is not in their own hands, as these men said:

...a lot to do with attitude. Don’t be stressed out, eat properly, exercise, take meds, being prayful. God can turn anything around.  
(*An African-American man in his mid-50s who has been living with HIV infection for almost 20 years*)

God has everything to do with my health.  
(*African-American man in his mid-50s who has been diagnosed for over 20 years*)

I pray. I'm a believer. I'll be gone when its time to go. I just pray on it.  
(*An African-American man, one of the oldest participants who has had the virus for almost 20 years*)

To me it’s one of the consequences I have to pay because of my actions so, ya know, when it comes to God forgiving me or did God do this or allow this, no, it be because of my lifestyle.  
(*An African-American man in his mid-fifties who has been living with HIV infection for almost 20 years*)

Many of the participants who talked about the importance of faith and prayer felt that God could heal them at any time, as these men noted:

It’s up to my higher power who decides to control it or get rid of it.  
(*Hispanic man in his 60s who has had HIV infection for almost10 years*)

Faith works with the meds. God heals. At any given time he could heal me. In meantime lean on science.  
(*Hispanic man in his fifties who has been diagnosed for almost ten years*)

None of the participants expressed the belief that their illness was a punishment from their spiritual power. An African-American man in his 50s who has had HIV infection for over 20 years said,  

He (God) may allow certain things to happen to you to get your attention but He’s not going to let something bad happen to you.
One man expressed a personalistic explanation for his illness this way:

Spiritually I think it’s a demon that God didn’t put on me or wish on me. It was something because of my own actions. Play with fire you’re gonna get burned.

(An African-American man in his mid-50s who has been living with HIV infection for almost 20 years)

**Illness Trajectory**

“The trajectory of chronic illness assimilates to a life course, contributing so intimately to the development of a particular life that illness becomes inseparable from life history. (Kleinman, 1988)

A common theme in how participants talked about HIV was the perspective of time. Many said “in the beginning” to explain how they felt differently about HIV when first diagnosed compared to the present. Given the average length of time the study population has had HIV infection, about 15 years, most have had the opportunity to live with their infection for well over a decade.

**In the beginning**

Participants talked about being frightened, scared to death, and thought of the disease as a death sentence when they first found out about being infected with HIV as these men attest:

When I first got it I was devastated. It was the end of the world.

(African-American man in his mid-50s who has had HIV infection for almost 10 years)

Back then I thought it was a death sentence. Everybody I knew that had it before me seemed to pass away shortly after…I didn’t get sick for the first 15, 16 years. No side effects, nothing.

(Caucasian man in his late 50s who has had HIV infection for almost 20 years)
Indeed, there was little hope in the early days of the epidemic until well after the efficacy of HAART was identified in 1996. In the 1980s, people watched as others contracted the virus and died a rather horrible death because there was no effective treatment. When those who had experienced that era were diagnosed, it truly felt like a death sentence. Even as treatment became available, access to medications was limited to those who could afford it. For those who survived the early years of the epidemic or became infected after HAART became available, the ability to suppress the virus became a possibility. It allowed those infected with the virus to learn to survive.

_in the present_

Today, most HIV patients have learned to live with their illness; they have come to understand that the virus is likely to remain with them throughout their lives, much like other viruses. They have had the opportunity to see that the antiretroviral medications are effective with strict adherence, as these men indicated:

I don’t give it [HIV] any weight. Back then, it was a death sentence.  
_(Caucasian man in his late 50s who has had HIV infection for approximately 20 years)_

It doesn’t bother me as much as it did when I first learned about it, that was back in the 70s. Had it almost 15 years. I’m doing as well as can be expected.  
_(African-American man in his 40s)_

I think its hidden like chickenpox. It’s there but kept in check.  
_(An older participant who has had HIV infection for almost 10 years)_

Participants talk about HIV infection as a disease they have to live with on a “daily basis”. Learning to accept their illness has been part of its trajectory. They talked a
lot about acceptance and the need to stay positive in order to survive. One man in his mid-50s with almost 20 years of living with HIV infection indicated:

[It's] something you have to live with and accept. It is what it is. You got it, you got it. Didn’t feel like that in the beginning.

An African-American man in his early 50s who has had a diagnosis of HIV for over 10 years said,

[I] want to finally get rid of it. Millstone for 20 years. Didn't worry early on until I got sick. The doctor stood on the other side. Didn't want to touch you. Went few years before I saw a doctor. I had made a choice a few years back. Take meds or die…now it’s very little in the scheme of my life.

Transformation

Some of the participants talked about the benefits of acquiring HIV, how it transformed their lives, their behaviors, and their social interactions, as this man noted:

I’m better off with HIV. If not I might have gone on with a bad lifestyle. Grew up after I found out.

(African-American man in his mid-50s living with HIV infection for almost 10 years)

Many of the participants talked about how they have become more responsible in terms of their health and lifestyle choices. They changed their social environment, no longer associating with people who continued to participate in unhealthy and risky behaviors. HIV functioned as the proverbial “wake up call” prompting them to treat substance abuse, initiate healthy lifestyle choices, and understand the importance of protected sex. As this African-American man in his 50s who has been diagnosed for less than 10 years notes:
I really don’t think about it [HIV]. The only two times I think about it is in the morning and in the evening because those are the times that I have to take my medication. It has helped me to be very disciplined and other than that it’s not a burden. In fact HIV has kind of made me a better person, which is kind of weird to have a disease make you a better person but it makes me more responsible as when I view sex. I got HIV because I was irresponsible. I slept with a lot of women and I did a lot of drugs and I didn’t think I would get it.

Other participants also talked about HIV helping to make them “a better person” as the following quotes show:

[HIV] made me a better person. More responsible. I got it because I was irresponsible. Slept with a lot of women, did a lot of drugs. It changed my life.
(African-American man in his mid-50s who has had HIV infection for almost 10 years)

It changed my life, made me more honest. More open with people about what was going on.
(Caucasian man in his late 50s with a diagnosis of HIV infection for almost 20 years)

The transformative nature of illness has been discussed in relation to other illnesses. While HIV is transformative for some participants, for most it remains a deeply personal illness that is rarely shared within their social support system or even with others who have HIV infection.

Figure 5.2 provides a summary of some of the ways in which people infected with HIV come to understand their illness. It is multi-factorial and dynamic as is evident in the discussion of illness trajectory. The ways in which people conceptualize their disease frame and shape the illness experience.
Visualizing HIV in the Body

To further understand how people infected with HIV infection think about their illness, I asked the participants questions about whether there were any visualizations or metaphors that they used to picture or talk about their disease. I was especially interested in militaristic metaphors that they might use to conceptualize their illness. Metaphors have been associated with other diseases such as cancer to visualize the immune system cells acting as an "army" to fight the cancer cells. Similar metaphors have been associated with HIV in terms of the white blood cells of the immune system “fighting” against the virus that has invaded the body. Some participants had difficulty understanding this line of questioning, and others said they didn’t “think about it that way.” Only one verbalized a visualization, saying that HIV was “like bug eating me from the inside out” and a few said they thought about it simply as a virus. Most of the participants just viewed HIV as a
disease or medical condition that they had and did not report having visual images of precisely what was going on inside their bodies.

Responsibility for Acquiring HIV Infection

People often search for a reason or a cause when they become ill to help make sense of their illness. Why me? What did I do to deserve this? Why now? (Erickson, 2008) I deliberately probed for participants' ideas about the cause of their infection to gain insight into beliefs about disease causation, the social construction of illness and responsibility, and how they think about, and come to understand their illness.

In this part of the interview I was mindful of making the participants uncomfortable. I didn’t want to infer that they were responsible in any way for acquiring the virus or to stimulate or exacerbate self-blame. Blaming people for acquiring HIV infection is a sentiment that has been prevalent and contributes to the suffering of those infected because of its moral overtones. I found that most participants answered quickly, without pausing for thought. This may be, in part, due to the frequency with which the question is asked as a part of health care to collect information about transmission. While this information is used for public health statistics, treatment decisions are not made based on transmission so it raises the question of why these data are necessary. Not all infectious diseases warrant this question. When someone has a viral upper respiratory infection, they are not typically asked what they did to acquire the illness because the route of infection, the air we breathe, cannot be avoided. This highlights the social construction and resultant moral overtones that shape the illness experience of people with HIV infection.
Most of the participants ascribed responsibility for their infection to themselves, their choices and lifestyle behaviors, and to other people. These beliefs were not independent and, for many, they were interdependent. Only a few of the men said they didn’t know how they acquired the virus and only one man said he didn’t “assign responsibility”.

“Me. No one else.”

Most of the participants assumed personal responsibility for acquiring the virus. They talked about being “careless” or “stupid” and making “bad choices”. One man said, “No idea. I’m responsible.” These responses reflect a pattern of self-blame and an acceptance of their own “irresponsibility”. The lifestyle behaviors and choices that were discussed included sex and “promiscuity”, IDU, and alcohol use.

Unprotected sex was a prevalent theme. A few participants assumed full responsibility even though they believed that they had acquired the virus through sex with someone who was HIV positive and didn’t disclose the information as these men said:

I put myself in that situation. My partner was positive. I didn't know.  
(Hispanic man in his late 50s living with HIV infection for over 20 years)

Me, but with someone who didn't know they were infected. But I didn't take enough precautions. Responsibility is usually shared.  
(Caucasian man well over 60 years of age with a diagnosis of HIV infection for less than 10 years)

Don't put blame anywhere. If any, on myself. I was too promiscuous.  
(An African-American man well over 60 years of age who has been living with HIV infection for over 10 years)
In contrast, some participants placed the onus of responsibility on their sexual partners. Absent from these explanations was the lack of protection during sex reflecting an unawareness of their role in not protecting themselves. These men's comments illustrate this pattern of blaming a partner:

The person I caught it from is dead. I’m still living.

My ex-girlfriend who died.  
*(African-American man in his early 50s who has been living with HIV infection for almost 20 years)*

Someone else who didn't tell me.
*(Hispanic man in his early 50s who has been living with HIV infection for less than 10 years)*

Sharing needles with IDUs was mentioned by many of the men. Of the participants who participated in the interview component of the study, almost half had a history of drug use. Many of those who mentioned IDU talked about it as a “choice”, not aware of the social structural factors that influence this behavior, as one of these men indicated:

I'm responsible totally. In my younger years I was involved in IV drugs. 99.9% sure that’s how I got infected. I was careless.
*(Hispanic man in his early 60s who has had a diagnosis of HIV infection for less than 10 years)*

I had choices. I shared syringes. I took a chance.
*(Caucasian man in his early 50s who has had a diagnosis of HIV infection for over 20 years)*

Needles. I know that's how I got it. I shared with someone who had AIDS. I knew they had it. Drugs controlled me.
*(Caucasian man in his early60 who has had a diagnosis of HIV infection for almost 15 years)*
Many of the participants noted a lifestyle of risk through substance use, IDU, alcohol, and unprotected sex. One man said, “Too much partying.” while another said, “Alcohol is one of main reasons I have it.” Some explained that the use of alcohol and drugs fostered an environment that exposed them to increased risk through sharing of needles and unprotected sex. The comments form the men below reflect this theme:

The life I chose with drugs.
(*Caucasian man in his mid-50s who has had a diagnosis of HIV infection for almost 20 years*)

Needles; too many women. Too much drugs.
(*African-American man in his mid-50s who has been living with HIV infection for over 20 years*)

Women. Sex. Needles. I was promiscuous. I didn’t use protection.
(*African-American man well over age 60 who has been living with HIV infection for over 20 years*)

Me. Sex; I let other things take control. Alcohol. I hold myself responsible. I let others take control like alcohol.
(*Caucasian man in his late 40s who has been living with HIV infection for almost 15 years*)

Most of the participants expressed some degree of personal responsibility for acquiring HIV. Although they talked about drug and alcohol use as being responsible for their HIV infection, most expressed their own role in terms of lifestyle behaviors and decision-making. They assumed the negative connotations associated with alcohol and substance abuse and “promiscuity” and blamed themselves. A man in his 50s who has had the virus for over 20 years said,

I was living a promiscuous life and I shouldn’t have been doing half the things that I was doing far as getting high and having sex with all these females and not protecting myself, just promiscuous.
This reflects the moral judgments and “blaming the victim” mentality that has defined this disease since its inception and contributes to the social suffering of those afflicted.

Not one participant blamed God or a higher power for the illness but some talked about the power of prayer to assist with healing. None of the participants referred to HIV infection as a “punishment” for their behaviors and choices, but some viewed it as a “consequence” as previously discussed.

**Summary**

The beliefs illuminated through the interviews shape the individual illness experience; the participants' personal agency and that of others, including spiritual beings. The participants take responsibility for their health and for acquiring the infection; they live in fear of disclosure and mortality or learn to accept their illness and live with it; they are often more troubled by the diseases of aging rather than HIV infection; and many live in secrecy and isolation, which exacerbates their suffering. Many say they “don’t think about it” but in truth, they experience “it” daily and suffer because of it. Most don’t think about it because they have no one to talk to about it or with whom to share their fears and their feelings. They fear disclosure and the anticipated rejection and discrimination that come with it. The nuanced meanings of “I don’t think about it” tell us that the social suffering caused by stigma plays a large part in how people infected with HIV think about, and experience their illness. Table 5.1 provides a summary of the factors that shape the illness experience for people living with HIV infection.
In the next chapter I shift to a discussion of the construct of responsibility for health related to HIV infection and participants' beliefs about their ability to impact the course of their disease using both quantitative data from the MHLC survey and qualitative data derived from the interviews.

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<thead>
<tr>
<th>Responsibility for Acquiring HIV Infection</th>
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<tr>
<td>Personal</td>
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<tr>
<td>“Bad” Choices</td>
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<tr>
<td>Unprotected Sex</td>
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<tr>
<td>Social network of risk</td>
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<tr>
<td>“Bad” Behavior</td>
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<tr>
<td>Drug and/or Alcohol Impairment</td>
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<tr>
<td>Bad Luck</td>
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<td>Spiritual entities (God, Higher Power)</td>
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<tr>
<th>Illness Experience</th>
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<tr>
<td>Vigilance with medication adherence</td>
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<td>Health-enhancing behaviors</td>
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<td>Chronic Illness</td>
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<td>Co-morbidities</td>
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<td>Stigma</td>
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<td>Fear of disclosure and exposure</td>
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<td>Social Isolation</td>
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<td>Loneliness</td>
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<td>Fear of relationships</td>
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<td>Acceptance</td>
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<td>Transformation</td>
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<tr>
<th>Social Supports</th>
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<td>Doctors and health care team</td>
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<tr>
<td>Family, Friends, Partners</td>
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<tr>
<td>Other people with HIV infection</td>
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<tr>
<td>Spiritual/religious beliefs</td>
</tr>
</tbody>
</table>
Chapter 6  Locus of Control, Disease Management and HIV Viral Suppression

Overview

Responsibility has become an overarching theme in health management for all Americans but in particular for people with chronic diseases. In chronic disease care, the onus of responsibility and care-taking shifts from the health care team, whose focus is treating the acute phase of the disease, to the individual, who must then take on various levels of daily self-care in order to minimize disease progression.

This chapter explores beliefs about responsibility for health, disease management, and personal ability to impact disease progression. I use both qualitative and quantitative research methods. The quantitative data are from the MHLC survey, which explores health locus of control and was completed by 69 participants, It helps us to understand whether people believe they are responsible for their own health (i.e., have an internal locus of control) or whether they have an external locus of control exemplified by the belief that health is under the control of others (e.g., physicians; higher power; God), that health is controlled by external forces such as fate or chance, or that health is a combination of these beliefs. Qualitative data come from semi-structured personal interviews conducted with 57 participants in order to provide insight into the illness experience and beliefs about locus of control (i.e., beliefs about responsibility) both in terms of disease management and progression. In addition, HIV Health Care Visit Attendance data was used as a measure of personal responsibility for health. Attending routine HIV health care visits to monitor general health status and immune system health is viewed within biomedicine as a health-enhancing behavior. HIV viral load data, a
marker for disease suppression, were analyzed to determine whether beliefs about the ability to impact one’s disease were related to disease suppression in patients. The HIV viral load measures disease progression by letting the HIV health care provider and the patient know how much virus is actively circulating in the blood. HIV suppression is indicated by a non-detectable HIV viral load in the blood, although virions are still present in dormant state in particular body organs and tissues. Strict adherence to antiretroviral treatment has been shown to be effective in suppressing the virus resulting in a non-detectable viral load. Thus, the ultimate goal in HIV treatment is to attain viral suppression, which has a positive effect on immune health by decreasing susceptibility to opportunistic infections but requires strict patient adherence to medications and follow-up. Moreover, viral suppression decreases infectiousness preventing HIV transmission by as much as 30-fold (Quinn et al., 2000). Thus it is reasonable to expect that individuals who assume personal responsibility for their health would engage in behaviors that would enhance their health such as adhering to medication regimens as evidenced by HIV viral load suppression. In the main study, the outcome data of HIV health care visits and viral load test results occurred at four time points over the course of the year on study. Participants optimally attended four HIV health care visits with their health care provider and had a HIV viral load test performed in conjunction with each of these visits. These results are an objective measure of adherence and the construct of personal responsibility for health.

This chapter explores whether people who believe they have the ability to control the virus had a higher prevalence of adherence to health care visits and a higher rate of
suppressed HIV viral loads. A positive association would indicate that responsibility for
health manifested itself in health-optimizing behavior.

This chapter discusses the quantitative analysis of the MHLC survey and the
outcome data of HIV Health Care Visit Attendance and HIV Viral Load Suppression and
the qualitative analysis of the interview data.

Locus of Control and Disease Management: Results from the MHLC Form C
Survey

The MHLC survey was administered to 69 Veterans who were participating in the
main study. This survey measures four dimensions of health locus of control (HLOC) –
internal (self), chance, or external (doctor and others). Scores on the first two dimensions
range from 1 to 36 and on the second two dimensions from 1-18 as noted in Table 6.1, a
high score indicating greater agreement with that dimension.

<table>
<thead>
<tr>
<th>MHLC Dimension</th>
<th>Belief</th>
<th>Score Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal</td>
<td>The individual has responsibility for, and has the ability to control the course of their disease.</td>
<td>1-36</td>
</tr>
<tr>
<td>Chance</td>
<td>The course of a disease is due to chance or fate and not under the control of the individual</td>
<td>1-36</td>
</tr>
<tr>
<td>Doctor</td>
<td>Doctors are responsible for controlling a person’s disease</td>
<td>1-18</td>
</tr>
<tr>
<td>Others</td>
<td>Other people or entities are responsible for controlling a person’s disease (e.g., family; partner; God)</td>
<td>1-18</td>
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</tbody>
</table>

The median for each of the four health locus of control (HLOC) dimensions was
calculated (Table 6.2) and was used as the cut-off value to dichotomize the data into high
and low HLOC scores (i.e., above and below the median) for each dimension (Wallston
et. al, 1994). This provides a reference for determining high and low scores in each of the four dimensions. For example, for the Internal HLOC, which has a median of 26, a low Internal HLOC score would be between 1 and 25 and a high score would be between 26 to 36. Table 6.2 provides the mean, median, and range values calculated for each HLOC. This table provides information for both the survey and interview participant populations to show that there was little difference between the two groups, as the interview participants were a subset of the survey participant population. Table 6.3 provides the high and low ranges that were determined for all four HLOC dimensions.

Table 6.2. MHLC Dimensions Scores for Participant Populations

<table>
<thead>
<tr>
<th>MHLC Dimension</th>
<th>Survey Participants (n=69)</th>
<th>Interview Participants (n=57)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal HLOC score (range 1-36)</td>
<td></td>
<td></td>
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<tr>
<td>Mean</td>
<td>25.8</td>
<td>25.6</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>26 (21-31)</td>
<td>26 (20-31)</td>
</tr>
<tr>
<td>Range</td>
<td>11-36</td>
<td>11-36</td>
</tr>
<tr>
<td>Chance HLOC score (range 1-36)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>15.7</td>
<td>15.6</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>15 (11-21)</td>
<td>15 (11-20)</td>
</tr>
<tr>
<td>Range</td>
<td>5-36</td>
<td>5-34</td>
</tr>
<tr>
<td>Doctor HLOC score (range 1-18)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>15</td>
<td>15.5</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>17 (12-18)</td>
<td>17 (13-18)</td>
</tr>
<tr>
<td>Range</td>
<td>5-18</td>
<td>5-18</td>
</tr>
<tr>
<td>Others HLOC score (range 1-18)</td>
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<td></td>
</tr>
<tr>
<td>Mean</td>
<td>10.5</td>
<td>10.2</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>11 (8-13)</td>
<td>11 (8-13)</td>
</tr>
<tr>
<td>Range</td>
<td>3-18</td>
<td>3-18</td>
</tr>
</tbody>
</table>
T-tests determined there were no significant differences between the two samples for the HLOC scores by selected participant characteristics. The results are noted in Table 6.4 for the Internal HLOC scores and in Table 6.5 for the three dimensions that comprise the External HLOC. The analysis showed that there was no significant difference between any of the participant characteristics for each of the four MHLC dimensions.

### Table 6.3. MHLC High and Low Score Ranges for All Dimensions for Participant Population

<table>
<thead>
<tr>
<th>MHLC Dimension</th>
<th>Low Score</th>
<th>High Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal</td>
<td>1-25</td>
<td>26-36</td>
</tr>
<tr>
<td>Chance</td>
<td>1-14</td>
<td>15-36</td>
</tr>
<tr>
<td>Doctor</td>
<td>1-16</td>
<td>17-18</td>
</tr>
<tr>
<td>Others</td>
<td>1-10</td>
<td>11-18</td>
</tr>
</tbody>
</table>

### Table 6.4. Comparisons of Internal MHLC by Selected Participant Characteristics of Survey Participants

<table>
<thead>
<tr>
<th>Participant Characteristics (n=69)</th>
<th>MHLC Internal Mean</th>
<th>p-value*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self-reported Race</strong></td>
<td>0.79</td>
<td></td>
</tr>
<tr>
<td>Black/African American (n=36)</td>
<td>25.7</td>
<td></td>
</tr>
<tr>
<td>White (n=26)</td>
<td>25.8</td>
<td></td>
</tr>
<tr>
<td><strong>IDU</strong></td>
<td>0.39</td>
<td></td>
</tr>
<tr>
<td>None (n=27)</td>
<td>25.1</td>
<td></td>
</tr>
<tr>
<td>History (n=35)</td>
<td>26.7</td>
<td></td>
</tr>
<tr>
<td><strong>Alcohol Abuse</strong></td>
<td>0.88</td>
<td></td>
</tr>
<tr>
<td>None (n=25)</td>
<td>26.6</td>
<td></td>
</tr>
<tr>
<td>History (n=33)</td>
<td>26.5</td>
<td></td>
</tr>
<tr>
<td><strong>Hepatitis C infection</strong></td>
<td>0.59</td>
<td></td>
</tr>
<tr>
<td>Yes (n=35)</td>
<td>26.1</td>
<td></td>
</tr>
<tr>
<td>No (n=34)</td>
<td>25.5</td>
<td></td>
</tr>
<tr>
<td><strong>Depression</strong></td>
<td>0.45</td>
<td></td>
</tr>
<tr>
<td>Yes (n=26)</td>
<td>25.1</td>
<td></td>
</tr>
<tr>
<td>No (n=43)</td>
<td>26.3</td>
<td></td>
</tr>
<tr>
<td><strong>Psychiatric Diagnoses</strong></td>
<td>0.64</td>
<td></td>
</tr>
<tr>
<td>No diagnoses (n=36)</td>
<td>26.1</td>
<td></td>
</tr>
<tr>
<td>1 or more diagnosis (n=32)</td>
<td>25.5</td>
<td></td>
</tr>
</tbody>
</table>

* Based on Wilcoxon Two-Sample Test
Table 6.5. Comparisons of External HLOC by Selected Demographic Characteristics

<table>
<thead>
<tr>
<th>Population Characteristic (n=69)</th>
<th>MHLC Chance Mean</th>
<th>p-value</th>
<th>MHLC Doctor Mean</th>
<th>p-value</th>
<th>MHLC Others Mean</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race</td>
<td>0.38</td>
<td>0.60</td>
<td>10.3</td>
<td>0.56</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black/African American (n=36)</td>
<td>15.8</td>
<td>15.0</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White (n=66)</td>
<td>14.9</td>
<td>15.6</td>
<td>10.9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IDU</td>
<td>0.27</td>
<td>0.58</td>
<td>0.74</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None (n=27)</td>
<td>14.7</td>
<td>15.3</td>
<td>10.2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>History (n=35)</td>
<td>16.3</td>
<td>15.6</td>
<td>10.5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcohol Abuse</td>
<td>0.26</td>
<td>0.50</td>
<td>0.39</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None (n=25)</td>
<td>14.8</td>
<td>15.7</td>
<td>11.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>History (n=33)</td>
<td>16.6</td>
<td>15.3</td>
<td>9.9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hepatitis C Infection</td>
<td>0.95</td>
<td>0.55</td>
<td>0.73</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (n=35)</td>
<td>15.8</td>
<td>15.7</td>
<td>10.4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No (n=34)</td>
<td>15.6</td>
<td>15.0</td>
<td>10.6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychiatric Diagnoses</td>
<td>0.92</td>
<td>0.77</td>
<td>0.44</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No Diagnoses (n=36)</td>
<td>15.9</td>
<td>15.4</td>
<td>10.3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 or More Diagnoses (n=32)</td>
<td>15.4</td>
<td>15.2</td>
<td>10.8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>0.86</td>
<td>0.58</td>
<td>0.23</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (n=26)</td>
<td>15.9</td>
<td>15.5</td>
<td>10.1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No (n=43)</td>
<td>15.4</td>
<td>15.1</td>
<td>11.1</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

MHLC and Adherence to Health Care Visit Attendance and HIV Viral Suppression

Table 6.6 provides basic data on the outcome variables for the survey and interview participants. Data for both the MHLC survey and interview participants are included to demonstrate that there were no apparent differences; in fact, the data are almost identical for both groups. A little over half of the participants in both groups attended all of their HIV Health Care Visits and achieved HIV Viral Load Suppression over the course of the study year and almost all attended all of their HIV health care
visits. Regarding HIV Viral Load Suppression, 52-53% had a non-detectable viral load at all of the four time points during the course of the study year. Approximately one third of the participants achieved viral load suppression at 75% of the time points during the study year. The percentage of participants who had viral load suppression \( \geq 50\% \) of the time was only 19% and 8.5% respectively for the survey and interview participants. Thus, while adherence to visits was high, viral suppression was more variable. As discussed earlier there are many factors beyond adherence to visits and medication that can affect viral load.

Table 6.6. HIV Health Care Visit Attendance and HIV Viral Load Suppression Data Over the Study Year*

<table>
<thead>
<tr>
<th></th>
<th>Number (%) who Attended all HIV Health Care Visits and had HIV Viral Load Suppression at all time points</th>
<th>Number (%) who Attended all HIV Health Care Visits</th>
<th>Number and Percent with HIV Viral Load Suppression by Number of Time Points</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>4/4 time points</td>
</tr>
<tr>
<td>MHLC</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Survey Participants (n=69)</td>
<td>36 (52%)</td>
<td>64 (93%)</td>
<td>36 (52%)</td>
</tr>
<tr>
<td>Interview Participants (n=57)</td>
<td>30 (53%)</td>
<td>54 (95%)</td>
<td>30 (53%)</td>
</tr>
</tbody>
</table>

* Note: 4 time points over the course of the study year for both HIV Health Care Visits and HIV viral load suppression. HIV suppression relates to a non-detectable viral load.

To begin the investigation of the relationship of the MHLC dimensions to the outcome variables described in Table 6.6, Pearson’s correlation coefficients were used to determine the relationship of the four MHLC dimensions to the outcome variables of interest, HIV Health Care Visit Attendance and Viral Load Suppression over the course
of the study year. The analysis showed that for HIV Health Care Visit Attendance, only
the Other HLOC dimension was borderline significantly associated with the outcome
\( \text{Rho}[\rho] = -.23; \text{p-value}= .06 \). Although this inverse association was weak it indicates that
those participants who believed that other people or entities control the course of their
disease (i.e., high Other HLOC score between 11 and 18) were less likely to attend their
HIV Health Care Visits, which represent personal responsibility for health in the context
of this research. In relation to HIV Viral Load Suppression, the two HLOC dimensions
that were significantly associated were the Chance HLOC \( (\rho = -.26; \text{p-value}= .03) \) (i.e.,
the course of their disease is determined by chance or fate) and the Doctor HLOC \( (\rho =
.29; \text{p-value}= .02) \). These results indicate that participants who had a high Chance HLOC
score (i.e., between 15 and 36) were less likely to achieve HIV Viral Load Suppression.
They also suggest that a high Doctor HLOC score was associated with greater HIV Viral
Load Suppression. Interestingly, there was no association between internal LOC and
either of the outcome variables.

Chi Square tests were also conducted to determine whether there was an
association between the MHLC dimensions and the outcome variables. The findings are
represented in Tables 6.7 and 6.8. There was no statistically significant association
between any of the HLOCs and the HIV Health Care Visit Attendance outcome variable.
The only statistically significant finding for the HIV Viral Load Suppression outcome
variable was the Chance HLOC for which a low score was related to higher suppression.
There was also a trend \( (p=.12 \text{ but not significant at the } .05 \text{ level}) \) for higher scores on the
Doctor HLOC to be related to greater viral suppression. These results suggest, overall,
that rejection of Chance HLOC and embracing Doctor HLOC are the important factors in
the psychology of disease management among these veterans. Indeed, the role of doctors as health providers and perceived nonjudgmental witnesses may be a primary motivator for adherence.

Table 6.7. HIV Health Care Visit Attendance Over the Study Year by Level of MHLC Dimension

<table>
<thead>
<tr>
<th>MHLC Dimension</th>
<th>Number (%) All Visits Attended</th>
<th>Number (%) Not All Visits Attended</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal HLOC</td>
<td></td>
<td></td>
<td>NS</td>
</tr>
<tr>
<td>High</td>
<td>33 (48%)</td>
<td>3 (4%)</td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>31 (45%)</td>
<td>2 (3%)</td>
<td></td>
</tr>
<tr>
<td>Chance HLOC</td>
<td></td>
<td></td>
<td>NS</td>
</tr>
<tr>
<td>High</td>
<td>34 (49%)</td>
<td>3 (4.5%)</td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>30 (43.5%)</td>
<td>2 (3%)</td>
<td></td>
</tr>
<tr>
<td>Doctor HLOC</td>
<td></td>
<td></td>
<td>NS</td>
</tr>
<tr>
<td>High</td>
<td>36 (52%)</td>
<td>2 (3%)</td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>28 (41%)</td>
<td>3 (4%)</td>
<td></td>
</tr>
<tr>
<td>Others HLOC</td>
<td></td>
<td></td>
<td>NS</td>
</tr>
<tr>
<td>High</td>
<td>34 (49%)</td>
<td>4 (6%)</td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>30 (43.5%)</td>
<td>1 (1.5%)</td>
<td></td>
</tr>
</tbody>
</table>

Table 6.8. Viral Suppression Status Over the Study Year by Level of MHLC Dimension

<table>
<thead>
<tr>
<th>MHLC Dimension</th>
<th>All Visits Attended</th>
<th>Not All Visits Attended</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal HLOC</td>
<td></td>
<td></td>
<td>0.71</td>
</tr>
<tr>
<td>High</td>
<td>18 (26%)</td>
<td>18 (26%)</td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>18 (26%)</td>
<td>15 (22%)</td>
<td></td>
</tr>
<tr>
<td>Chance HLOC</td>
<td></td>
<td></td>
<td>0.01</td>
</tr>
<tr>
<td>High</td>
<td>14 (20%)</td>
<td>23 (33.5%)</td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>22 (32%)</td>
<td>10 (14.5%)</td>
<td></td>
</tr>
<tr>
<td>Doctor HLOC</td>
<td></td>
<td></td>
<td>0.12</td>
</tr>
<tr>
<td>High</td>
<td>23 (33%)</td>
<td>15 (22%)</td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>13 (19%)</td>
<td>18 (26%)</td>
<td></td>
</tr>
<tr>
<td>Others HLOC</td>
<td></td>
<td></td>
<td>0.76</td>
</tr>
<tr>
<td>High</td>
<td>18 (26%)</td>
<td>20 (29%)</td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>18 (26%)</td>
<td>13 (19%)</td>
<td></td>
</tr>
</tbody>
</table>
Odds ratios were calculated to identify which MHLC and patient characteristics predicted the outcome variables (i.e., HIV Health Care Visit Attendance which represents responsibility for health, HIV Viral Load Suppression which is a measure of disease progression) (Table 6.9). The analysis showed that none of the MHLC dimensions (i.e., Internal, Chance, Doctor, Others) had a significant effect on HIV Health Care Visit Attendance. For participant characteristics (e.g., demographic information, IDU, alcohol abuse, Hepatitis C infection, psychiatric diagnoses), the only Years from HIV Diagnosis was a significant negative predictor for this outcome variable. The greater the length of time since HIV diagnosis, the less likely the participants were to attend all of their HIV Health Care Visits. In regards to HIV Viral Load Suppression, only the Chance HLOC dimension (i.e., control due to chance or fate) was a significant predictor of non-adherence to scheduled visits. The data suggest a trend toward high Chance HLOC score i.e., control over disease assigned to chance or fate) was related to less likely HIV Viral Load Suppression. However, none of the participant characteristics was significant for this outcome variable.
A stepwise logistic regression model was performed to predict whether the participants attended their HIV Health Care Visits and had HIV Viral Load Suppression based on the MHLC dimensions and participant characteristics. Variables with a p-value that was less than 0.2 significance in the univariate analysis were included in the multivariate models (Table 6.9). A conservative cut-off was established in order to
include those variables that might be associated and to exclude those variables for which an association is unlikely.

Variables included in the logistic regression analysis of HIV Health Care Visit Attendance (Table 6.9) were religious affiliation (p value 0.12), years of HIV diagnosis (p value 0.04), and having one or more psychiatric diagnoses (p value 0.17). As with the univariate analysis, only the Years of HIV Diagnosis remained significant in the model. The longer the participant had been diagnosed with HIV adherence to attendance at HIV Health Care Visits decreased. However, the sample size for this variable was very small as there were only five missed visits for all of the participants over the study year. This represents a 2% missed visit rate for this participant population.

In the logistic regression analysis of HIV Viral Load Suppression, the variables that were included in the models were level of education (p value 0.07), Chance HLOC (p value 0.01), and Doctor HLOC (p value 0.12). Only the Chance HLOC (i.e., control over disease assigned to chance or fate) emerged as a significant predictor of HIV Viral Load Suppression. Participants with a high Chance HLOC score were less likely to have HIV Viral Load Suppression.

### Table 6.10. Multivariate Logistic Regression Model for HIV Health Care Visit Attendance and HIV Viral Load Suppression

<table>
<thead>
<tr>
<th>Variable</th>
<th>HIV Health Care Visit Attendance OR (95% Confidence Interval)</th>
<th>HIV Viral Load Suppression OR (95% Confidence Interval)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chance HLOC</td>
<td>NS</td>
<td>0.28 (0.10, 0.75)</td>
</tr>
<tr>
<td>Years of HIV Diagnosis</td>
<td>0.81 (0.67, 0.99)</td>
<td>NS</td>
</tr>
</tbody>
</table>
In sum, for the most part, neither the MHLC dimensions nor the participant characteristics had a significant impact on the outcome variables of interest – adherence to HIV Health Care Visits and HIV Viral Load Suppression. For HIV Health Care Visit Attendance, the longer the participant was infected with HIV infection, the less likely he was to attend their HIV health care visits (Table 6.10). This may be related to beliefs about the controllability of the disease and its chronicity or simply after years of living with HIV to feeling that in the long run missing an appointment is not going to affect health significantly. Thus, patients may not adhere to their visit schedule if they feel that their disease is under control or they may be experiencing health care visit fatigue. In terms of the HIV Viral Load Suppression, it makes intuitive sense that those participants who believe that they have no control over their disease (i.e., high Chance HLOC score) would be less likely to have HIV Viral Load Suppression (Table 6.10). If an individual does not believe that he can impact the course of his disease, he may not engage in behaviors that would enhance viral suppression (i.e., adherence to antiretroviral medication).

**HIV Health Care Visit Attendance and HIV Viral Load Suppression Data By MHLC Dimension**

Table 6.11 reflects how selected MHLC dimension scores relate to the outcome data of HIV Health Care Visit Attendance and HIV Viral Load Suppression. Data are presented for the number of participants who had a high score in each dimension in order to explore whether one or more dimension was dominant. Although the number of high scores in each dimension is presented (i.e., Internal, Chance, Doctor, Others), some of these scores were in combination with other dimensions (e.g., high Internal HLOC, high...
Chance HLOC, low Others HLOC). For example, a participant could have a high score in more than one dimension but each is counted separately in the first four rows of this table. Data are also presented for participants who had high or low scores in all four dimensions as well as for selected combinations of MHLC scores.

An overview of the data show that the number of high scores for each MHLC dimension was very similar with a range from 36 to 38. The percentages for higher visit attendance and viral load suppression were very similar among all four dimensions with the exception of the Chance HLOC dimension. The men who had a high Chance HLOC score were less likely to have HIV Viral Load Suppression at all time points during the study year, which is what was found in the quantitative analysis. The participants with high scores in the Doctor HLOC dimension had the highest percentages of HIV Health Care Visit Attendance and HIV Viral Load Suppression and were the least likely to have at least one episode of viral non-suppression.

In addition, data for those participants who had high scores or low scores in all dimensions are included. Although the numbers are small, those participants who had high scores in all of the MHLC dimensions had a higher occurrence of a missed health care appointment and at least one episode of viral non-suppression than those with low scores in all of the dimensions. For those with low scores in all of the MHLC dimensions, there was a higher incidence of viral non-suppression although all of these participants attended all of their health care appointments.
Table 6.11. HIV Health Care Visit Attendance and HIV Viral Load Suppression Data By Selected MHLC Dimension Scores During the Study Year*

<table>
<thead>
<tr>
<th>MHLC Score</th>
<th>Number (%) who Attended all HIV Health Care Visits and had HIV Viral Load Suppression at all time points</th>
<th>Number (%) who Attended all HIV Health Care Visits</th>
<th>Number (%) with HIV Viral Load Suppression at all time points</th>
</tr>
</thead>
<tbody>
<tr>
<td>High Internal (n=36)</td>
<td>19 (53%)</td>
<td>33 (92%)</td>
<td>19 (53%)</td>
</tr>
<tr>
<td>High Chance (n=36)</td>
<td>22 (61%)</td>
<td>33 (92%)</td>
<td>14 (39%)</td>
</tr>
<tr>
<td>High Doctor (n=38)</td>
<td>24 (63%)</td>
<td>36 (95%)</td>
<td>24 (63%)</td>
</tr>
<tr>
<td>High Others (n=37)</td>
<td>19 (51%)</td>
<td>33 (89%)</td>
<td>19 (51%)</td>
</tr>
<tr>
<td>High all dimensions (n=13)</td>
<td>6 (46%)</td>
<td>11 (85%)</td>
<td>6 (46%)</td>
</tr>
<tr>
<td>Low all dimensions (n=9)</td>
<td>5 (56%)</td>
<td>9 (100%)</td>
<td>5 (56%)</td>
</tr>
<tr>
<td>High Internal, Doctor, Others (n=7)</td>
<td>5 (71%)</td>
<td>7 (100%)</td>
<td>5 (71%)</td>
</tr>
<tr>
<td>High Internal, Doctor, Chance Others (n=4)</td>
<td>2 (50%)</td>
<td>4 (100%)</td>
<td>2 (50%)</td>
</tr>
<tr>
<td>High Chance Others (n=5)</td>
<td>2 (40%)</td>
<td>4 (80%)</td>
<td>2 (40%)</td>
</tr>
<tr>
<td>High Doctor Others (n=4)</td>
<td>4 (100%)</td>
<td>4 (100%)</td>
<td>4 (100%)</td>
</tr>
<tr>
<td>High</td>
<td>4 (100%)</td>
<td>4 (100%)</td>
<td>4 (100%)</td>
</tr>
</tbody>
</table>
Responsibility for Disease Management and Viral Suppression: Results from Semi-structured Interviews

In the semi-structured interviews I wanted to understand whether people infected with HIV believe that they are responsible for disease management and progression and overall health. Individuals who believe they have responsibility for their health would be expected to engage in behaviors that would enhance their health such as adhering to medication regimens. To elicit this information, the participants were asked who they thought was responsible for suppressing their HIV viral load. Do they think they are primarily responsible and if not, if anyone or anything else was primarily responsible? I also asked if HIV viral suppression (i.e., controlling their disease) made them feel successful. Given the moral overtones and perceived and enacted stigma associated with HIV infection, I wanted to know if they internalized the need to be responsible and translated that into feeling like a success or failure regarding viral suppression and would they use other qualifiers like “successful”, “failure”, “good” or “bad” in reference to themselves?

In the presentation of these data I was constrained in my freedom to include detailed characteristic and demographic information about participants to contextualize the quotes that are presented. The Infectious Diseases Clinic is small and the people who

<table>
<thead>
<tr>
<th>Doctor Internal (n=4)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>High Chance Internal (n=3)</td>
<td>1 (33%)</td>
<td>3 (100%)</td>
</tr>
</tbody>
</table>

* Note: 4 time points over the course of the study year for both HIV Health Care Visits and HIV viral load suppression. HIV suppression relates to a non-detectable viral load.
participate in the clinic for their HIV care are distinct individuals. The rich detail that permeates their responses could potentially identify them to those who know them thereby creating more burden for them than they already carry due to their illness. Their words, without identifiers, provide a lens into their lives and illness experience.

**Responsibility for Viral Suppression**

**Personal Responsibility**

Approximately two-thirds of the participants expressed the belief that they were primarily responsible when their HIV viral load was suppressed. They were very clear about their beliefs about personal responsibility.

It’s always an individual responsibility.

One of the older participants who has had the virus for about 10 years related,

Yes. I think so because I do what I’m told by the doctor.

Absolutely because I take care of myself.  
*(African-American man in his early 50’s who has been diagnosed for approximately 25 years)*

Demonstrating responsibility by following instructions given by their health care provider was a common theme. They used phrases like “doing what I’m supposed to do” and “doing what the doctor tells me to do”. Doctors, in addition to representing an authority figure, also served as a trusted person for their patients, because so many had little or no support system. This may be a major driver of their belief about responsibility and the significant role of the health care provider. Following orders was also expressed in militaristic terms by a few participants; “army discipline” and “obey the rules and regulations”. This was the only context in which any reference was directly made to their
military background, but the comments about doing what they’re “supposed to do” and what they are “told to do” may reflect this influence. Some also referred to the VA health care system and the need to follow the rules expressing concern that failure to do so might jeopardize their entitlements. One man, well over 60 years old, who has lived with HIV infection for almost 20 years said,

   First do exactly what I’m told to do by the doctor, don’t drink, smoke, get rest, don’t eat things I shouldn’t and eat things I should.

An African-American man in his mid-50s, who has been diagnosed with HIV for at least two decades, said,

   I’m responsible for doing what I’m told to do. Dr. X tells me to take these medicines. Can’t take credit for myself. If up to me, probably wouldn’t take my meds. They encourage me to do it and that’s a lot.

   Doing what they were told to do involves taking their antiretroviral medications, attending their HIV health care appointments, and engaging in positive lifestyle behaviors like “eating right”, exercising, getting enough rest, and avoiding drugs and alcohol. They discussed medication adherence as a primary driver of viral suppression. One participant talked about his “compliance with medications” using biomedical language that he clearly absorbed from his health care provider. Following doctors' orders is recognized as important in managing their illness.

   The participants who believed that they were not responsible for viral suppression ascribed responsibility to the antiretroviral medications, their doctor, and their higher power or “God”. This reflects the nuances in belief systems; for those who believe in personal responsibility, it is their agency that enhances viral suppression while for those
who don't it is their doctors and the medications that impact disease progression rather than their own actions. As one participant, who assumes responsibility, said,

   The doctor can only say here's your meds. You have to take the meds every day.

I gained more insight into this understanding by probing whether there was anyone or anything else that may be primarily responsible for viral suppression. Some of the participants said that they shared the responsibility for suppressing the viral load with their doctors or attributed the suppressed virus to the antiretroviral medications. Others believed the responsibility for disease progression was not in their control but rather in the hands of others who included doctors, who were the most frequently mentioned, family and friends, and God or a higher power.

**Doctors as Motivators**

   My doctor of course. That bond. The confidence you have between you and the doctor.

*(Hispanic man in his late 50s who has been infected with HIV infection for over 20 years)*

   A participant in his 60s with multiple psychiatric diagnoses and HIV infection for almost 15 years said,

   My doctor. The people who help me along. I couldn't do it myself but it’s basically on my back.

   The importance of trust and reliance on the physician is not surprising particularly in the face of chronic disease. What emerged from my interviews was that this reliance was intensified when the disease is so stigmatized that it is often not shared outside of the clinic creating an environment with little social support for many of those who are infected. The participants talked about the secrecy of their HIV infection and not
speaking to anyone else about it except their health care provider. One man said that he couldn’t identify anyone else who is responsible because he keeps his illness hidden.

I don’t speak about it to anyone else. Keep it to myself.

Some participants acknowledged that the VA health care system and its staff were responsible for their disease suppression. A man well over 60 years of age, with the disease for almost 15 years, said,

Very few things you do by yourself…the VA doctors, all the people the VA provides access to.

I’m lucky to have the VA or I’d be dead by now. I feel safe when I’m here.

(Hispanic man in his 50s with a diagnosis of HIV infection for almost 20 years)

Although only a few of the participants mentioned the health care team, it is clear from spending time in the ID clinic that there are other people with whom the men are comfortable discussing their HIV infection. The clinic nurses, the ID administrative assistant who schedules appointments and fields patient calls when clinic is not in session, and the PA-C are all available and willing to talk to the patients. Yet it is during the clinical appointment that much of the discussion of disease progression and management takes place. The time with the health care provider provides an opportunity to discuss other issues that impact health as well (e.g., smoking cessation; housing) and to talk openly about their disease and illness without fear of repercussions.

**Family and Friends as Social Support**

The significance of the social support system is clearly referenced in how the participants talked about who or what was responsible for the management of their
disease. This support system was primarily related to spouses and parents and, as this man indicated

The people surrounding you who care about you regardless of who you are.
*(An African-American man in his mid-50s who has had HIV infection for less than 10 years.)*

One participant said that his mother reminded him to take his medications, and another man said that his “grandkids” were responsible because he wanted to live to see them grow up.

An African man in his 50s who has had HIV infection for only a few years said,

My wife and family. They’re very supportive. That's helpful.

My wife since I live with her. She knows and isn’t ignorant of the disease. It makes it easier. Don’t talk about it much. She accepts me. That’s the most important thing.
*(A Caucasian man in his 50s who has been diagnosed with HIV for over 20 years)*

Some of the men recognized that being “accepted” and cared about “regardless of who you are” had a profound effect on disease and health. They attributed viral suppression to their support system. This is particularly poignant given the stigma and marginalization that many people infected with HIV face and their lack of spouses or partners and family and friends to lean on. It is interesting to note that some of the participants have disclosed their illness to their families or significant others but indicated that no one talks about it like the man quoted above who said they “don’t talk about it much”. He seems to value acceptance more than being able to talk about his illness. Optimally, though, the ideal environment would allow people feel accepted and also be able to share thoughts, feelings, and the burden of the illness.
Spiritual Beliefs: God and Higher Power

For some of the men I interviewed success or failure at viral suppression was ascribed to fate, but for most of them it was about faith. This is not surprisingly given that 85% ascribed to a religious affiliation, mostly Christian. Approximately one-third of the men I spoke with talked about God in relation to their illness. Of the participants who talked about God, approximately three-quarters were African-American and over half of this group had been infected with HIV for two decades. There were only a few Hispanic men who talked about God but they represent almost half of that ethnic group in the participant population. The following quotes illustrate their reliance on God:

Just me and God
(A man well over 60 years of age who has been diagnosed with HIV infection for almost 20 years)

God has everything to do with my life as far as my health is concerned. I have no control over it.

God. Who could do what he does?
(African-American man in his mid-50s who has been diagnosed with HIV infection for almost 25 years)

Some of the men believed that they had no control over their disease or health, while others said that they shared the responsibility with God or a higher power.

I realize that it’s something I have to accept and it’s up to my higher power and my doctor to control it or get rid of it.
(Hispanic man in his 60s who has been diagnosed with HIV infection for less than 10 years)

An African-American man in his mid-50s who has been diagnosed with HIV infection for almost 25 years believed the responsibility was shared between God and the medical team expressing that he had no control.
God has everything to do with my health; along with the doctor and nurses. I have no control over it.

Another African-American man in his early 50s who has been diagnosed for approximately 25 years had a holistic perspective about managing his disease,

“God, the medical team, my family, the whole picture. Well I can go into my spiritual thing. I pray and thank God on a daily basis but with the medical team and the love of my family helps. It's the whole picture. I have a lot of support, tremendous amount. It makes a difference. It affects your attitude, how you view yourself.”

Feelings about Successful and Unsuccessful Viral Suppression

I was curious about how the men responded to successful and unsuccessful viral load suppression and asked them directly about this in the interviews. To understand the nuances of belief systems related to responsibility, I asked whether they felt successful when their HIV viral load was suppressed and paid careful attention to the use of words like “success”, “failure”, “good”, or “bad” when they discussing their agency and disease progression. Society tends to “blame” people for acquiring the disease based on lifestyle choices so the use of these words might elucidate whether people infected with the virus internalized this “blame” if their virus was not suppressed.

Feelings of Success

Some of the participants clearly felt a sense of success and accomplishment in relation to viral load suppression and talked about the importance of having a positive attitude, as this man noted:

Yes. From day one I feel very successful because people who
contracted the disease, they're dead in less time than I had it and I'm still here.

(African-American man well over 60 years of age who has been diagnosed for almost 20 years)

Another man in his 50s, who has been infected for over 10 years, said,

I’m keeping the virus under control. I was told early on to have a positive attitude so I would have positive outcomes.

I tell myself I'm standing up against HIV. I laugh to myself a lot because I got the best of it.

(Caucasian man in his 60s with HIV infection for over a decade)

Some of the men used words like “good,” reflecting their need to be good and “to do what I’m told to do.” They expressed feeling proud of themselves for doing the “right thing” lending some insight into the common theme of having made “bad” choices in the past.

It makes me feel good. Proud of myself. I’m doing the right thing. I share with the whole family, my wife, my sister, my son.

(African-American man in his early 50s who has been diagnosed for over 25 years)


(African-American man in his mid-50s who has been diagnosed for over 20 years)

**Feelings of Gratitude**

A number of the participants expressed gratitude rather than feelings of pride or success in relation to viral suppression. One man in his 60s, who has had the infection for a decade, said that it wasn’t a “success-failure thing” but that he just felt grateful.

Another man who has been infected with HIV for over 20 years said that when his viral load was non-detectable he “got to live another day”. Some talked about “doing what I
need to do to survive,” referring to both adherence to and the effectiveness of the medications. Some of the participants talked about having watched others die who didn’t have access to treatment, hadn’t been adherent to their antiretroviral medication, or had continued to participate in risky behaviors. This “survivor” perspective has created an awareness of feeling grateful.

Yes because I know a lot of people who didn’t survive.
(African-American man in his early 50s who has been diagnosed for over 25 years)

Not feeling successful

There were some participants who said that they did not feel successful despite having a non-detectable viral load. This may reflect their realization that viral suppression is not easy to achieve and that viral resistance often occurs in spite of medication adherence leading to disease progression. Many of the participants had at least one episode of viral non-suppression over the course of the study year. One man said that he doesn’t feel successful but feels less worried while another said it was “part of God's plan.” A Caucasian participant in his 50s who had the infection for over 20 years said,

No, I'm just glad the med I'm now taking is strong enough to make me not get sicker.

No. I feel I'm doing the best I can do under situation. Not jumping for joy.
(African-American man in his 60s who has been diagnosed for almost 10 years)

Feelings when Viral Load Is Not Suppressed

I also asked the participants how they felt when they were not successful in suppressing their viral load, what they thought was responsible for failure, and whether
they felt they had failed themselves or others. Approximately half of the participants said that they would feel responsible if their viral load was not suppressed like this man:

Me. That’s me because of something I did wrong.

*(African-American man in his 40s who was diagnosed with HIV infection over 10 years ago)*

Many men had experienced a detectable viral load at some point during their illness and most related it to non-adherence to their medication regimens. This reiterates the strong sense of responsibility that many people with HIV infection feel to manage their illness. They not only feel responsible for positive results but also take responsibility when the outcome is not favorable. It was not completely clear that all of the men were aware that viral non-suppression can occur even with strict adherence to medication regimens. One participant, who is in his 50s, with multiple psychiatric diagnoses and Hepatitis C, said,

I start recollecting about missed doses. Not much you can do when you miss a dose. Just be aware. It's not deliberate. I take so many meds you just forget.

An African-American man who was one of the oldest participants, and has had HIV infection for almost two decades said,

I didn't take meds on time. I was disobedient to myself, not the doctor. The doctor told me what to do. I took a gamble. Thought I didn't need it but I do.

A few believed that they had some responsibility but that viral resistance was also a factor. This is in contrast to those participants who took full responsibility for viral suppression despite the fact that they cannot fully control the virus.

I don't know what caused it. Is my body immune to drugs? Did I do something wrong? Combination of both.
(An Hispanic man in his late 50s who has been diagnosed for over two decades)

60% me; 40% resistance.
(African man in his 50s who has had HIV infection for almost a decade)

The participants who did not assume responsibility for a detectable viral load ascribed failure to suppress to lack of efficacy of the antiretroviral medications or the virus “becoming more aggressive”, which relates to viral resistance. Their sense of responsibility is mediated by the reality that viral suppression is difficult to achieve and maintain. A few of the men assigned responsibility to fate believing that they have no control over disease progression. One of the men said, “No. Fate. It is what it is”. None of the participants blamed other people, their doctors, or God; they blamed themselves and fate.

A man who is in his late 50s who has been diagnosed with HIV infection for a few years said,

No just the med. It happened when the meds stopped working. I don’t get depressed. Even sickness builds resistance. I just took a different med and I knew the doctor will do the right thing. Me and my doctor, we’re partners. I do my part and he does his part.

Approximately a third of the participants said that they held only themselves responsible when viral load was not suppressed. When asked if anything else could be responsible they said things like "just me" and "only me". These beliefs are present even though most have the understanding that HIV has the ability to mutate and become resistant to the antiretroviral medications. Although viral resistance is more common in the presence of non-adherence to medications, it can also occur in people who are strictly adherent to their medication regimen. The sense of responsibility is compelling in view of
the medical uncertainty of effectively controlling the virus and the deeply rooted cultural ideology about individual responsibility.

Others believed that they shared responsibility for non-suppression with their doctors and the antiretroviral medications themselves. Some thought that the medications were “not strong enough” or were “not working anymore”. This reflects an understanding that viral resistance is often the reason for a detectable HIV viral load. A Caucasian man in his 60s who has been diagnosed with HIV infection for almost 15 years said,

No, because I would see if I missed a dose here and there but I don’t. Maybe the pills aren’t working anymore.

A man who is in his 50s who has lived with HIV infection for over 20 years attributed disease progression to the failure of his body to suppress the virus.

No, my body. Me, myself, no, because since I decided to fight this. I take my meds at the right time. I don’t like losing…me against this virus.

For others, responsibility fell to their mental illness or addictions. A few talked about their alcohol abuse while one man discussed his addiction to sex which he thought impacted his ability to fight the virus. Although he did not have a clinical diagnosis of depression, one man in his mid-50s who has had HIV infection for over five years, said, ...could be depression that's partly responsible.

Other participants believed that suppressing the virus is not under their control. An African-American man in his mid-60s who has long-standing HIV infection expressed,
Feelings of Failure with Viral Non-suppression

Participants' responses to my questions about whether failure to suppress the virus made them feel like a failure to themselves or others indicated that only a small number felt a sense of failure when their viral load was not suppressed. They voiced responsibility for management of their disease even in the face of other contributing factors like viral resistance. One man believed he was responsible because he knew he had not been strictly adherent to his medication regimen. Another talked about failing his family, friends, and doctor stating that everyone tried to help but it was his fault that his viral load was detectable.

Certainly I feel failure because I’m the one responsible for the virus in my body so I’m a failure that it’s there but as far as the progression of the viral load, that’s something I have tried to control. Then if it gets detectable then it’s because I’m not being treated properly.

Of course, because I don't want to fail. It's a function of the strength of the virus versus the treatment available. There's only so much I can do.

Me or the meds. I failed or something failed like the drugs. (An Hispanic man who is in his mid-fifties and has been diagnosed with HIV infection for over two decades)

An African-American man in his late fifties who has been diagnosed for less than ten years said,

No, just stupid. All I had to do was take the medicine.

We're responsible for our problem. The doctor helps you but the problem is yours. (An Hispanic man in his mid-50s who has been living with HIV infection for a few years)
Interestingly, though, the pervasive response from participants was denial of the feeling of failure. They attributed disease progression to factors outside of their control such as viral mutations, God, and fate.

    No, I always take my med. I can't affect the way the meds work in my body.

A Caucasian man in his 60s who has had HIV infection for at least 15 years said,

    No, its just part of life. I also believe HIV has a mind and a will of it’s own and I try to outsmart it.

Gratitude surfaced again as a response to disease progression. One man, who is in his mid-50s with over 20 years of experience living with HIV infection, said with respect to feeling like a failure,

    No, no, no…so many people passed away. I'm so grateful.

    Others did not relate to the concept of failure and viewed viral non-suppression as a call for action. An African-American man in his mid-50s who has been diagnosed for less than 20 years used militaristic terms to discuss his response to failure to suppress:

    Ask what I need to do. Snap into line. Got to step it up.

    In sum, the concept of responsibility peppers the narratives of most participants when talking about their illness; responsibility for their health and for disease management (i.e., viral suppression). Their relationship with their health care provider and their reliance on their spiritual entities are also significant elements of their belief systems. They talk about obedience; following their doctor’s orders and obeying the rules and regulations. This speaks in part to the authoritative role of the physician in the
biomedical system but may be also driven by their military background and the social and economic control of the VA health care system in their lives.

**Beliefs about the Ability to Impact Disease Progression**

Through the interview process, I wanted to explore how the participants understood their illness experience and their role, if any, in trying to limit disability and disease progression. In particular, I asked whether they felt they had the ability to impact the course of their disease (i.e., have some control over it) and how that related to engaging in health optimizing behaviors. I also wanted to understand whether people who do not believe they have control over disease progression still try to impact it’s course as opposed to becoming fatalistic about the outcome. These questions were raised with the understanding that beliefs and any related agency may not successfully translate to disease suppression.

**Taking Medications, Living Healthy Lifestyles, Maintaining a Positive Attitude**

Of the 57 men who participated in the interview component, well over half clearly expressed their belief that they could affect the amount of HIV in their blood. Some felt that they could do so with the help of medications, their doctor, and/or God. Only a small number talked about not having any control over their disease or that control was in the hands of others (e.g. doctor; God).

Among those who believed that some measure of control is possible, the themes discussed were similar to those that emerged when talking about responsibility for disease management: the importance of antiretroviral medication adherence; following
the instructions given by their health care providers; and making good lifestyle choices, as these men explained:

Yes, I can, by taking the medicines and continuing to take care of myself and not doing what I used to do.”
*(African-American man in his late 50s who has been diagnosed with HIV infection for less than five years)*

If I don't take med. Drug interruptions a big thing a while ago. Didn't work out for me.
*(African-American man in his early 50s who has been diagnosed with HIV infection for over 10 years)*

I know I need to take my HIV medicine but it’s beyond that. You have to live healthy in every way, um, and what you do. Get up at a certain time, get enough sleep, get enough exercise, eat your food, pay your bills so there’s nothing stressful in your life. Don’t hang out with people who don’t do good things, use drugs or steal or get in trouble.
*(African-American man in his early 50s who has been diagnosed with HIV infection for less than 10 years)*

According to many of the participants, impacting their disease was not only about positive actions, it was also about avoidance of behaviors and choices that could have adverse effects on their health and the disease. An awareness of the deleterious effects of alcohol and drug use was apparent, particularly in combination with antiretroviral medications. One man said, “drinking, drugs, not taking meds speeds it up.” Another talked about being a “lifetime drug addict” and said “taking drugs affects how the meds work.”

A few of the men talked about avoiding behaviors that could potentially cause re-infection. They have been educated, primarily by their HIV health care providers, about the risk of acquiring a different strain of HIV (i.e., a drug-resistant strain) through risky
behavior such as sharing needles or participating in unprotected sex. One man said that he could impact his disease by a “lack of habits that cause reinfection”.

Only a few of the participants said that didn’t believe they could impact the course of their disease. “It’s too tricky.” One man said he could “make it better” by taking medications as a precaution but that disease management is the responsibility of the doctor. Another participant who is well over 60 years of age, with HIV infection for almost 20 years said that he could get “rid of it through faith if you have enough belief, enough faith.”

Many of the participants expressed an understanding of what they needed to do to impact the course of their disease. This likely reflects information that they have received from discussions with their health care providers as well as their personal experience with the disease. Many of these men have watched others who had not engaged in health-optimizing behaviors and suffered deleterious effects or didn’t survive.

Because you’re healthy and it affects your health and if your health is deteriorating then the virus has a free ride, but if your organs and your basic metabolism is a function of the exercise, the health and lifestyle you lead then the virus is going to be suppressed and is going to be contained by the regimen you’re on.

If I were to drink or smoke, if I were sedentary and ate poorly, I think my viral load would go up tremendously regardless of the regimen.

I take care of myself. I exercise. I don’t drink. No cigarettes. No drugs. My whole lifestyle is healthy. I’m better off with HIV. If not I might have gone on with a bad lifestyle. I grew up after I found out.

(African-American man in his early 50s who has been diagnosed with HIV infection for less than 10 years)
The men's beliefs about the importance of adherence to antiretroviral medications were predominant, which reflects a biomedical understanding and hence the influence of their doctors and other providers as well as their own experience. As previously noted, many of the men had experienced HIV viral progression when they had not been taking antiretroviral medication or had seen a similar effect with other people infected with the virus. They defined a healthy lifestyle as getting exercise and rest, eating a healthy diet, abstinence from drugs, alcohol, and tobacco. They also identified the importance of having a “positive attitude” or mindset.

Some of the things the participants talked about as health-enhancing included; “socialize with different people”; “follow doctor orders”; “don't do things detrimental to my health”; “continue to take meds. Pray. It helps you a lot.”; “No promiscuity, no drugs, no stress.”; “live healthy”; “safe sex…pray”; “living clean”. One man, in response to the question, replied, “hope”.

Table 6.12 summarizes the behaviors and lifestyle choices that emerged when the participants talked about impacting the course of their disease. Adherence to antiretroviral medications is only one piece of the “illness work” that people infected with HIV feel that they must to do to manage their disease.
Table 6.12. Impacting HIV Infection

<table>
<thead>
<tr>
<th>Impacting HIV Infection</th>
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<tbody>
<tr>
<td><strong>Adherence</strong></td>
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<tr>
<td>Antiretroviral Medications</td>
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<tr>
<td>Health care appointments</td>
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<tr>
<td>Prescribed medical orders</td>
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<tr>
<td><strong>Healthy Lifestyle</strong></td>
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<tr>
<td>Diet</td>
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<tr>
<td>Rest</td>
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<tr>
<td>Exercise</td>
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<tr>
<td>Positive mindset</td>
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<tr>
<td><strong>Avoidance</strong></td>
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<tr>
<td>Stress</td>
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<tr>
<td>Drugs and alcohol</td>
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<tr>
<td>Smoking</td>
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<tr>
<td>Reinfection</td>
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<tr>
<td>Unprotected sex</td>
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<tr>
<td>Shared or old needles</td>
</tr>
<tr>
<td>People with risky behavior</td>
</tr>
<tr>
<td><strong>Prayer</strong></td>
</tr>
<tr>
<td><strong>Hope</strong></td>
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</tbody>
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In sum, this line of questioning revealed that almost all of the men believed that there were measures and behaviors that they could undertake to impact disease progression and morbidity. This gave them a sense of hope and some control over their lives, which is important for those who are afflicted with a disease that is associated with significant mortality. The participants have been educated about their responsibilities related to suppressing the virus and optimizing their health. Strict adherence alone is difficult to achieve but to add the other lifestyle behaviors that they talk about multiplies...
the self-care that is expected of them. Belief in the ability to impact HIV progression ultimately provides hope but also intensifies the burden of the person who is ill.

Integration: Feelings about Personal Responsibility for Health and Disease Management Outcome Data

The following discussion reflects the analysis of the qualitative data from the semi-structured interviews with the outcome data (i.e., HIV health care visit attendance; HIV viral load suppression), which provides some insight into the potential translation of belief systems into agency. Quantifying qualitative data risks reductionism yet I believe that this quantitative information may enhance our understanding of how people think about their illness. In quantifying responses to the interview questions, I used only those responses that were definitively “yes” or “no” or “me” as a preface to the rest of their answer to questions about responsibility. This analysis is not hard quantitative evidence but rather provides some information about how the participants talked about responsibility and impacting their disease and how their beliefs relate to adherence to care (i.e., HIV Health Care Visit Attendance, HIV Viral Load Suppression).

Responsibility for Viral Load Suppression

Table 6.13 details the number of the participants who believed they were responsible for viral suppression and non-suppression and the extent to which they related to the concepts of success and failure.
Table 6.13. Participant Responses to Interview Questions related to Responsibility

<table>
<thead>
<tr>
<th>Interview Questions Related to Responsibility</th>
<th>% Yes Response</th>
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<tbody>
<tr>
<td>What do you think when your health care provider tells you your viral load (i.e., amount of virus in your blood) is well controlled? Do you think you are primarily responsible?</td>
<td>61%</td>
</tr>
<tr>
<td>Does this make you feel successful?</td>
<td>56%</td>
</tr>
<tr>
<td>What do you think when your health care provider tells you your viral load (i.e., amount of virus in your blood) is not being well controlled? Do you think you are primarily responsible?</td>
<td>44%</td>
</tr>
<tr>
<td>Does this make you feel like a failure?</td>
<td>14%</td>
</tr>
</tbody>
</table>

The data show that 61% of the participants believe that they are responsible when their HIV viral load is suppressed suggesting that many believe in their ability to impact the course of disease progression. As previously discussed, many of the participants talked about the importance of taking antiretroviral medications as prescribed and participating in other positive lifestyle behaviors in suppressing the virus. Over half of the participants felt successful when their HIV viral load was suppressed which suggests that they believed their actions could impact the course of their disease and translated into positive results. This data suggests that many of the participants believe that they can impact the course of their disease through their actions and that when they receive positive results they feel that they are able to make a difference in their health status.

When asked about personal responsibility in relation to non-suppression of the virus, only 44% believed that they were responsible. As previously discussed, the
participants felt that there were other reasons for non-suppression over which they had no control (e.g., viral resistance) which may help explain why only 14% felt as though they had failed when the virus was not suppressed. It is interesting to note that, in general, they felt successful when their HIV viral load was suppressed but did not feel like a failure if it was not suppressed. This may be an indication that they understand that viral load suppression is not completely under their control. Even with strict adherence, some people are unable to achieve a non-detectable HIV viral load due to their response to the medications or viral resistance among other factors.

Table 6.14 shows that of the participants who ascribed responsibility to themselves for viral load suppression, 60% had a non-detectable viral load during the entire year on study. All of these participants attended all of their HIV health care visits. Seven participants said that they did not believe they were responsible for HIV viral load suppression and of these men, only 43% had a suppressed viral load over the course of the study year and five of them (71%) attended all of their health care visits. All of the participants were suppressed at some point during the study year. The remaining participants were either unclear in their response or believed that they shared responsibility for viral load suppression with others who included their doctor, family and significant others, and God. The data suggests that the participants, who believed they were responsible for viral suppression, also engaged in the health-enhancing behavior of attending their health care visits. The fact that 60% of these participants achieved 100% viral load suppression over the study year exceeds the result found by Braithwaite et al. (2010) of 40% in the U.S. Veteran population.
Beliefs about Impacting Disease Progression and Outcome Data

When asked whether they believed they could impact the amount of HIV in their blood, 63% of the participants responded affirmatively (Table 6.15). Of these men, 97% attended all of their HIV health care visits but only 58% had a suppressed viral load over the course of the study year. Of the 14% of participants who expressed a lack of ability to impact disease progression, only 50% achieved viral suppression and only three-quarters attended all of their HIV health care visits. Belief in the personal ability to impact disease progression seems to have a weaker effect on HIV viral load suppression than beliefs about responsibility for disease progression. It may be that beliefs about the ability to suppress the virus are mitigated by the illness experience and having had a non-suppressed viral load in spite of adherence to medication regimens. There may also be
dissonance between beliefs about importance of positive lifestyle behaviors and choices and the ability to engage in those behaviors.

Table 6.15. Participant Beliefs about Impacting Disease Progression and Adherence Outcome Data

<table>
<thead>
<tr>
<th>Number (%) who believe they can impact disease progression</th>
<th>Number (%) Attended all HIV Health Care Visits</th>
<th>Number (%) with HIV Viral Load Suppression</th>
</tr>
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<tr>
<td></td>
<td></td>
<td>4/4 time points</td>
</tr>
<tr>
<td></td>
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<td>3/4 time points</td>
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<td>2/4 time points</td>
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<tr>
<td></td>
<td></td>
<td>1/4 time points</td>
</tr>
<tr>
<td>Yes 36 (63%)</td>
<td>35 (97)</td>
<td>21 (58)</td>
</tr>
<tr>
<td>No 8 (14%)</td>
<td>6 (75)</td>
<td>4 (50)</td>
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<tr>
<td>Ambivalent or unclear 13 (23%)</td>
<td>13 (100)</td>
<td>5 (39)</td>
</tr>
</tbody>
</table>

* Note: 4 time points over the course of the study year for both HIV Health Care Visits and HIV viral load suppression. HIV suppression relates to a non-detectable viral load

Integrating Locus of Control, Attitudes towards Responsibility and Ability to Impact Disease, and Adherence Outcome Results

In this section I integrate the quantitative and qualitative results to gain some understanding of how people infected with HIV think about their illness and the construct of responsibility and then link these qualitative results with the locus of control (MHLC) and adherence outcome results. I include information on the number of years form HIV diagnosis to help further contextualize the data.

Among participants who had high scores in all of the MHLC dimensions (Internal, Chance, Doctor, Others), there was little consistency in how they talked about responsibility for disease progression. This reflects how the beliefs about locus of control can be concurrent. One man who has had the infection for 19 years said that it is “always an individual responsibility” but that the outcome is part of “God’s plan”. He had rarely missed any doses of antiretroviral medication but the virus was only suppressed at 75%
of the time points. Another participant said that the responsibility for viral suppression belongs to the medications. This man has been infected with the virus for 17 years and missed one of the health care visits and had viral suppression at 75% of the time points. Another man who was diagnosed six years ago said that responsibility for disease progression was shared between him and “God”. He talked about HIV as a death sentence and said that when his viral load was detectable that it could be due to depression. He attended all of his health care visits but had viral suppression at only one of the time points. Overall, participants with high LOC scores showed little consistency in how they talked about responsibility and with whom they shared it.

Inconsistencies also exist with participants who had low scores for all of the MHLC dimensions. One participant who has had HIV infection for 10 years, expressed no beliefs about responsibility or the ability to impact disease progression but attended all of his health care visits and had consistent viral suppression. For him, HIV infection is “not a death sentence anymore.” He shared that his family doesn’t know about his illness and that he only talks about it to others who have HIV infection. Another man who has had HIV infection for the same period of time, expressed responsibility for his disease management and affirmed that he believed he could impact it. Although he attended all of his health care visits, he had viral suppression at only one of the four time points. He talked about the importance of his family support although this was not reflected in his MHLC Others score. One other participant with all low scores talked about responsibility for viral suppression but also had a non-detectable viral load at only one of the four time points. He was diagnosed with HIV infection 18 years ago and said, “they say it’s a death sentence”.
There was more consistency for those participants with high MHLC Doctor scores. They talked about sharing responsibility for disease management with their doctors and being able to impact the course of their disease. Most attended all of their health care visits and had consistent viral suppression. One man who has had the infection for seven years believes he can affect disease progression and shares responsibility with his doctor. He said that he thinks about HIV every day. Another participant who was diagnosed 20 years ago said that he is responsible for doing what his doctor tells him to do. He shared that he feels alone with his illness and “lives in secrecy.” He has been diagnosed with depression and anxiety yet he attended all of his health care visits and had consistent viral suppression like the others discussed. This data highlights the significance of the relationship with the health care provider.

Two participants who had only high Other HLOC scores differed in how they talked about their illness. Both have had HIV infection for over 20 years. One of the men, who suffers from depression and anxiety, expressed that it was “too tricky” to impact the course of his illness and he didn’t think about responsibility in relation to his illness. This man attended three of four health care visits and had viral suppression at only one of the time points. He says that he tries not to think about his HIV infection and didn’t talk about people who impact his life. There was little congruence between his high Other HLOC score and the significance of other people or entities. The other participant believes that he can impact disease progression and said that he shared responsibility for viral suppression with God and the doctors and nurses. He said that “everyone expects to live forever, I don’t” but that with strong faith, God could rid him of the virus. This man attended all of his health care visits but had viral suppression at only two time points. For
this participant, there was some consistency between his MHLC score and the importance of others that he expressed during the interview.

Many of the participants who had a high Chance HLOC score, attended all of their health care visits but did not achieve HIV viral load suppression at all time points. Interestingly many of them expressed a high level of responsibility for viral load suppression but were ambivalent about the ability to impact disease progression. One participant, who has been infected with HIV for 11 years, attended all of the health care visits but only achieved viral suppression at half of the time points. He shared that he feels responsible because “too much partying” caused him to acquire the virus, but that he was acting responsibly because he was taking his medications. Another man said that he was responsible for viral suppression but did not believe he could impact disease progression. He attended all of his health care appointments and had viral suppression at 75% of the time points. He has had the disease for 18 years and shared that no one knew that he has been taking antiretroviral medications and that he doesn’t “see anyone anymore” by his choice. He has been diagnosed with depression. A participant who has only had HIV infection for seven years, expressed a high sense of responsibility and thought that he might be able to impact disease progression. He shared that he doesn’t think about his illness and tries to always be a “positive person”. One of the men with a high MHLC Chance score but a low Others score, talked about sharing responsibility with his doctor and his support group of friends who also have HIV infection. He has had the infection for 16 years but said that it is a “daily disease”. He attended all of his health care visits but only experienced viral suppression at half of the time points. He has been diagnosed of depression. In reviewing the participants who had a high MHLC
Chance score, the only consistencies seem to be that they express a belief in their responsibility for disease management but have difficulty achieving consistent viral suppression. They also tended to have a higher incidence of other co-morbidities (e.g., depression; anxiety, Hepatitis C).

None of the participants had only a high Internal HLOC score. This dimension was always associated with other dimensions with a high score, most typically Doctor and/or Others. One participant who had high scores in both the Internal and Doctor dimensions has had HIV infection for 17 years. He believes that he shares responsibility for disease progression with his doctor. He doesn’t think about his illness because he considers it controllable and that it is “up to me to do everything.” Another man who had high scores in the Internal, Doctor, and Chance dimensions expressed little responsibility but believes he can impact the course of his disease. He said that he takes his medications but “can’t affect the way the meds work in my body.” He has had HIV infection for 23 years. The Internal dimension seems to be an adjunctive component of locus of control rather than a primary focus.

**Summary**

In sum, the quantitative and qualitative analyses discussed in this chapter illuminate themes related to beliefs about responsibility for disease progression and health optimization. The MHLC survey data provided insight into beliefs about whether people infected with HIV believe they have control over their health and their disease. The availability of outcome data allows further exploration into whether beliefs translate into agency. The quantitative analysis found that the Chance HLOC was significant for
predicting non-achievement of HIV Viral Load Suppression. This is not surprising given
that one would expect that if someone believes strongly that health and disease
progression are related to chance or fate, they may be less likely to engage in behaviors
that would optimize viral load suppression (e.g., medication adherence). Wallston and
Wallston (1982) found that people with chronic illness tended to have a high scores in the
Chance HLOC and Others HLOC dimensions and hypothesized that they shifted
responsibility for their illness over time to their health care providers and their family,
significant others and friends. The information obtained in this research shows that the
majority of the participants assume responsibility for not only acquiring their disease but
for helping to suppress it.

My original hypothesis for this research was that individuals with greater Internal
HLOC would be expected to maintain better adherence to their medication regimens and
participate in health-enhancing behaviors to optimize therapeutic benefit resulting in HIV
viral load suppression. The results show that the hypothesis was not upheld. While it
seems intuitive that people who take responsibility for their health would have a high
Internal HLOC, this dimension did not significantly predict either HIV Health Care Visit
Attendance or HIV Viral Load Suppression. It would be of interest to study HLOC with
people who do not have access to health care and treatment or are receiving an incentive
for viral suppression. What does hold true is that people seem to hold concurrent beliefs
about responsibility for management and control of their disease. All of the MHLC
dimensions (Internal HLOC, Chance HLOC, Doctor HLOC, Others HLOC) were
similarly distributed in various iterations for the participants. Some assumed full
responsibility for their health, others shared responsibility with their social support
system, their doctor, or a spiritual entity, and some felt that their health was controlled by fate. Most assigned responsibility and control to multiple entities validating that HLOC beliefs are concurrent.

The other significant finding from the quantitative analysis was that the length of time the participants had been diagnosed with HIV infection predicted their attendance at their HIV health care visits; the longer the years of diagnosis, the lower the attendance at HIV health care visits. Possible explanations might include visit fatigue due to years of attending multiple visits per year for health monitoring, or that some felt that their disease was under control and that they only need to see their HIV health care provider when they are feeling ill. This finding bears more research to try to understand how people think about their health care visits. What is more interesting is that the percentage of missed health care visits is so low for the participants in this study. This may be driven by the access to health care that is provided to those with VHA benefits eliminating financial barriers to health care visit attendance. It is not known if this is representative of the overall population of people infected with HIV in developed nations.

Although the quantitative analysis did not show any statistical significance for the Doctor dimension related to the outcome data, it is apparent that those participants with a high Doctor score were more likely to have HIV Viral Load Suppression and to attend all of their HIV Health Care Visits. The influence of the physician may seem intuitive given the seriousness of the disease and the need for treatment to prevent morbidity and mortality. This may also reflect the authoritative status of biomedicine within society, and the social control of biomedicine and resultant sufferer reliance on the health care provider. Yet the interview data illuminated that this reliance on the health care provider
also has a social support component. For those individuals who hide their illness and do not talk to anyone about it, the opportunity to trust and talk to their doctor intensifies the relationship.

The value of HLOC for this research was in trying to determine if the participants believed they had responsibility for and control over their health and where these beliefs were situated. This information, in the context of the interview and outcome data, provided an opportunity for multi-layered analysis. In general, the results of the MHLC survey did not provide any consistent or significant findings to help us understand how people infected with HIV think about responsibility and control in relation to their illness. It does suggest, as Wallston came to realize, that it is not as important to know where the LOC is situated but that it exists.

The interviews provided insight into the beliefs held about responsibility for health and disease management as well as the illness experience. Responsibility is clearly a driving force in most of the participants' lives; responsibility for acquiring their illness and for impacting disease progression. In this participant population, many of the men believed that they could impact disease progression and this may be one of the most significant findings because it indicates they have hope. They talked about a constellation of behaviors and choices that they believed would impact the amount of virus in their bodies.

The interviews also gave the men an opportunity to share their thoughts. Even though many said that they “don’t think about it”, they talked about it. They shared with me the ways that they think about their illness, their beliefs about disease management and health optimization, and how they feel about viral load suppression and non-
suppression. Some only spoke to their health care team members, mostly their doctor, about their HIV infection. Most expressed their gratitude for the opportunity to talk about it even though it was clearly an uncomfortable experience. It is significant to note that many of them waited after their clinic appointment to participate in the interview, and some scheduled time to come back to the clinic to do so. They were not compensated for the interview, but many told me how valuable it was to be able to talk about their illness and tell their story to a nonjudgmental person.

As the interviews progressed, I could see some of the threads that comprised their belief systems about disease and illness. Their beliefs were constructed by how society views HIV infection and those who have acquired it. They experienced or perceived the stigma, and it constrains their activities and their social relationships.

Their reliance on their health care provider was driven in part by the need for the biomedical treatment. Whether they believed they could impact disease progression and assumed responsibility for managing their disease or the converse, the themes that emerged were the importance of adherence to antiretroviral medications and health care provider instructions, engaging in health-enhancing lifestyle behaviors and choices, and maintaining spiritual beliefs. Of note, the lack of access to health care or medications was not expressed by any of the participants, which might heighten their sense of responsibility. Gratitude was often expressed for the entitlements and access to care and support services provided by the VHA. These men were aware that others do not have the same access to health care and medications. While there may be other mitigating factors that might affect responsibility (e.g., mental illness and substance abuse), access to medications and care was not an issue. While reliance on biomedicine and their health
care provider is understandable for disease management, some of the participants expressed that the psychological and social aspects of HIV infection are not adequately addressed by biomedicine.

The following chapter will attempt to synthesize the quantitative and qualitative findings that have been presented to contribute to the understanding of the belief systems and illness experience of people with HIV infection.
Chapter 7  Synthesis and Discussion

“In the course of socially constructing an illness, symptoms are identified, and the disease is named. Theories of origin, transmission, prevention, and cure are formulated, promulgated, criticized, and revised. Responsibility and blame often are assigned. Those who contract the disease come to be regarded as victims or patients, guilty or innocent, dangerous or benign, heroic or pitiable.” (Herek et al., 2003:533)

As the quote above indicates, belief systems about health and illness are constructed by biomedicine, the individual sufferer's experience and the local and wider social worlds. They are shaped by cultural, social, political, and economic forces and assigned cultural meanings. My research, though grounded in a clinical space, examined meaning-centered understandings of HIV infection and responsibility from the patient's perspective. It provides a lens into the illness experience of those who have been diagnosed with this disease. In this chapter I summarize the understanding that I have gained from my research about how people infected with HIV think about their illness and their beliefs about responsibility related to health optimization and disease management and I contextualize this information within the context of the social construction of illness and the social suffering experienced by the men with whom I talked about HIV infection in the clinic. I hope this analysis will help medical professionals and patients achieve a nuanced understanding of how some people think about and experience HIV infection in the world today.

Conceptualizing HIV

How people infected with HIV conceptualize their disease is multifactorial and is ultimately socially constructed; it is learned and shaped by cultural and structural factors,
particularly social. This is evidenced by the men’s narratives about how they think about HIV infection, which ranged from “I don’t think about it” to “a death sentence”.

The concept of ‘not thinking” about a disease that is responsible for the mortality of millions is difficult to comprehend. Although denial can be a coping mechanism for people with life-threatening illnesses, this is not what seems to taking place with the people with HIV infection with whom I spoke. They are aware of their illness because they take medications daily to treat it but their conceptualization encompasses multiple intercurrent and nuanced understandings. They talked about the chronic manageability of the disease, the acceptance of the illness over time and learning “to live with it”, other co-morbidities that are more distressing and disruptive, and the stigma that they face which results in social isolation among other deleterious effects. In addition, some of the participants have internalized the belief that biomedicine and their own adherence to antiretroviral medication regimens and health-enhancing behaviors can control this disease. They have seen evidence that adherence to antiretroviral medication and the avoidance of IDU and alcohol can suppress the virus for some people turning HIV into a chronic condition. Baumgartner (2007) has written about how people integrate their chronic illness into their lives over time such that it becomes less part of their everyday consciousness, except for times of ill health. This sums up what many of the men I interviewed meant by "not thinking about it."

Alternatively, Kendall and Hill note that, “HIV/AIDS continues to be experienced by many, through intermittent acute episodes of symptoms of disease, with underlying worry about disease progression and worry about the perpetuity and life-threatening nature of the illness, rather than a relatively low-level, long-lived, condition “under
control” (2010:176). A small number of the men I interviewed appeared to adhere more to this interpretation of HIV. Hence they tended to think more about the disease than not to think about it.

With the advent of efficacious treatment, however, biomedicine has transitioned the labeling of HIV from an acute, fatal disease to one that is chronic and manageable with an extended life expectancy. Manderson and Smith-Morris (2010) write that while this dichotomized labeling is functional within biomedicine for understanding disease, it ultimately contributes to the “invisibility of suffering”. Acceptance of this revised biomedical labeling of HIV infection allows those afflicted, and the wider social community, to think of the disease as no longer imminently fatal. Although this may be true for some with access to antiretroviral medications, the disease still causes significant morbidity and continues to be a deadly epidemic in many areas of the globe.

Antiretroviral treatment is not a cure, and the virus often develops resistance to many of the available medications, requiring constant medical supervision. Some of the men talk about HIV as a chronic or a manageable disease and say they are living longer, yet chronic and manageable diseases do cause disruption and require self-care on the part of the ill person. One man said that it is a “daily disease” illustrating how HIV shapes the everyday lives of the people it infects and how they interact in their local world. They may integrate their illness and not “think about it” but it is perennially running in the background shaping their lives and their social relationships. This kind of “illness work includes all the daily caretaking that becomes the responsibility of the patient once diagnosed with a chronic illness resulting in the majority of the care shifted from the
health care system to the patient who manages disease in the home with occasional monitoring by the health care team (Corbin and Strauss, 1995).

The men that I talked with have accepted the responsibility for managing their own health by adhering to their prescribed medication regimens and other health-enhancing behaviors and choices. They talk about “following orders” and “doing what I’m supposed to do.” They say that they don’t think about HIV but they do think about adherence to medication regimens, about making sure to eat well and sleep enough, and about doing what they’re “supposed to do”. In fact, it consumes their lives.

Another major concern is protecting others from transmission and themselves from reinfection. The majority of the participants have not disclosed their HIV status. These men worry about disclosure, how to hide their medications, and how to maintain secrecy about their infection. Taking medications, living a healthy lifestyle, and maintaining secrecy -- this is also the daily work and the daily suffering of HIV. They say they don’t think about it, but they suffer because of how the disease called HIV is constructed in contemporary society.

The stigmatization and marginalization of those afflicted with HIV infection disease has a long history and has socially constructed HIV infection as a “hidden thing” as one man said, adversely affecting health and quality of life and intensifying the suffering that is part of the illness experience. Stigmatization is experienced on an individual level, but is a socially constructed phenomenon. I suggest that stigma is a major driver in why many of the participants "don’t think about it.” They are aware of the stigma whether they have faced it themselves or have seen how others have been treated. It is a solitary illness for most; they don’t talk about their illness, which drives, in part,
why they don’t think about it. Thus, another part of the illness work for this “daily disease” is not disclosing their illness.

However, different men keep different levels of secrecy. Some actively keep their illness a secret; disclosing to no one, hiding their medications, and isolating themselves from social relationships. They are concerned that others will treat them differently if it becomes known they are infected with HIV. They guard themselves from this perceived stigma but ultimately deny themselves social support. This active secrecy is in contrast to what I have termed passive secrecy. This refers to the disclosure of their HIV infection to someone but no one speaks about it. Both the person with the illness and their significant other/family member/friend avoid the topic thereby constructing HIV infection as the proverbial “elephant in the room”. This validates the isolation and stigmatization that people with HIV experience, even with the people with whom they are close.

The presence of a social support system and the ability to discuss fears and concerns as well as positive outcomes can help to alleviate the stress of being ill and improve quality of life. It is hard to discern which causes more suffering, having no one to talk to about one’s illness or having those who know, avoid addressing it. It is now clear that lack of support and psychological stress resulting from stigma can contribute to disease progression (Golub et al., 2003). Hence, we need to help HIV sufferers to “reconstruct social networks according to the new boundaries set by the disease” after a diagnosis of AIDS (Baroso and Powell-Cope 2000:346). This renegotiation of social relationships occurs on the interpersonal level and within the local and broader social worlds. The social isolation that results from stigmatization has shaped HIV infection for many into a solitary illness and created silent suffering.
Some of the men talked about various co-morbidities, such as cancer, respiratory problems, and other diseases of aging being more of disruption in their lives than HIV infection. These other diseases have become much greater health concerns for them. Since recent research has shown that people with HIV seem to have accelerated aging and an increased susceptibility to other co-morbidities such as cardiovascular disease, cancer, osteoporosis and bone fractures, and neurocognitive conditions (Brooks et al., 2012), it is not surprising that these more disruptive co-morbidities and the physical effects of what they termed “getting old” have replaced HIV as the major concern since they impact daily life and even life itself more directly than HIV. However, the stigma of HIV may erase its daily presence in the lives of people with serious co-morbid conditions, which are much easier to talk about and garner social support for than HIV, and which, symptomatically, may be much more pressing on their daily lives and experiences.

While the men talked about many of their other illnesses, there are some co-morbidities that they hide. While almost half of the participants had at least one psychiatric diagnosis, most did not mention their mental health issues. A few talked about depression and feeling anxious or “nervous” and some talked about PTSD. Even when they talked about what they needed to do to manage their health (i.e., diet, exercise, rest), no one mentioned mental health care issues. Mental illness is another devaluing “medical condition” that ultimately multiplies and layers the stigma that many people with HIV infection face. It would be worth investigating whether those with HIV consciously hide their mental health issues, whether it is a biomedical diagnosis that they don’t accept or acknowledge, or whether it is just another illness that they don’t think about because they
anticipate further stigmatization.

“I don’t think about it” provides insight into the nuances of how people infected with HIV conceptualize their illness. The men talked about learning to accept their diagnosis and integrating their illness into their lives and about the degrees of disruption created by various illnesses, HIV infection among them. They talked about the stigma they perceived and felt, but didn’t consciously relate this to why they didn’t think about their illness.

Other participants acknowledged the impact of HIV infection on their lives and talked about it on a continuum that ranges from a death sentence to a transformative agent. In spite of the current rhetoric of HIV as a chronic manageable disease, some people with the illness acknowledge that it is still an illness that is limiting, both in terms of time and capacity.

One of the common themes during the interviews was the acknowledgement of how time and experience have changed how they think and feel about their illness, expressed as “in the beginning” and “now”, reflecting the trajectory of illness narratives. When first diagnosed many understandably were frightened and anxious and thought about the disease as fatal. With the availability of treatment, many have survived long past the time they had expected to die and it is no longer life-consuming. They believe that for the majority of those who have access to medical care and treatment, the disease has become manageable. While this has helped some to learn to live a “normal” life, for others, the disease remains a daily reminder of mortality.

For those who think about their illness, their suffering is apparent in their discourse. Some of the men expressed their fear of incapacitation and death. They talked
about trying not to think about it because of the distress caused by these thoughts. Many talked about HIV infection as a misfortune or a consequence of their behavior or choices. They believed that their illness was a result of their history of IDU, unprotected sex, and their social environment of risk and risk taking. These beliefs illustrate the trajectory of their belief system related to HIV infection and were shaped not only by individual experience, but also by social, political, and economic forces – what Brown has framed as “… a set of understandings, relationships, and actions that are shaped by diverse kinds of knowledge, experience, and power relations, and that are constantly in flux.” (Brown, 1995: 37). HIV as a transformative force reflects the sometimes subtle shifting that takes place over time as people try to find meaning in their illness. People living with HIV infection become introspective and integrate the illness into their lives (Allan, 1990). The men who talked about the changes that HIV has wrought in their lives referred to becoming more responsible and leading lives without substance abuse and other risks.

Erickson (2008) wrote that how people understand an illness is dynamic both for the individual experiencing the illness and for society at large. One result of this reframing of HIV as chronic disease is that it has receded from the previous panic discourse of the wider community during the first two decades of the epidemic when AIDS was a large part of the societal, biomedical and public health discourse. As mortality has decreased for those with access to medical care and antiretroviral medication, the general public has come to view HIV infection as a manageable disease. While progress has been made in treating the physical disease, the stigmatization, discrimination, and social isolation of those with HIV infection persists. This increases
the marginalization of the disease, making the epidemic and those who suffer from it diminished in the consciousness of our society.

**Responsibility for Health Optimization and Impact on Disease Progression**

Responsibility is a central theme in the disease of HIV infection. People afflicted with this disease hold themselves responsible for acquiring the infection, for health optimization, and for disease management. The labeling of HIV as a chronic disease by biomedicine has created more responsibility for the person who is infected and creates more “illness work” for the patient (Corbin and Strauss, 1995). In chronic disease management, treatment adherence and maintaining other health-enhancing behaviors become the work of the patient. This is also true for HIV patients who also become responsible for doing what they are “supposed to do” to suppress the virus and optimize health. Gaskins and Brown (1992) termed these activities the everyday work of living with HIV infection, which has been shown to give patients a sense of control over their illness (Allan, 1990; Barroso, 1995; Barroso and Powell-Cope, 2000).

**Regimens for Life**

Strict adherence to antiretroviral medications and the importance of engaging in other health-enhancing behaviors has been stressed for people infected with HIV. Beyond taking medications, the participants talked about a constellation of lifestyle behavior and choices that were crucial for HIV viral suppression and disease management. They talked about getting sufficient rest, exercise, and eating a healthy diet; avoidance of drug, alcohol, and tobacco use; and incorporating safer sex into their life regimens. Many also talked about the spiritual side of health, such as the importance of
prayer and faith in God or a higher power, as favorably impacting the course of their disease.

Adherence applied not only to taking medications but also to attending HIV health care appointments. My research suggests that how long a person had been living with HIV infection had little effect on medication adherence, but did make him less likely to attend all HIV health care visits. Men who did not attend all of their visits have had HIV infection for over 15 years. One could posit that as the disease becomes more “chronic” or “controllable”, and the symptoms less pressing compared to those of co-morbid conditions attendance at health care visits becomes less important. This illustrates that there are many factors that impact adherence to disease management and health optimization behaviors.

My research also suggests that awareness of what needs to be done to help suppress the virus and optimize health does not always translate into agency or success for a variety of reasons. HIV is an evolving organism that can mutate to render medications ineffective, and human behavior is notoriously inconsistent. Overall, however, those living with HIV infection have to adhere to their medication regimens and the prescription for health-enhancing behavior to protect their immune system; and as the participants said, they do so to live even though they may have setbacks along the way.

**Importance of Biomedicine and Doctors**

“The deep involvement of medicine in reorganizing the disruptive experiences of chronic illness in reordering its arbitrary and threatening characteristics, inevitably involves issues of social control.” (Bury, 1982: 179)

My research elucidated the significant role that the health care provider, most often referred to as "my doctor", plays in the lives of people infected with HIV. The
doctor is often the one person with whom people infected with HIV discuss their illness. The importance of trust in and reliance on the physician is not surprising particularly in the face of this devastating disease. Moreover, this reliance is intensified in the setting of a disease that is stigmatized and creates an environment of little social support for many of those who are infected. Many of the participants talked about the secrecy of their HIV infection and not speaking to anyone else about it except their health care provider. Yet the time with their health care providers is often spent discussing the clinical aspects of their disease (e.g., symptomology, medication adherence, laboratory results) and there is little time to talk about their illness experience.

In biomedicine, the doctor’s main role is to monitor health and prescribe treatment. As Kleinman notes, this “…ethnocentric and reductionistic view of the biomedical model, in which biological processes alone constitute the “real world” and are the central focus of research interpretation and therapeutic manipulation” (Kleinman, 1980: 25) leads the clinical encounter to exclude other important aspects of health, especially the psychological, social, and spiritual aspect. As I have shown in this thesis, these aspects are of tremendous importance to the patient.

A few of the men expressed a desire to have their time with their doctors involve more than discussing “the numbers” (their HIV viral load and T-cells counts) that measure immune health. This focus on physiological functioning and diagnostic testing is the hallmark of biomedicine and does not recognize and value the mind-body connection, the whole person. It ignores the distress and suffering that people with HIV infection experience. The disconnect between the full scope of the patient’s needs and the
physician’s focus is intensified when dealing with HIV given the lack of social support that many people face and their reliance on the physician.

Although the health care provider is the only person that many of the men speak to about their disease, there is little time or attention paid to their illness experience. Educating health care providers to increase their awareness of their role as social support for their patients would enhance the patient-provider relationship, allow them to assess the psychological, emotional, social needs of their patients holistically, and hopefully improve the quality of life for people infected with HIV. Many of the participants talked about spiritual beliefs but this is typically not addressed at all during clinical care appointments. Physicians have parceled out their patient’s psychological and spiritual dimensions to other practitioners and religious or spiritual entities.

How people infected with HIV come to understand and experience their illness is socially constructed. Knowledge that people infected with HIV and the contemporary society have attained about the disease has been constructed by biomedicine and other political, economic, and social forces, many of which have an interest in how this information is constructed and conveyed (Conrad and Barker, 2010). Health care providers assume the authoritarian role in the patient-provider relationship, which is illustrated by how the participants talked about “doing what I’m supposed to do” and following “doctor’s orders” and the “rules and regulations. This social control is evident even in the ways participants talk about the medication and behavioral regimens that have been prescribed by their health care providers. They must take prescribed medicines at the right times, monitor their viral load on a regular basis, and follow other health-
enhancing advice. The Veterans who participated in this study not only felt the pressure to obey the instructions set forth by their providers, but also those of the VHA.

Even the term “adherence”, a seminal word in biomedicine, connotes obedience and social control. When a person’s HIV viral load is detectable, one of the first questions asked by the health care provider is whether the person was adherent with their antiretroviral medications. This question clearly places the onus of responsibility for suppressing the virus on the person with the illness. It also creates suffering because the individual is held responsible not only for their infection but now also for disease progression.

Some of the participants worried about losing the benefits and entitlements that they have attained through the VA, constructing the VHA as a benefactor that must be pleased. They valued the access to medical care and medications as well as the other support services and feared doing something that would cause them to lose this aid. They had to follow orders given by their physician as well as obey the rules and regulations of the VA, which is a difficult system to navigate. Reliance on the VACHS for medical care as well as other services is another layer in the power differentials inherent in the patient-physician relationship. The issue of power and authority is also a part of the military culture (i.e., hierarchy; obedience) and contributes to the social control that infuses the relationship that the men have with their doctors and the VA system. The onus of responsibility that is placed on people afflicted with a “chronic” illness intensifies this power inequity, given the expectation to “obey orders”.
Social Suffering

“Social suffering results from what political, economic, and institutional power does to people and reciprocally from how these forms of power themselves influence responses to social problems.” (Kleinman, Das, and Lock, 1997:1033)

HIV has become a source of suffering on many levels for those who have acquired the infection. As the disease has transitioned from one that was imminently fatal to one that is “chronic” for those with access to treatment, so has the suffering that people living with HIV infection experience. At the beginning of the epidemic, the public health system identified risk groups (e.g., homosexuals, IDU) (Farmer, 1988, Singer 2006), which allowed the wider social world to moralize and label these groups of people as “the other”, contributing to the stigmatization and marginalization of people with the disease. Kleinman stated this more succinctly writing that “Cultural representations, authorized by a moral community and its institutions, elaborate different modes of suffering.” (Kleinman et al., 1997:2).

Such labeling continues as biomedicine’s practitioners continue to ask people with HIV infection how they acquired the virus so that public health can monitor the epidemic. This question is asked whenever the person with HIV infection sees a new health care provider and reiterates the blame and stigma that society places on those with this disease. For many of the participants in this study, their physician is their main social support for their illness. Thus, the one person that represents a safe place is also an authority figure, even for those who express a partnership with their health care providers. The social construction of HIV and the social structure of biomedicine has created a reliance on the physician, both for medical care and social support, which
contributes to an intensified power differential for people with HIV infection and exacerbates distress and suffering.

Biomedicine has struggled to find effective treatment that endures but has yet to find a cure. What it has done is to reframe the illness into one that is chronic and manageable, extending the lives of people with HIV infection but also intensifying the responsibility and illness work. This has created additional disruption, distress and suffering for HIV patients. Biomedicine has focused on curing the physical disease, but the social disease and suffering persists.

**Summary**

The state of ill health causes disruption and distress on many levels, physically, psychologically and socially among others, and creates suffering on all dimensions. Although mortality associated with HIV is decreasing where antiretroviral treatment is available, HIV is still a non-curable disease that results in significant morbidity and mortality. It is a disease for which personal responsibility is an overarching theme. It is also a disease that causes significant suffering both on an individual and social level. In spite of this, people with HIV infection have assumed responsibility for acquiring their illness, optimizing their health and managing (i.e., suppressing viral load) their disease. They believe in the value and effectiveness of ART and in their ability to impact the course of their disease. They trust their health care providers and believe that adherence to their prescriptions for medications and lifestyle is paramount. They take responsibility for managing a disease that is not truly controllable and remains associated with uncertainty and peril. Much of their illness work is conducted in a social milieu that is
stigmatizing and marginalizing, creating dependence on their physicians as their sole social support for their illness.

The process of constructing disease and illness is a dynamic social processes in which biomedicine, whose practitioners are recognized as the experts of biological disease (Singer, 2004), plays a major role. As my research suggests, biomedicine’s focus on treating and curing disease needs to broaden to include how patients understand, think about, and experience, their illness. While this is imperative for all who are ill, it has an even greater relevance for people living with HIV because of their reliance on their health care providers for both medical and social support. Each individual has a unique understanding of health and disease that is based on individual worldview. It is this understanding that shapes the patient’s role in managing health and illness. As discussed in Chapter 2, the questions that Kleinman (1978) developed to elicit beliefs systems of illness and curing are constructed for cross-cultural care, these questions would be useful for gaining an understanding of how any patient thinks about his illness. One of the ways that people come to understand their illness is by talking about it, which is often constrained in the case of HIV infection. These understandings provide powerful and symbolic information that can inform health care providers about how to participate in their patients’ health care and help to heal as well as cure. These understandings need to become more valued and recognized as a necessary component of the treatment plan.

Through the narratives of the study participants I listened to their silent suffering. They say that they don’t think about their illness but it still impacts their everyday lives. By not talking about it, they construct a solitary illness. They value and appreciate opportunities to tell their stories in an environment that is free from judgment.
Understanding the forces that contribute to the social construction of the illness experience and the resulting suffering is the beginning of learning how to heal holistically, a lesson that biomedicine needs to embrace.

**Conclusion**

“…so that he should not be one of those who held their peace but should bear witness in favor of those plague-stricken people; so that some memorial of the injustice and outrage done them might endure; and to state quite simply what we learn in a time of pestilence; that there are more things to admire in men than to despise” (Camus, 1948: 278).

In concluding my thesis I want to make the case, like Camus, that medicine and society need to take a new direction in treating HIV patients from one that treats just the physical body to one that reduces the multiple physical, psychological, and social suffering related to this disease and restores dignity to the patient. It is my hope that by bearing witness to the personal struggles of the men who talked to me about their illness experiences that the medical profession will begin to understand the desperate need for connection among their HIV patients so poignantly expressed by this participant: .

“I feel, I feel, whew, somewhat alone, I do. I feel like it ain’t nobody that’s there. I feel like I live my life in secrecy.”  
* (A man in his mid-60s with a diagnosis of HIV infection for over 20 years)*

Life with HIV infection, whether it is acute or chronic, is one of disruption. The focus of biomedicine is on treatment, extending the lifespan of those who are infected with HIV, and ultimately curing the disease. In the beginning of the epidemic, people were in a desperate fight alongside their doctors to control the disease and to survive. Although biomedicine has developed treatment and disease management that has allowed those infected with HIV who have access to treatment and medical care to live longer and
with better physical quality of life, many still suffer emotionally and socially. The social isolation, stigmatization, often co-morbid mental illness (e.g., depression; anxiety), and fear of disclosure causes significant suffering affecting, and constraining their everyday lives, opportunities, and social relationships. This social suffering also impacts medication adherence and hence the ultimate course of the disease. Biomedicine has made great strides in accomplishing these goals of fighting the physical disease but the social disease persists.

The reframing of HIV infection as a chronic illness has had many affects. To some degree it has been a source of reassurance and comfort for people who are infected because they no longer believe their illness is imminently fatal. As this research has demonstrated, they believe that they can impact the course of their disease; they have hope. Yet it has also increased the illness burden by placing more responsibility on the patient for disease management and disease progression. Not only do people infected with HIV believe that they need to strictly adhere to their antiretroviral medication regimens in hopes of suppressing the virus, but they must also adhere to a constellation of health-enhancing behaviors that they are told is necessary to optimize health and suppress the virus. Yet for most, this is solitary work; they do not have, or choose not to utilize, their social support system. In the developed world, where people have access to antiretroviral medications, many people view HIV infection as a chronic, manageable disease that is no longer fatal. The belief that fewer people are dying from the disease has diminished the urgency and discourse about the disease over the years the world has been living with HIV. Yet the marginalization and stigmatization of people with HIV infection continues; fear of transmission still exists and those afflicted continue to hide their
illness, their medications, and their suffering. HIV is a solitary disease for most and the suffering that was so apparent in the early days of the epidemic has become more invisible.

As one participant said so eloquently,

“The social ramifications on the individual, cultural, family, friends because there is no doubt that it has a psychological effect. That should be addressed, the psychological effect of HIV/AIDS and that’s a who different set. See, the physical thing is one thing, how you feel, but what you do psychologically. That bothers, I’m sure, everyone including myself. You have to think about how it constrained what you do in life. It’s important to look at the other side. It’s not just the physical side, it’s the psychological side. It’s not just the viral load, it’s really suffering mentally.”
(Man well over 60 years old who has had HIV infection for less 10 years)

HIV is the last epidemic nor will it be the last one where people are blamed, stigmatized and marginalized for acquiring a disease. Biomedicine’s practitioners, as well as the global community, need to understand how the labeling of disease and the social construction of health and illness creates more distress and suffering for people who are already enduring the physical and social life disruptions that are part of the illness experience. Many health care providers are aware of the mitigating factors that impact the patient’s ability to manage their disease including other co-morbidities, mental health issues, and structural factors such as housing, transportation, and economic means. However the social aspects of the disease often do not receive the same consideration. Health care practitioners also need to understand the belief systems and illness experience of their patients and recognize the extraordinary level of reliance that many of their patients have on them for both medical and social support. Biomedicine has evolved in such a way that treatment of the social body has been moved out of the realm of the
physician and parceled out to other health practitioners (e.g., psychologists; social workers, support groups). HIV infection has created a renewed dependence on the physician for social healing. Biomedicine’s practitioners need to be aware of their role in the social construction of illness, the power that they hold in their relationship with their patients who are infected with HIV, and the need to treat both the physical and the social disease. Kleinman talks about the dynamic interaction between the biological, psychological and socio-cultural dimensions that construct illness (Kleinman, 1978). For those who participate in the health care of people infected with HIV, the calling is to not only treat the disease but to heal the whole person.

**Implications of the Research**

“They should get out about the effects of HIV. There should be more commercials. It’s a closed society. It should be more open. What it's really like to have the disease. Doctors should do more of that. We all should.”

*(African-American man in his late 50s who has had HIV infection for less than 5 years)*

Those who are infected with HIV have much to say and they can teach us about what it means to have this extraordinary and devastating disease. It is through their stories that the sufferers make sense of the disruption in their lives and help us to understand their illness experience. Much of this knowledge is not being passed on to those who can make a difference in the ways this disease continues to constrain those who are afflicted. Many people infected with HIV have no one with whom to share their thoughts, feelings, and how they understand and experience their illness. The social suffering persists, although it is less visible, and has been intensified through the relabeling of HIV infection as a
chronic disease. For those living with HIV infection, managing their disease and experiencing their illness is solitary work and their suffering is often silent.

The research, education, and communication cannot not stop until HIV/AIDS is part of the discourse of everyday life, when those who are afflicted with this disease can talk about their illness, their treatment, and their suffering without fear of discrimination or stigma. Even though HIV/AIDS has been seemingly over studied, so much needs to done to combat the ignorance and prejudice that still exists. Only then, can those who are infected with HIV not suffer alone. The onus is not just on biomedicine, but it is on all of us who study humankind. We produce knowledge about the human experience but to whom do we communicate this information. It is the global community that needs to be educated about the disease that has been labeled HIV so that they do not further intensify the burden of those who are ill with an incurable disease. Cultural knowledge is dynamic and while much of the onus is on biomedicine as the “medical experts”, it is also our responsibility as social scientists to bear witness to the suffering and share our understandings with the wider social network and advocate for education and policy change.

Limitations

There are some limitations to this research that can be identified. Major limitations include the gender and age homogeneity of the participant population given that the research was conducted with U.S. Veterans at the VA Health Care System in West Haven, Connecticut. All of the participants were male and almost all were over the age of 50. Another limitation is that the participant population has long-term experience with HIV infection. Another confounder was the Veteran’s Healthcare system which is
similar to a socialized medical system in that it provides health care, medications, and other supportive services (e.g., transportation; housing) for those who qualify for little, if any, financial, outlay from the veterans. While this has provided a unique vehicle to study responsibility for health, some of the factors that affect antiretroviral adherence and disease management may not be relevant.

The uniqueness of the study setting in the American health system, however, may also have been an advantage. My research clearly showed that even under the best medical conditions, the social suffering of HIV patients is omnipresent. Under conditions of lack of access to good health care how much more would people be suffering?
Appendices

Appendix A  Informed Consent Form
Appendix B  Consent for Use of Picture or Voice
Appendix C  MHLC Form C Survey
Appendix D  Semi-structured Interview Guide
Appendix E  Data Dictionary
APPENDIX A

VA RESEARCH CONSENT FORM

Subject Name: ________________________________ SSN#: _________-_______-_______ Date: __________
First Name MI Last Name
(Use full SSN)

Title of Study: Implementing symptoms assessment into clinical HIV care and incentivizing viral
load control
Principal Investigator: Ronald Scott Braithwaite, MD, MSc
VA: VA Connecticut Healthcare
System/682 (v3/8/11)

DESCRIPTION OF RESEARCH BY INVESTIGATOR

SECTION I. THE PURPOSE OF THE STUDY AND HOW LONG IT WILL LAST.

You are invited to participate in a study that is designed to evaluate if we can help patients better manage
their HIV care by giving them cash “rewards” when their blood tests show excellent HIV control. In
addition, we would like to better understand how people think about HIV and whether or not they believe
they have control over their HIV or any responsibility for their health. Every 3 months (whether or not
you decide to participate in this study), your HIV provider orders a blood test called “viral load.” This
blood test indicates how much of the HIV virus you have in your blood. If you decide to participate in this
study, you can receive $100 each time your provider orders this test (up to a maximum of 4 tests per year).
If the viral load shows successful or improving control of HIV, compared your best results in the
previous year.

You have been invited to participate in this study because you are attending Infectious Disease clinic, and
you have been prescribed HIV medications in this clinic for at least 1 year. Your participation will last for
1 year. Enrolling in the study would take about 15 minutes today (to discuss the study, together with
filling out a brief symptom questionnaire) and 5 minutes on future visits (going over your viral load
results, and determining whether you qualified for the “reward”). The final study visit will take
approximately 30 minutes in order to complete two brief questionnaires.

In order to decide whether or not you wish to be a part of this research study, you should know enough
about its risks and benefits to make an informed judgment. This consent form gives you detailed
information about the research study which a member of the research team will discuss with you. This
discussion will go over all aspects of this research; its purpose, the procedures that will be performed, any
risks of the procedures, and possible benefits. Once you understand the study, you will be asked if you
wish to participate; if so, you will be asked to sign this form.

SUBJECT’S IDENTIFICATION (I.D. plate of give name - last, first, middle)

INITIALS

VA FORM JAN 1990 10-1086 (v 11.04.10)
SECTION II. DESCRIPTION OF THE STUDY INCLUDING PROCEDURES TO BE USED.

This study is designed to improve HIV control by rewarding patients for successful participation in their care, and by helping doctors and other health care providers become more aware of their patients’ symptoms. The study will test a new system for rewarding patients for better control of their HIV, together with a system to improve communication of symptom information. Approximately 100 patients will participate in this study.

Participating in this study will involve filling out the same survey twice; once at the beginning of the study, and once at the end. It will also involve going over HIV “viral load” test results every three months with your provider, and seeing whether your test results are improving or staying the same.

Symptom Survey: You will be given a survey before your clinic visit today by our research coordinator, which will ask you about symptoms that you may be having. This survey will contain 20 questions, each of which may or may not be followed up by two additional questions. This information will automatically be given to your provider so he/she can better work with you to manage your symptoms better. Because symptoms are often from side effects of HIV medications, managing your symptoms better may enable you to take your HIV medications more carefully (or to change your medications so that you tolerate them better) and this can help to improve your control of HIV viral load.

HIV Viral Load. Today your provider and/or the study coordinator will go over your HIV viral load results for the past year. Each of these results will be scored with a letter grade (A through D) that tells you how good they are. Each time you have another viral load taken while you are in the study (as long as it occurs no more than once every three months) you will be told the result of this viral load, together with its letter grade. If this letter grade is an improvement over your best letter grade in the last year, or if this letter grade is an “A”, then you will receive the cash “reward.” You will be given a score-sheet with this information, so you can keep track of how well you do.
Chart Review: Our study coordinator may review your medical records from clinic visits while you are enrolled in this study, as well as clinic visits prior to your participation in this study while you have been on HIV medications. Our coordinator will be paying most attention to (1) your viral load test results, (2) whether you changed your HIV medications, (3) your clinic attendance, (4) how often you refilled your HIV medications, and (5) whether your symptoms improved.

Participants can receive up to 4 payments of $100 during the year that this study will be conducted (up to $400 total). Participants can help their blood tests to show good HIV control by (1) making sure they never miss a dose of HIV medications, even just one; (2) working more with their providers to better control symptoms from HIV medications that may be getting in the way of taking them as prescribed, and (3) working more with their providers to change HIV medication regimens that are causing symptoms or are otherwise not working so well. You will be asked about those symptoms that make it especially difficult to take medications properly or that lower quality of life.

If you decide to participate in this study, you can receive $100 each time your provider orders a viral load (up to a maximum of 4 tests per year) IF the viral load shows successful or improving control of HIV, compared your best results in the previous year.

If you decide to participate in this study, every HIV viral load test you’ve taken in the last year will be assigned a letter grade, based on how good the result was. You will be told the letter grades of your most recent test result, as well as your best test result in the last year. You can get a reward either by improving your HIV control (getting a better letter grade than any others you have received in the last year) or having excellent HIV control (getting an “A” letter grade). For example, if your best letter grade you have received in the last year is a “C” then you would need a “B” or an “A” to get the cash reward. If you keep getting “A”s you can continue getting cash rewards.
Title of Study: Implementing symptoms assessment into clinical HIV care and incentivizing viral load control
Principal Investigator: Ronald Scott Braithwaite, MD, MSc
VA: VA Connecticut Healthcare
System/689 (v.3/8/11)

<table>
<thead>
<tr>
<th>Best letter grade from HIV test results in the last year</th>
<th>Letter grade from next HIV test result needed to get cash reward</th>
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<tbody>
<tr>
<td>D</td>
<td>C or better</td>
</tr>
<tr>
<td>C</td>
<td>B or better</td>
</tr>
<tr>
<td>B</td>
<td>A or better</td>
</tr>
<tr>
<td>A</td>
<td>A</td>
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</table>

Grading "key"
D = viral load 5000 or greater
C = viral load between 500 and 4999
B = viral load between 50 and 499
A = viral load less than 50 or undetectable

In addition we would like to gain insight into how people with HIV/AIDS think about their disease and whether or not they believe they have control over their HIV or any responsibility for their health. We will obtain this information through a questionnaire that will ask questions about your beliefs about HIV and whether you feel responsible for whether your condition improves or worsens over time. The questionnaire will take approximately 15 minutes to complete. Patients who are willing to participate in an optional interview will be asked more in-depth questions about their beliefs about this subject. If you are willing to participate in an interview your participation will last approximately 30-45 minutes.

Permission for Optional Interview
☐ I agree to participate in an interview to discuss how I think about HIV and whether I think I can control my health or have any personal responsibility for it. I understand that the interview will last approximately 30-40 minutes and will take place in a private room primarily in the Specialty Clinic. The interview will be audiotaped and the interviewer may also take notes about our conversation. The interview will be conducted by a research coordinator who is associated with the study. I will also be asked to sign a "Consent for Use of Picture and/or Voice". I understand that this interview is optional and if decide to not participate it will not affect my participation in the rest of the study.

Signature of Participant
Date

INITIALS
SECTION III. DESCRIPTION OF ANY PROCEDURES THAT MAY RESULT IN DISCOMFORT OR INCONVENIENCE.

The study is not anticipated to result in any discomfort although you may feel some emotional distress when asked to think about HIV and your health. The time required by the surveys (approximately 5 to 15 minutes for each survey) may cause minor inconvenience.

SECTION IV. EXPECTED RISKS OF STUDY.

This study involves no experimental drugs or devices. No blood or other bodily fluids will be collected. There will be no invasive or painful procedures. For these reasons, there is no risk of physical harm. There is a very small risk of psychological harm because (1) you will be asked to think about symptoms that may be frustrating and bothersome, (2) you may get frustrated if you expect to earn the “reward” but you don’t qualify, and (3) you may get used to receiving cash rewards for doing well, but after the study ends in 1 year, you may not get them anymore.

Confidentiality of Information

Participation in research may involve a loss of privacy. Your research records will be kept as confidential as possible. Only a code number will identify your research records. The code number will not be based on any information that could be used to identify you (for example, social security number, initials, birth date, etc.) The master list linking names to code numbers will be kept separately from the research data. A note describing your participation in this research study will be placed in your VA medical record. All research information will be secured in locked files. Your identity will not be revealed in any reports or publications resulting from this study. Only authorized persons will have access to the information gathered in this study. Authorized persons may include regulatory agencies such as the Food and Drug Administration, (FDA), the Government Accounting Agency (GAO), or the Office for Human Research Protection (OHRP), Office of Research Oversight (ORO), as well as members of the Research

Administrative staff of VA Connecticut. The Department of Veterans Affairs (VA) requires some information to be recorded in the VA electronic medical record for all veteran and non-veteran research subjects. Therefore, if you participate in this study, a medical record will be created if you do not already

INITIALS
Title of Study: Implementing symptoms assessment into clinical HIV care and incentivizing viral load control

Principal Investigator: Ronald Scott Braithwaite, MD, MSc

System/682 (v.3/8/11)

have one. Notes from your visits, procedures, and laboratory tests will be included in this record. In addition to the research team, and the VA staff who provide clinical services, other researchers may be granted approval to access this information in the future. Federal laws and regulation that protect privacy of medical records will apply to your VA record.

SECTION V. EXPECTED BENEFITS OF STUDY.

This study may benefit you because it may inspire you to participate more in your care, and to improve control of your HIV. Your clinician may become more aware of your symptoms and may treat them more effectively. However no benefit has yet been demonstrated. This study may benefit society because the system we are testing may be applied to other clinics and hospitals, and may end up improving the success of HIV management and lowering the likelihood of transmitting HIV to other people. This study may benefit future patients with similar conditions because if this system is found to be effective and easily used, it may become part of routine care for patients like yourself.

SECTION VI. ALTERNATIVE THERAPY OR DIAGNOSTIC TEST.

Your alternative to this study is to not participate at all. Participation in this study is entirely voluntary. Your care will not be harmed or affected in any way if you choose to not participate in this study. You may discontinue your participation at any time.

SECTION VII. USE OF RESEARCH RESULTS.

The results of your surveys will remain in the possession of the investigators and staff of this study, and in your medical records. They will be secured in a locked drawer within a locked office. No one will have access to this information except for research staff. These results will be maintained according to VA guidelines.

If results of this study are reported in medical journals or at meetings, you will not be identified by name, by recognizable photograph, or by any other means without your specific consent. Your medical records will be maintained according to this medical center's requirements.
SECTION VIII. SPECIAL CIRCUMSTANCES.

You will not be paid directly for your participation in this study. In other words, agreeing to participate does not automatically get you any money. However, if you decide to participate in the study, and if you qualify for "rewards" you may be paid as much as $400 over the year that you participate in the study. We expect that about half of all people participating in the study will get one or more cash rewards, but we are not certain how many people will actually qualify.

If you are injured as a direct result of your participation in this research study, VA will provide necessary medical treatment at no cost to you. There are no plans to provide compensation for disability or other losses occurring over the long term or if an injury becomes apparent after your participation in the study has ended. However, by agreeing to participate in this research study, you are not waiving or giving up any legal rights to seek compensation. If you have any questions about your right as a participant, you may contact the Chairman of the Human Studies Subcommittee at 203-932-5711, extension 3350. If you have any questions about compensation for injury you may contact the Research Office at 203-937-3830.
RESEARCH SUBJECTS' RIGHTS

I have read or have had read to me all of the above and I voluntarily consent to participate in this study. The study has been explained to me and my questions have been answered. I have been told of the risks or discomforts and possible benefits of the study. I have been told of other choices of treatment available to me.

I understand that I do not have to take part in this study, and my refusal to participate will involve no penalty or loss of rights to which I am entitled. I may withdraw from this study at any time without penalty or loss of VA or other benefits to which I am entitled. I will receive a signed copy of this consent form.

The results of this study may be published, but my records will not be revealed unless required by law.

In case there are medical problems, a research related injury or complaints, concerns, or pertinent questions about the research. I have been told I can call Dr. Braithwaite (203) 932-5711 x4341 during the day and Dr. Braithwaite at (203) 867-0243 (his pager) at after hours.

Signature of Participant ___________________________ Date __________

Signature of Witness ___________________________ Name of Witness (print) ___________________________ Date __________

Signature of Person Obtaining Consent ___________________________ Name of Person Obtaining Consent (Print) ___________________________ Date __________

Signature of Principal Investigator ___________________________ Date __________
**APPENDIX B**

Department of Veterans Affairs

**CONSENT FOR USE OF PICTURE AND/OR VOICE**

**CONSENT OF (Name)**

NOTE: The information requested on this form is solicited under the authority of title 38, United States Code. The execution of this form does not authorize disclosure of the materials specified below except for the purpose(s) stated. The specified material may be used within the VA for authorized purposes, such as for education of VA personnel or for VA research activities. It may also be disclosed outside the VA as permitted by law. If the material is part of a VA system of records, it may be disclosed outside the VA as stated in the 'Routine Uses' in the "VA Privacy Act Systems of Records" published in the Federal Register. A copy of the 'Routine Uses' is available upon request to the administrative office of the VA facility involved. You do not have to consent to have your picture or voice taken, recorded, or used. Your refusal to grant your consent will have no effect on any VA benefits to which you may be entitled.

I hereby voluntarily and without compensation authorize pictures and/or voice recording(s) to be made of me (or of the above-name individual if the individual is legally unable to give consent) by (specify the name of the VA facility, newspaper, magazine, television station, etc.)

VA Connecticut Healthcare System

<table>
<thead>
<tr>
<th>While I am (describe the activity, if any to be photographed or recorded)</th>
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<tr>
<td>being interviewed for a research study</td>
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I authorize disclosure of the picture and/or voice recording to (specify name and address of the organization, agency, or individual(s) to whom the release is to be made)

Scott Braithwaite, M.D.  
Steven Farber, PAC  
Cynthia Frank, RN

I understand that the said picture, video and/or voice recording is intended for the following purpose(s):

Research study "Implementing Symptoms Assessment into Clinical HIV Care"

I have read and understand the foregoing and I consent to the use of my picture and/or voice as specified for the above-described purpose(s). I further understand that no royalty, fee or other compensation of any character shall become payable to me by the United States for such use. I understand that consent to use my picture, video and/or voice recording is voluntary and my refusal to grant consent will have no effect on any VA benefits to which I may be entitled. I further understand that I may at any time exercise the right to cease being filmed, photographed or recorded, and may rescind my consent for up to a reasonable time before the picture, video or voice recording is used.

**SIGNATURE OF INDIVIDUAL OR OTHER LEGALLY AUTHORIZED PERSON**

**DATE**

**PERMISSION OBTAINED BY (NAME - TITLE - ADDRESS)**

**SIGNATURE OF INTERVIEWER OR INDIVIDUAL OBTAINING CONSENT**

**DATE**

**PRODUCTION TITLE**

**PRODUCTION NUMBER**

**INDIVIDUAL'S NAME AND ADDRESS**

MAY 2005

10-32

VA FORM 10-5345, Request for and Authorization to Release Medical Records or Health Information is required prior to the release of such data to any source.
APPENDIX C

Protocol: Implementing symptoms assessment into clinical HIV care and incentivizing viral load control
Study ID: ____________________________ Date completed: ____________________________

Form C
Instructions: Each item below is a belief statement about your medical condition with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you agree or disagree with that statement. The more you agree with a statement, the higher will be the number you circle. The more you disagree with a statement, the lower will be the number you circle. Please make sure that you answer EVERY ITEM and that you circle ONLY ONE number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

<table>
<thead>
<tr>
<th>1=STRONGLY DISAGREE (SD)</th>
<th>2=Moderately Disagree (MD)</th>
<th>3=SLIGHTLY DISAGREE (D)</th>
<th>4=SLIGHTLY AGREE (A)</th>
<th>5=MODERATELY AGREE (MA)</th>
<th>6=STRONGLY AGREE (SA)</th>
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<td>1. My HIV goes down, my own behavior which determines how soon I will get better or worse.</td>
<td>1 2 3 4 5 6</td>
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<td>2. As to my HIV, what will be will be.</td>
<td>1 2 3 4 5 6</td>
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<td>3. Most things that affect my HIV happen to me by chance.</td>
<td>1 2 3 4 5 6</td>
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<tr>
<td>4. I am directly responsible for my HIV getting better or worse.</td>
<td>1 2 3 4 5 6</td>
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<tr>
<td>5. People play a big role in whether my HIV improves, stays the same, or gets worse.</td>
<td>1 2 3 4 5 6</td>
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<tr>
<td>6. Whatever goes wrong with my HIV is my own fault.</td>
<td>1 2 3 4 5 6</td>
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<tr>
<td>7. My HIV is a result in determining how my HIV improves.</td>
<td>1 2 3 4 5 6</td>
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<tr>
<td>8. In order for my HIV to improve, it is up to other people to see that the right things happen.</td>
<td>1 2 3 4 5 6</td>
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<tr>
<td>9. What the improvement occurs with my HIV is what I myself do.</td>
<td>1 2 3 4 5 6</td>
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<tr>
<td>10. Following doctor’s orders to the letter is the best way to keep my HIV from getting any worse.</td>
<td>1 2 3 4 5 6</td>
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<tr>
<td>11. I am lucky, my HIV will get better.</td>
<td>1 2 3 4 5 6</td>
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<tr>
<td>12. My HIV takes a turn for the worse, it is because I have not been in proper care of myself.</td>
<td>1 2 3 4 5 6</td>
<td></td>
<td></td>
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<tr>
<td>13. The type of help I receive from other people determines how soon my HIV improves.</td>
<td>1 2 3 4 5 6</td>
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</table>
Implementing symptoms assessment into clinical HIV care
and incentivizing viral load control

Interview Guide

When you think about HIV, how do you think about it?

How do you picture it inside your body?

When do you think about HIV in your body, how do you picture it? What do you picture as happening?

Do you ever think of HIV as something other than a virus; do you have any other images you have of it when you think about it?

(Ask how they would describe it. Try to elicit any metaphors.)

Who or what is primarily responsible for your HIV infection?

Whatever the answer, ask why?

Do you think you can affect the amount of virus in your blood? (i.e. things you do…)

By how much (percent) do you think this can affect the amount of virus?

What is the most important thing you can do to control the amount of virus in your body?

How do you think this has an effect?

Why do you think this has an effect?

Do you think you can affect the amount of virus in your blood by taking all of your medicines?

By how much (percent) do you think this can affect the amount of virus?

Could you control HIV in your body without taking your medicine?
What do you think when your health care provider tells you your viral load (i.e., amount of virus in your blood) is well-controlled?

Do you think you are primarily responsible?

If yes, does this make you feel successful?

Whether the answer is yes or no, ask why.

Is there anyone or anything else that may be primarily responsible?

What do you think when your health care provider tells you your viral load (i.e., amount of virus in your blood) is not being well-controlled?

Do you think you are primarily responsible?

Whether the answer is yes or no, ask why?

Is there anyone or anything else that may be primarily responsible?

Does this make you feel like a failure?

Do you think you have failed yourself?

Whether the answer is yes or no, ask why?

Do you think you failed anyone else?

If yes, ask who and why. If no, ask why.

What do you think when you receive an incentive for the HIV being controlled?

Does receiving an incentive for achieving or maintaining a low viral load motivate you to try to improve your health?

Does receiving an incentive for achieving or maintaining a low viral load motivate you to take all of your HIV medications?

What would you think if you are told that you are not eligible for the incentive because the HIV is not being controlled?
How do you think you will feel when the study is completed and you are no longer eligible for receiving an incentive?

Do you think anything will change?
Do you feel you will be less motivated to control your HIV?
Do you feel you will be less motivated to take your meds?

Do you trust that your health care provider is doing everything possible to help you treat the HIV?

If no, ask why.
What else should they be doing?

(Try to have the patient expound if words like success, failure, blame, punishment, good, bad, right, wrong, or control are used)
APPENDIX E

Exploring HIV medication adherence through patient illness narratives and beliefs about personal responsibility for health.

Data Dictionary
October 17, 2011

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<th>Item</th>
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