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# Intimacy Uncertainty and Identity in Gay Male Couples Dealing with a Serodiscordant HIV Status

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I am submitting herewith a dissertation written by Scott Allen Eldredge entitled "Intimacy Uncertainty and Identity in Gay Male Couples Dealing with a Serodiscordant HIV Status." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Communication.

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# Intimacy Uncertainty and Identity in Gay Male Couples Dealing with a Serodiscordant HIV Status

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## DEDICATION

As I write in this dissertation, our significant, close relationships in life are central to our health and well-being. This dissertation is dedicated my significant, close relationships: to my Mom and Dad, my brother (Dare), my sister (Stacy), and my Aunt Eddie (Edwina). I cannot adequately express how grateful I am for the love and support of my family. I truly am fortunate to have these people there in my corner, believing in me, even when I have trouble believing in myself. I love you all very much.

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## ABSTRACT

When individuals are diagnosed with a chronic illness, their lives instantly change. Daily routines are interrupted and attendance to the symptoms and side effects of illness and medication become a daily chore. However, the patients are not the only ones who feel the disruptive effects of illness and the partners of the chronically ill patients must also contend with the daily effects of an illness that they themselves do not have. In the case of HIV, the infectious nature of the disease, along with the stigma associated with the disease, serve to be additional sources of stress in an already-stressful situation for the HIV patients and their romantic partners.

Because of the infectious and stigmatized nature of HIV, the present study was designed to explore the issues of uncertainty, management of uncertainty, and the related identity implications faced by the HIV-negative partners of HIV-positive individuals. Because relatively little research has been done on the health issues faced by the lesbian, gay, bisexual, and transgendered (LGBT) population, this study recruited gay male romantic partners with a serodiscordant HIV status. Focusing on the experience of the HIV-negative partner, the findings in the present study represent the data collected during nine intensive, semi-structured interviews. Data collection efforts produced 193 pages of interview transcriptions and these data were analyzed inductively using techniques associated with grounded theory.

Findings indicate the study's participants experience intimacy-related uncertainties that disrupt the role intimacy plays in the overall development and progression of the relationship. To manage these intimacy uncertainties, the participants engage in a variety of identity-reinforcing behaviors designed to deny HIV any influence over the relationship or the individual partners. As a result, these men redefine what it means to engage in safe-sex and the role of preventative

tactics designed to stem the spread of the disease. Theoretical and practical implications for relational communication and public health are also discussed.

## TABLE OF CONTENTS

## CHAPTER ONE: BACKGROUND AND SIGNIFICANCE

The lesbian, gay, bisexual, and transgender (LGBT) population within the United States is an important population to consider when addressing health issues affecting the larger society and working to eliminate health disparities. While the LGBT community faces a higher incidence of disease than the general population, relatively little research has been dedicated to LGBT health issues (Institute of Medicine [IOM], 2011). Research focused on unique risks associated with sexual activity is certainly relevant to the study of LGBT health; people holding a sexual minority identity face a variety of negative social conditions that contribute to public-health concerns (Meyer, 2001). Conditions affecting the administration of LGBT health care may include the obvious issues of violence, discrimination, and poor delivery of clinical care; however, stereotypical thinking, cultural insensitivities, and a lack of knowledge also contribute to LGBT individuals receiving less than adequate health care (Meyer, 2001).

Practicing medicine is more than a physician gathering biomedical information regarding a patient's illness; it also is the meaning-making process undertaken by providers and patients to co-construct and co-interpret what occurs during the provider-patient interaction (du Pre & Crandall, 2011). Personal health-care management not only happens because of the information exchange between patients and providers, but also is influenced and affected by a variety of communicative processes associated with identity management, coping, social support, and illness uncertainty management (Babrow & Mattson, 2011).

Thus, the delivery of health care and the management of an individual's health involve communicative processes; these processes are affected by the context and social conditions within which they occur. Because social conditions influence an individual's communication concerning health, the messages and processes associated with health care contribute to both

positive and negative, or even somewhat neutral, health outcomes. Thus, the communicative processes associated with LGBT health issues become an important aspect of health care to study. To that end, the purpose of this study is to explore issues of uncertainty and the associated communication behaviors used to manage the uncertainty of HIV-negative men engaged in a committed, romantic partnership with an HIV-positive man. Also known as mixed-status or magnetic couples, couples with a serodiscordant status are those where one partner is HIV-positive and the other is HIV-negative (U.S. Department of Health and Human Services, AIDS.gov, 2012). Given the communicative nature of healthcare and that gay men often experience identity-related stigmatization, this study seeks to identify the salient uncertainties held by the HIV-negative partner and to understand how the HIV-negative partner's interactions and uncertainty management efforts shape his sense of both personal and relational identity. In the following chapters, HIV as a salient health issue for gay men is first be reviewed, along with a discussion of the interdependent nature of illness. Next, an overview of the methodology used to guide this research effort followed by findings associated with uncertainty and related behaviors are presented. Identity-related findings as well as a discussion of the theoretical and practical implications of this research follow. Finally, limitations and recommendations for future research are addressed.

## Background

When LGBT health issues are discussed, particularly health issues of significance for gay men, HIV/AIDS is of primary concern. When the first cases of AIDS were diagnosed in the 1980s, little was understood about the HIV virus, and any patient receiving an HIV-positive diagnosis was essentially sentenced to death. In the 30 years since those first cases of AIDS, new drugs and advances in treatment have been developed enabling people diagnosed with

HIV/AIDS to live much longer lives (Centers for Disease Control and Prevention [CDC], 2012a). Now, HIV-positive individuals face the prospect of living for decades with the uncertainties that accompany an infectious and potentially lethal disease. While the advances in HIV treatment and increases in life expectancy for HIV patients are positive, the certainty of death from the disease has been replaced by a lifetime filled with uncertainties the patient must face. Not only are uncertainties faced by patients related to their personal health and the management thereof, illness uncertainties also affect patients' personal relationships. Particularly, HIV, an infectious, contagious disease, presents additional problems in both disease management and personal relationships when considering the virus is readily transmittable.

**HIV Incidence in the United States**

Despite advances in understanding and treating the HIV virus, the CDC reports that the incidence of HIV infection, while remaining stable in total number of new cases reported, continues to disproportionately affect certain populations and areas of the United States. Incidence, as defined by the CDC (2012a), refers to the number of new HIV infections reported within the United States in a given year. In particular, men who have sex with men (MSM) remain the group most heavily affected by HIV with 63 percent of all new HIV infections occurring within that population (CDC, 2012b). More troubling, the CDC (2012b) reports a 22 percent increase in the number and rate of new infections among young, gay and bisexual men (CDC, 2012b). This increase in new infections is not only disturbing on its face, but it also means that particular populations are dealing with more people living longer lives while dealing with the effects of HIV/AIDS. While living a longer life is positive, it also has implications for this particular population in terms of their interactions and relationships.

The overall rate of new HIV infections has remained stable in terms of total numbers; however, the overall numbers of people living with HIV/AIDS is on the rise. The total number of people living with an HIV infection in the United States reached nearly 1.2 million by the end of 2009, an increase of 8.2 percent since 2006 (CDC, 2012c). Of that 1.2 million, 684,900 persons living with HIV were between 35 and 54 years of age and 592,100 were men who have sex with men (CDC, 2012c).

### HIV Distribution in the United States

Not only has HIV disproportionately affected certain groups of people, different geographic areas of the United States are also experiencing dramatic differences in the rates of new infections and deaths from HIV/AIDS. In the United States, the states with the most HIV diagnoses were found in the South, and 50 percent of the deaths of people with AIDS in the United States occurred in the South (CDC, 2009). The area comprising the South region includes Alabama, Arkansas, Delaware, District of Columbia, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, and West Virginia (CDC, 2012d). In addition, the South has the largest proportion of HIV/AIDS cases from less urban and nonurban areas (CDC, 2009), and the number of AIDS diagnoses in these less-populated areas has seen modest increases since the beginning of the epidemic (CDC, 2012d). As the incidence of HIV/AIDS remains the highest in the South and the CDC's statistics demonstrate the spread of HIV into even less populated areas of the South, there is a need to need to study how HIV/AIDS affects populations across this region of the country.

## Significance

Health care is a social process involving a variety of communication processes and behaviors. Communication processes facilitate the development and maintenance of

relationships; patients rely on their close relationships as they experience illness and make sense of interactions regarding their health and health care (Goldsmith, 2009). Because this study focuses on mixed-status couples, it highlights the important role that relationships play in the management of life-threatening, infectious illnesses, specifically in gay male relationships. Insights gained from this study emphasize the special concerns relevant to gay male couples who have thus far been underrepresented in illness research (Institute of Medicine [IOM], 2011). Because the effects of a serious illness, particularly one that is life-threatening and infectious, impact both partners, a definition of serious illness is presented followed by a conceptualization of illness as an interdependent phenomenon.

**Illness as an Interdependent Phenomenon**

Life-threatening illnesses and other serious health issues have a significant impact on the relationships in which people experiencing illness are involved. The U.S. Department of Labor's Family and Medical Leave Act (FMLA) is useful in defining serious health conditions. According to the FMLA:

> A serious health condition is defined as an illness, injury, impairment, or physical/mental condition that meets any one of the following:
>
> - Involves inpatient care in a hospital, hospice, or residential medical care facility, including any period of incapacity or any subsequent treatment in connection with such inpatient care.
> - Continuing treatment by a health care provider that consists of a period of incapacity for more than three consecutive days that also involves treatment two or more times by a health care provider, or treatment at least once by a health care provider which results in a regimen of continuing treatment.

- Periods of incapacity related to pregnancy and childbirth, including prenatal care.
- Chronic conditions-episodic incapacity (e.g. diabetes, epilepsy), permanent/long-term conditions (e.g. Alzheimer's, terminal cancer), or multiple treatments (e.g. chemotherapy, dialysis) (U.S. Department of Labor, Wage and Hour Division, 2013. "The Family Medical Leave Act," para. 9).

Thus, serious illness potentially involves significant disruptions to the daily life and routines of the individual experiencing the illness as well as the individual's close relationships.

A patient's relationship and communication with a spouse or partner affect the conceptualization of illness and health care. In close relationships, one partner's stress can be shared or can affect the other partner either directly or indirectly (Goldsmith, 2009; Westman & Vinokur, 1998). However, most research looking at how people cope with stress focuses on an individual's response to stress, even though stress is a shared experience in interdependent relationships. Further, responding to, and coping with, stress is done through interactions with others (Afifi, Hutchinson, & Krouse, 2006); stress is managed through communication.

Arguably, chronic illness and uncertainty regarding the illness introduce stress into close relationships and influence the day-to-day lives of relational partners in many ways. Stressors from illnesses affecting the relationship are not solely felt by the patient. When someone suffers a spinal cord injury, is diagnosed with cancer, or tests positive for HIV, the primary story told is often that of the patient; however, even though not diagnosed with an illness, the patient's partner must figure out how to navigate the effects of illness in his own unique manner (Goldsmith, 2009). Essentially, the patient has a health-care provider available to treat the symptoms and side effects that come with being sick; the partner, while not actually being sick,

still has to deal with the situations brought on by his partner's illness, often without asking for help and receiving little attention from health-care providers (Kuyper, & Wester, 1998).

**HIV/AIDS as an Interdependent Phenomenon**

In looking at HIV specifically, advanced treatment protocols have made the HIV experience much more like a chronic condition. However, HIV, being an infectious disease that carries high levels of social stigma, brings with it a unique set of circumstances that couples who are experiencing other serious illnesses may not face. Committed, romantic partners where one partner is HIV-positive and the other HIV-negative must address issues of intimacy including sex and risk of HIV infection; they must decide about HIV disclosure to family and friends; they must investigate issues surrounding reproductive decisions; they must anticipate disability or death; and they must negotiate care-giving concerns (Derlega, Winstead, Oldfield III, & Barbee, 2003; Kalichman, 2000; Wrubel & Folkman, 1997). Each of these circumstances introduces additional illness-related stress into the relationship thereby having the potential to exacerbate the effects of illness and create additional relational stress. For example, disclosing one's HIV status has been shown to be an acute and recurrent stressor to both the patient and the patient's partner (Holt, et al., 1998). For the HIV-positive partner, disclosure of one's status is often used to increase positive outcomes, such as gaining both practical and emotional support, sharing responsibility for sex, and facilitating self-acceptance of one's condition; however, the stigmatizing nature of HIV also presents risk of negative outcomes for the HIV-positive partner (Holt, et al., 1998). For the HIV-negative partner, the partner's HIV-positive status also carries with it meaning that has implications for the negative partner. Essentially, disclosure of the partner's HIV status also says something about the HIV-negative partner. In this way, the

negative partner must deal with the effects of a disease without actually having the disease. Stress arises from the fallout of managing disclosure.

In addition to the stress associated with disclosure of one's HIV status, gay male, mixed-status couples must deal with the illness effects, stigma, and social isolation often associated with the disease to successfully maintain their relationship and prevent relational decline (Haas, 2002). Social support, an important buffer against the negative effects associated with the disease, helps individuals living with HIV manage uncertainty (Brashers, Neidig, & Goldsmith 2004).

Uncertainty Reduction Theory discusses uncertainty in terms of an individual's ability to predict the future behavior of another (Berger & Calabrese, 1975). Uncertainty, in this context, is a negatively oriented state of not knowing information about another person. When considering uncertainty within the context of illness and health, uncertainty is defined as the inability to determine the meaning of illness-related events (Mishel, 1988). For gay male mixed-status couples, social support by both the HIV-negative partner and other family members is important to relationship maintenance as the couple handles the illness stressors (Haas, 2002). Relational partners, as opposed to close friends and family, are the primary and irreplaceable source of social support for both the HIV-positive and HIV-negative partner (Haas, 2002). Providing social support is also complicated by the fact that the stressors associated with illness are interpreted and responded to by close partners. In this way, the illness is affecting partners directly, making the partner more than just a source of social support, but rather a co-participant in the illness experience (Goldsmith, 2009). The way illness is felt and experienced within a close, romantic relationship is a complex, shared experience facilitated by communication. In an effort to

improve health care, it is important to investigate how this shared experience affects the couple involved.

**Communication Challenges Facing Mixed-Status Gay Couples**

The presence of serious illness makes communication between couples much more difficult and complex. Couples facing serious illness often report difficulties in communicating or ineffective communication (Goldsmith, Miller, & Caughlin, 2007). Couples find conflict more difficult to engage in when there is a serious illness present and couples may find it easier to talk about the medical aspects of disease rather than discuss more emotionally-based aspects such as meaning and feelings (Goldsmith, et al., 2007). Treatment decisions, discussions relating to changing relationship roles and responsibilities, and decisions related to appropriate methods for managing uncertainties all become relational landmines that must be negotiated through the partners' interactions.

Serious illness is a shared experience among all couples; however, gay males dealing with HIV also face some unique challenges and relational stress. While intimate partners, close friends, and family may be sources of social support, the partners of HIV-positive individuals face additional burdens in providing social support. HIV-positive individuals tend to request social support from their partners through the use of both direct and indirect communication behaviors, and that communication may be more emotionally-based (Derlega, et al., 2003). This requires HIV-negative partners to be more adept than family and friends at decoding and dealing with a variety of different communication messages and behaviors. The variety and complexity associated with these interactions can lead to many situations where the effectiveness of communication between partners is compromised, creating both uncertainties related to the illness as well as uncertainties related to the relationship. The day-to-day interactions between

relational partners, then, play a role in how each navigates and negotiates new roles, identities, and uncertainties brought on by the diagnosis and illness.

**Illness, Uncertainty, and Identity**

The concept of uncertainty has been a central construct in the research and development of communication theory for decades. Berger and Calabrese (1975) framed uncertainty in the context of an individual being able to both predict and explain another individual's behavior. In their view, the desire to eliminate uncertainty is the driving force that explains interpersonal communication as a goal-oriented process in which individuals behave to increase their ability to effectively predict and explain their interactions with others (Berger & Calabrese, 1975). Uncertainty, specifically within the context of illness, has been conceptualized as a cognitive phenomenon focused on creating meaning. Defined as the inability to determine the meaning of illness-related events, uncertainty takes four forms: 1) ambiguity around the state of the illness, 2) complexity regarding treatment and care, 3) lack of information about the diagnosis and seriousness of illness, and 4) the unpredictability of the course of the disease and prognosis (Mishel, 1988). While original conceptualizations of uncertainty assumed it to be a negative state that must be eliminated, research done within the context of serious and chronic illness demonstrates that uncertainty may also be desired. For this reason, uncertainty is appraised for its potential harm and/or benefit (Brashers, et al. 2000). This appraisal indicates uncertainties regarding an illness state are managed by an individual to a desired level of acceptability (Brashers, et al. 2000). This shift in the conceptualization of uncertainty as a completely negative state to one that can be either positive or negative is an important one. If uncertainty is conceptualized as only a negative state that needs to be eliminated, individuals experiencing uncertainty would then be limited to dealing with uncertainty in ways that maintain the status

quo in terms of their life outlook and identity. However, serious and chronic illness makes maintaining the individual's pre-illness identity virtually impossible. For example, people living with arthritis found it difficult to make long-range life plans; their outlook shifted from a future-orientation to one where they placed greater emphasis on the present (Neville, 2003). Learning to manage uncertainty is not easily achieved. Those same arthritis patients found that one method of managing uncertainty, learning to tolerate it, is a major task (Neville, 2003). However, this does suggest that patients suffering a serious illness must adjust their outlook and identities to achieve coherence. Coherence occurs when an individual's life is structured, ordered, and predictable (Mishel, 1990). In re-visiting her uncertainty in illness theory, Mishel (1990, p. 257) accounts for this change in the patient's identity:

> In an acute illness situation, learning how to manage the uncertainty results in the incorporation of this experience in the new level of self-organization and so is not a return to a previously existing level of function, but includes growth resulting from the current experience.

Without successful uncertainty management, life remains ambiguous, unstable, and unpredictable (Mishel, 1990). However, even if patients are successful at incorporating uncertainty into a new view of life, the growth they experience will still impact their partners and relationships. Furthermore, because illness and the uncertainties associated with it are a shared experience, it is important to understand both the HIV-positive and HIV-negative partners' efforts to manage their uncertainties.

As the HIV-positive patient is learning to deal with illness uncertainties, the patient's HIV-negative partner also feels the impact of the illness. Individuals with partners who are facing a serious illness must manage their own uncertainties, provide social support, and

potentially reconstruct their own sense of identity. In this way, the illness and the uncertainties associated with that illness have an impact on the couple's individual identities as well as the conceptualization of the relational or "couple identity" that they share.

With uncertainties and illness influencing the couple's relationship and identities, their interactions become the mechanism through which each partner interprets and reacts to the situation. If uncertainties surrounding the illness are interpreted and managed differently by each partner, not only is illness a source of unexpectedness, the couple's relationship lacks order, stability, and predictability. For example, as illness causes patients to begin to question their sense of self, the patient's partner may also act as a co-performer to the patient's illness experience (Goldsmith, 2009). Co-performance may manifest itself as changes to established relational roles or the patient being unable to continue to function as a partner within the relationship. Men, in particular, seem to face greater tension between their identities prior to illness and a more disparaged identity after facing a serious illness (Charmaz, 1994). Specifically, wives provide their seriously ill husbands with affirmation and validation of their identity and role in the relationship, whereas single and divorced men in similar circumstances receive no such support (Charmaz, 1994).

Gay male couples offer a different experience versus heterosexual couples in terms of the link between their relationship and identity roles. For example, social support originating from outside a gay couple's relationship plays a role in the identities of the couples involved in gay male partnerships. Being in a relationship strengthens and reinforces a positive gay identity for the individuals involved. The couple's social network becomes important in validating the couple's relationship as well as decreasing the social isolation that often goes hand-in-hand with an HIV diagnosis (Haas, 2002). Another example of how the different relational experiences

faced by gay men influence their identities can be seen in their communication regarding everyday tasks. Unlike heterosexual relationships, gay male couples often lack similar gender-related tasks and assignments within their relationships. Without the strict gender-related roles found in heterosexual relationships working to define their identities, gay male couples more easily move and share tasks associated with support (Haas, 2002). In this way, stress is shared differently between gay male partners versus heterosexual couples as illness creates the circumstances and uncertainties driving changes within the relationship (Haas, 2002). Fundamental differences in the communication behaviors and processes used by gay male couples in the construction of their shared identity as a couple occur, particularly when serious illness is present.

**Unanswered Questions in Health Communication Research**

This research sheds light on a subject that has thus far not been explored in depth: communication behaviors with respect to serious, life-threatening illnesses of gay men involved in committed partnerships where their partner is HIV-positive. In heterosexual relationships, research has shown each partner uses communication strategies associated with openness and avoidance to manage uncertainty about the illness or condition and to negotiate new personal and relationship identities brought on by the illness (Charmaz, 1994; Chesney, & Smith, 1999; Goldsmith, 2009; Goldsmith, et al., 2007). Many questions and aspects of uncertainty remain unexplored within the confines of heterosexual relationships, including how partners coordinate their uncertainty, the uncertainty experiences of the uninfected partner; how uncertainty affects the identities of each partner as well as the couple's sense of identity; and how ordinary communication routines contribute to, or help manage, uncertainty (Goldsmith, 2009). Even less research has focused on investigations involving these questions within gay male partnerships.

This study investigates the uncertainties held by the HIV-negative partner in mixed-status couples, as well as the construction and content of the day-to-day communication associated with managing those uncertainties. When dealing long term with a life-threatening, infectious disease, keeping uncertainty manageable is paramount. While most research has focused on how communication impacts the patient's sense of identity, there has been very little investigation into how specific communication behaviors affect the identity of the patient's partner or the shared identity of the couple (Chesney & Smith, 1999; Goldsmith, 2009). Given that most questions regarding uncertainty and illness have been explored primarily from the perspective of individuals experiencing serious illness, this study seeks to fill a gap in the current body of literature by exploring uncertainty of the HIV-positive individual's uninfected partner. Given that his partner is HIV-positive, the purpose of this study is to explore the ways in which an HIV-negative individual makes sense of his uncertainties and constructs an identity through his interactions.

RQ: In gay male couples facing a serodiscordant HIV status, what is the role of uncertainty in the formation and maintenance of the HIV-negative partner's identity?

# CHAPTER TWO: METHODOLOGY

Seeking to answer the research question necessitates considering the paradigmatic and meta-theoretical perspective that guides the mode of inquiry best suited to investigating this phenomenon. For any research inquiry, the theoretical orientation used impacts every aspect of the study from the use of literature, to the research questions, mode of data collection, analysis, and reporting the findings (Creswell, 2007). Within the realm of qualitative research, there are a variety of methodological traditions. However, while each tradition has its own specific emphasis, all research traditions associated with qualitative methodologies see people as active, interpreting individuals that, through interaction with one another, create and act upon meanings (Morrison, Haley, Sheehan, & Taylor, 2002). To better understand the question surrounding the role of uncertainty in relationships and how uncertainties factor into a sense of identity, the primary essence of the social phenomenon in question must be explored. In effect, this study is essentially concerned with how meaning is constructed by the HIV-negative partner of an HIV-positive individual. Given meaning-making as the nature of the question, it is important to consider the philosophy associated with an interpretivist viewpoint.

## The Qualitative Paradigm

According to Guba (1990), a paradigm, a way to see the world, helps to identify the boundaries associated with a particular way of thinking. Researchers must fully understand the paradigmatic perspective associated with the questions they have posed; there are implications for every decision that is made regarding how the overall investigation proceeds. Given an interpretivist paradigm, a discussion of the ontology, epistemology, and methodology associated with that perspective is helpful to justify data collection and analysis decisions (Guba, 1990). Ontology refers to the nature of reality, or what is knowable. For the researcher, the ontological

view defines the subject of inquiry. Epistemology, the relationship between the inquirer and the subject of inquiry, dictates how a researcher approaches the subject and should interact with the world to discover knowledge. Methodology refers to the process by which the researcher should pursue the discovery of knowledge.

Because the ontological view defines the subject of this particular study as concerned with the construction of meaning, Symbolic Interactionism is a useful meta-theoretical perspective to govern the methodological approach in this investigation. Symbolic Interactionism posits that individuals assign representative signification to events, objects, and circumstances creating objects of orientation; meaning associated with those objects is then co-constructed through individuals' interactions (Blumer, 1966). The purpose of the proposed study focuses on how interactions regarding HIV contribute to the HIV-negative partner's sense of identity. Because the HIV-negative partner's sense of the couple's relational identity is a co-constructed phenomenon negotiated through their everyday communication behaviors and messages, Symbolic Interactionism provides a useful perspective for investigating how these interactions are impacted by the uncertainties brought on by an HIV-positive diagnosis.

**Qualitative Methods**

Using Symbolic Interactionism as a guiding meta-theoretical perspective has specific implications for the methodology associated with identifying and gathering data. Identifying research problems and questions, research techniques, and theoretical concepts should be done by putting those questions to nature and directly interacting with nature to uncover evidence that answers the question (Blumer, 1969). As a guiding principle for the use of previous literature and theory, Creswell (2007) outlines several accepted uses of literature in a qualitative study: a sensitizing concept, support for the importance and purposes of the study, or a means to help

confirm findings. Other uses of literature can be in generating interview questions, supporting findings, or bringing additional insight and nuance to previous research (Strauss & Corbin, 2007). These viewpoints on the use of literature are consistent with Symbolic Interactionism and Blumer's (1969) discussion of sensitizing concepts. Thus far, the literature regarding the shared nature of illness situates the phenomenon under study squarely within the context of relationships. In addition, the literature surrounding uncertainty, particularly uncertainty in the context of illness, has been used to bring a base-level understanding and to sensitize the reader to uncertainty and its effects on others.

**The Researcher's Role**

How qualitative research is evaluated depends on the researcher's role. The researcher acts as the key instrument, and as such, the researcher's history, culture, and personal experiences affect and shape how inquiry is conducted (Charmaz, 2006). Because of this, qualitative researchers must identify what they bring to the research and their interactions with research participants, spending time thinking about what they have observed and how they make sense of those observations (Charmaz, 2006; Corbin & Strauss, 2008). To better integrate this reflexivity into the research and assist the reader in gaining a deeper understanding of the topic and phenomenon under investigation, comments regarding the researcher's background and personal history as they relate to the research phenomenon should be incorporated into the research report. This sensitizing agent allows the reader to better relate to the researcher's perspective (Creswell, 2008).

A life-threatening illness to anyone who has not experienced it personally exists as a highly abstract concept. While we intuitively know patients dealing with illness face numerous difficulties, both physically and emotionally, it is difficult to truly understand how it feels. When

my sister was diagnosed with leukemia, the idea of facing a disease that had the potential to end her life brought a level of concreteness to the idea of serious illness that I had not known before. In a matter of moments, the diagnosis forever changed the way my family related to health-care providers and dramatically impacted the way we communicated with one another. Leukemia dictated what we talked about as a family as well as what we did not openly discuss with one another. Living to see tomorrow is a taken-for-granted assumption that we all carry with us; my sister's leukemia left me and my family to ponder our own individual vulnerabilities. That my sister could be young, vibrant, and alive one day, and fighting for her life the next, changed how individual members of my family saw themselves.

My sister fully recovered. However, the effects of fighting leukemia linger, and as time continues to take me farther away from that experience, I can better understand how deep and lasting the changes are to my, and my family's, sense of self. It is against this backdrop that I began my journey as a health communication scholar, wanting to understand and make sense of how illness impacts people. My interest in the effects of HIV/AIDS is more recent; as a gay man, I had never met anyone who was HIV-positive until I moved to the foothills of the Southern Appalachians. However, living in this part of the world quickly brought me to the realization that HIV is still a serious problem, particularly in the southern United States. The changes in my own self-concept from having experienced the effects of life-threatening illness in my own family had brought my attention and interest to the problems faced by those suffering from HIV or AIDS.

## Participants

### Participant Recruitment

As with most qualitative studies, purposeful sampling is most appropriate (Patton, 2002). While the present study reports only on data collected from HIV-negative gay men in a romantic

partnership with HIV-positive men, recruitment and data collection followed along procedures designed to capture the experience of both relational partners. Data collected from the HIV-positive partner are not included in the present investigation. For this study, mixed-HIV status gay male couples were recruited throughout the Southern United States in the South Region as identified by the CDC (2012d). Because this study investigates the formation and maintenance of identity at both the personal and relational level, gay male couples who identify as being part of a committed, mix-status, romantic partnership with each other were sought. Participants were identified using contacts made by the researcher through health departments, non-profit HIV/AIDS education and counseling organizations, teaching hospitals conducting HIV-related research and providing HIV-related care, and other LGBT community organizations and media. Each member of the couple was offered a $25 incentive for agreeing to be interviewed. Recruitment was conducted via posted fliers, email recruiting announcements sent to organization listservs, postings to social media websites of the above organizations, and advertisements in HIV/AIDS newsletters and newspapers published by the above organizations. An initial sampling was done to identify HIV discordant couples. Couples agreeing to be interviewed were also asked to forward recruiting announcements to additional couples who met the participation criteria.

**Participant Characteristics**

For inclusion in the study, couples must, 1) both be at least 18 years of age, 2) both identify as gay, 3) both have a male gender identity, 4) both identify as being in a committed, romantic partnership, 5) have one partner identify as HIV-positive and the other as HIV-negative, and 6) both agree to be interviewed for the study. Volunteer couples were asked to contact the researcher via phone or email. The researcher then screened both members of the

couple via phone to ensure both men met the participation criteria. This recruiting process resulted in the identification of nine mixed-status couples. Eight of the couples currently reside in the South region as defined by the CDC (2012d). The additional couple currently resides outside of the South; however, the couple has lived in three different states of the South region, and only recently moved away from the South. In addition, the HIV-positive partner received his diagnosis while living in the South, and the couple continued living in the South for several years after his diagnosis. As mentioned, the present study reports on the nine HIV-negative partners who participated in the study. The following demographics characterize those nine individuals. Eight of the participants identify as White. One participant identifies as Latino. The average age of the participants is 45 years (range 26 to 66 years). One participant reports he has finished high school. One participant holds an Associate's Degree. Two participants hold Bachelor's Degrees. Four participants have Masters Degrees, and one participant holds a PhD. The average length of time these men identify being in a committed, romantic relationship with their partner is 7.5 years (range 2 years to 17 years).

## Procedures

For this study, qualitative data were generated via semi-structured, long interviews. Symbolic Interactionism emphasizes learning about a participant's viewpoint, experiences, and actions; thus, interviewing is a data collection method well-suited to the in-depth explorations of the participants' experiences necessary for interpretive inquiry (Charmaz, 2006). Because uncertainty and identity involve highly abstract concepts developed in the mental world of the individual, the interview is an especially useful method to gain access to the mind of the participant and thereby experience the world from his perspective (McCracken, 1988).

Interviews were conducted in person at a location of the participants' choosing where the researcher and the participant could conduct the interview without any outside individuals, including the participants' partners, overhearing the conversation. Seven interviews were conducted in the participants' homes; one interview was conducted in a private room at a coffee shop, and one was conducted in a private room at a public library. Each of the relational partners was interviewed separately, and immediately, one after the other, to prevent and discussion of the interviews between the partners until both interviews were completed.

At the onset of each interview, an informed consent form was reviewed with each participant, and participants were given additional time to review the informed consent form and ask questions as needed (for informed consent form see Appendix C). The form reviewed the purpose of the study, stated that participation was voluntary and could be withdrawn at any time, outlined potential risks and benefits to the participants, identified the $25 incentive, reviewed procedures to ensure the confidentiality of the participant's data, and provided contact information for the researcher and the University of Tennessee Institutional Review Board (for IRB application see Appendix B). Informed consent was obtained from each of the participants.

After informed consent was obtained, and prior to the start of the interview, each participant was given the $25 incentive. Discussion guides were developed to support the interviewing process, and the guide for facilitating the HIV-negative partner interview is attached (see Appendix A). The interviews were recorded and transcribed. Interviews with the nine HIV-negative partners resulted in 12 hours, 22 minutes of recordings, with the average length of the interviews lasting 1 hour, 22 minutes (range 59 minutes to 2 hours). The interview recordings were then transcribed verbatim. Transcriptions were done by the researcher and two

outside transcriptionists who had signed a pledge of confidentiality. The transcription process yielded 193 single-spaced pages of interview data.

## Analysis

The verbatim transcripts were then used for analysis. Many methodologists (Charmaz, 2006; Creswell, 2008; Lincoln & Guba, 1985; Strauss, & Corbin, 2007) recommend sample selection to the point where the researcher gets saturation and redundancies. Commonalities uncovered by continuing analysis of the prior interviews done during the research process helped drive continued sampling, and helped guide the interviews to the point where no new properties emerged, while also providing a high level of information and detail about the participants' experiences. Analysis followed guidelines identified by McCracken (1988) as each interview was transcribed throughout the data collection process. According to McCracken (1988), there are five required stages to the analysis of long interview data with the primary objective being to identify the categories and relationships used by the participants to inform their descriptions of the experience. In each stage of the analysis, the researcher moves from identifying specific utterances made by the participant to high levels of generality and abstractness (McCracken, 1988). The resulting categories, themes, and descriptions form a basic, generic form of qualitative analysis (Creswell, 2008).

According to Charmaz (2006), memo-writing is an integral part of the qualitative research process. In keeping with Charmaz (2006), the researcher incorporated the process of writing memos throughout the analytic process. Memos are used in qualitative analysis in a variety of ways including open data exploration, identifying and developing the properties of concepts, making comparisons, and discussing the relationships between concepts, actions, and relationships (Strauss & Corbin, 2007). The researcher engaged in reflexive memo-writing after

each set of interviews with the participant couples, using memos as a method to explore emerging themes, categories, and patterns found within the data. In addition, Charmaz (2006) recommends free-writing as a memo-writing technique to assist with keeping the researcher involved in the process and increasing the level of abstractness of ideas. The researcher kept a dissertation journal as a free-writing technique that allowed for ongoing reflection and analysis of emerging themes and categories.

To develop a deeper understanding of the phenomenon, the researcher followed additional grounded theory techniques for data analysis as outlined by Charmaz (2006). Grounded theory consists of two phases of coding: initial coding, where coding is done on fragments of data at the level of word, line, segments, and incidents, and focused coding, where coding is done by selecting initial codes and comparing them against extensive data (Charmaz, 2006). In the present study, the researcher performed initial segment coding using the Atlas.ti qualitative software package to track codes identifying specific actions related by the participants. Focusing coding then followed where those initial codes were compared against the broader, more extensive data of the transcripts. In keeping with Creswell (2007), the identified clusters of meaning and themes resulting from the focused coding phase were then used to write additional memos serving as textual descriptions of the research participants' experiences. Finally, a composite description, representing the essence of the experience was written from the textual descriptions (Creswell, 2007). These textual and structural descriptions served as part of the reflexive process of writing memos. Finally, a written account of the results of this analysis, as well as a discussion of those results, has been generated. Pseudonyms have been used in reporting the findings to protect the participants' identities.

## Evaluative Criteria

Rigor an important concept for any course of naturalistic inquiry, along with trustworthiness are important aspects of interpretivist work, and, indeed, trustworthiness is the central goal of any qualitative study (Creswell, 2007; Haley, 1996; Lincoln & Guba, 1985). In general, quality research must have credibility, dependability, confirmability, and transferability (Lincoln & Guba, 1985). Employing well-recognized, established methods and procedures and incorporating negative case analysis and member checks into the analytical process increases the study's credibility and dependability. With negative case analysis, data that are in contrast to other data are used to help refine and expand the interpretations and findings (Creswell, 2007). With member checks, the researcher takes findings back to the research participants to determine if the researcher's interpretation rings true with participants' experiences. For the present study, the composite findings were reviewed by all nine participants to establish credibility of the report. Credibility and dependability are also ensured by the academic dissertation process. Subjecting the research to peer review enhances credibility and dependability through a rigorous questioning of methods and findings (Creswell, 2007).

Finally, confirmability and transferability are also important to the development of high-quality research. With confirmability, the methods used are spelled out in detail, and access to findings, procedures, and data are made available to other researchers (Creswell, 2007). In this way, other researchers can work to replicate the findings. With transferability, researchers should be able to take the findings of the study and apply them to other settings (Creswell, 2007). By following the procedures outlined in this chapter on methodology, the rigor and trustworthiness of this investigation are ensured, and, with that rigor and trustworthiness, further contribute to the existing body knowledge on illness and uncertainty.

## CHAPTER THREE: UNCERTAINTY FINDINGS

### HIV is No Big Deal

"The HIV has never altered or affected our relationship," Steve said. This is a common, consistent theme among the negative partners of HIV-positive men. Steve is a vivacious, talkative man, and it is easy to believe he is the life of the party when he discusses his outgoing nature.

> I am going to be boisterous. I am the talker. When [partner name] and I go somewhere, I'm the loud, obnoxious one, and he's the quiet, um, ah, reserved; it's opposites attract. Um, I'm usually the one that likes to get the party started, let's laugh, cut up. You know, let's hang out and do something. I'm the one saying, 'Hey, let's go have dinner,'; 'Hey, let's have a party' that kind of thing. Um, I'm a smart ass.

Discussing HIV and his relationship with his partner on a chilly, autumn evening, Steve's attitude toward HIV and the place HIV holds in his relationship is emblematic of the men participating in this study. Steve tends to deflect focus from HIV, downplaying its significance. In fact, HIV has no place in the busy, fast-paced life of this man. However, illness has taken over his relationship with his partner. Steve's partner was HIV-positive when they met, and, according to Steve, HIV was never a consideration.

> That's when somebody had leaned over and said, 'Oh by the way, in case you don't know, he's HIV-positive.' And I just said, "Oh. OK. What? What does that mean? I don't really care. You know, [I said,] somebody could have diabetes, or cancer or whatever, does that mean they are black-balled? And I said…I don't really…it's very…I found that to be extremely, and I had only come out for a small amount of time, but I was very blown away with how people viewed people that were HIV-positive. Like, you guys stay

over there. And we stay over here. Like, very segregated. At so many different levels. Not a lot of my friends that I have now…but a lot of those were…and I was like, 'wow.' I found that odd. Him being HIV-positive never was, has ever been, an issue in our relationship. It's never been. Other than the fact of, you know when he got sick.

HIV has, today, morphed from a near certain death sentence to a very manageable, chronic, almost invisible condition (U.S. Department of Health and Human Services, AIDS.gov, 2012). In many ways, it seems remarkable that anyone can even declare that HIV does not affect a romantic relationship, given the history of HIV. Clearly, a stigma still exists surrounding the disease, and no matter how well it is managed, it is, after all, still a contagious, infectious disease. No matter how well a treatment regimen progresses, HIV still cannot be completely eradicated; yet, the participants in this study were very quick to state sentiments similar to Steve's quote above.

Carlos' comments follow along the same pattern as the other men participating in this study, and in an echo of Steve's sentiments regarding HIV, Carlos downplays the importance of HIV to a couple who are in a close relationship. Carlos acknowledges that HIV will be a consideration; however, he describes HIV as an issue so small that it will be forgotten.

> There's a lot of good guys out there that are [HIV] positive, but it doesn't mean that it's the end of them. That means they are still human, they still have goals, they still have plans, they still have a future… just don't think about it. They only think about it when it comes down to…if you…when you're serious. That will be the last of your worries. It will be in your mind, but it will be not as much because you will have a routine that you guys will follow, and you will … it will be like a normal routine and you will eventually forget that it's a routine.

For these men, HIV eventually becomes something that is forgotten about not only on a day-to-day basis, but also as a future consideration. Caleb, in relating how he does not even think about HIV, also looks into the future of his relationship with his partner and dismisses HIV as having any kind of impact on their lives.

> And I would say in my mind, I don't think about it. I mean, it doesn't cross my mind. I put it aside, and there's some days when I never, it never even occurs to me that my partner has a disease. I don't, I don't, now, I think that, um, as far as my concern that I'm going to get it, I think that we're being careful enough where we need to be careful, the chances are very low. Um, I expect to spend the rest of my life with him, so in the next thirty or forty years or whatever hopefully that we're together is there a chance that, you know, for whatever reason I may contract it? Maybe. But I'm not going to worry about that, I'm not going to, I don't even think about that. I don't think, "Oh my God, I could get it, too." I mean, if it were to happen, we'd deal with it if it happened, but I don't think it's going to happen, and I don't worry about it happening.

Despite these expressed feelings that HIV is really not a factor in their daily lives, the men participating in this study proceed to spend hours telling stories that include a myriad of ways they accommodate HIV on a daily basis. It is in this disconnect between the expressly stated assessment of HIV and the lived experience of these men where the story lies. Commonly referred to as mixed status or magnetic couples, the negative partners of HIV-positive men must contend with the effects of an illness they do not themselves have, yet are potentially at risk for contracting.

In exploring the issues of uncertainty and identity, it is apparent that, in discussing their relationships, these men are doing more than just relating their day-to-day lived experience.

Rather, in describing HIV as a non-issue in their lives, these men do reveal what is often described as small or minor considerations brought about because of HIV that must command their attention. In this way, these men, even in their participation in this study, are answering questions posed by the researcher in ways that help them make sense of HIV and categorize it in their lives and in relation to their sense of self. These men push disease and illness out of their lives in general, and specifically discuss HIV as almost non-existent.

## "Happily Ever After" and Relationship Archetypes

Once upon a time. Happily ever after. These are the familiar openings and closings to the common fairy tale archetype, and, with some slight modification to the pronouns involved, these stories follow a pattern where a boy dreams of growing up, and while pursuing a grand, life-changing adventure, meets the man of his dreams, falls in love, and lives happily ever after. What actually happens in the "happily ever after"? The desire and pursuit of a long-lasting, intimate relationship certainly is not confined to heterosexual couplings, and the men participating in the current study tell stories of catching their partner's eye at a dinner party, pursuing flirtatious opportunities, long late-night talks on the phone, dreaming of marriage, planning for their future, and growing old together.

In following these types of relational scripts, gay men are no different than their heterosexual counterparts (Peplau & Fingerhut, 2006). We know that relationships grow, intensify, develop, change, and even dissolve over time. While there are many factors that affect relationships, gay men entering into committed, romantic partnerships with another man encounter their own unique set of conditions. Romantically paired men must navigate a world where their relationship will often be stigmatized, misunderstood, discriminated against, and limited in the formal recognition society offers to state-sanctioned, heterosexual marriages

(Peplau & Fingerhut, 2006). Any of these factors alone is certain to add additional stressors to the relationship, but in addition to these situations, gay men also must navigate a world where being gay is often associated with HIV. Gay men remain one of the groups most at risk for contracting HIV (CDC, 2012b), and the simple act of giving blood is prohibited if one identifies as gay. In addition, gay men are encouraged to get tested for HIV infection on a regular basis, often several times a year depending on their sexual habits. For the men participating in this study, HIV is a constant consideration. As Steve indicates, being gay is inextricably linked to HIV. "When I started realizing, oh man I'm gay, too. I had to understand what that was about. So, you know, I had read, and understood. And it never became a factor." In this quote, Steve demonstrates an almost automatic link between being a gay man and HIV. As part of the coming out process, you have to think about HIV. HIV, on some level, is part of what it means to be a gay man.

It is against this backdrop of stigmatization and an ever-present disease threat that HIV-negative men attempt to form close, romantic partnerships. A serious, chronic illness is one of the more significant factors that couples must deal with in their close relationships. For the HIV-negative man, every potential romantic partner represents both the possibility of a fulfilling relationship, as well as a threat to health and well-being. After all, who wants to think about disease when trying to find your Prince Charming? Catching a disease that at best will mark you as sick and require constant treatment, or at worst kill you is not exactly something that helps set a romantic mood. However, as Carlos describes his first kiss with his partner, it is apparent that even at those most romantic moments, HIV lurks in the background.

> We were walking that day, and it was sunset, and so happened it was a full moon also on the opposite side. You know how you can sometimes see on the other side…and I was

> like, 'that moon is so…' It was just the perfect day for him to tell me, in other words. And, um, he caught me on a day that I wasn't with my walls up and protecting myself all the time. And when he told me [that he was HIV-positive], and then I thought about all the stuff we talked about and everything. I basically became more comfortable, and he was looking toward the view of the city and the sun just hit him perfectly. I remember that, and I was like, 'Damn! He looks nice even though he has that bug in him!' But, um, and I just leaned over and gave him a kiss.

For Carlos, the mood was right, the setting was perfect, and he felt that connection with his partner. The moment of the first kiss in a new relationship is commonly told in fairy tale romances to signal the triumph of love and the beginning to the "happily ever after." However, for Carlos, even though the desire to connect with his partner won out at that moment, HIV intruded on his thoughts, and he had to overcome the issue that is HIV.

## HIV and Uncertainties

In order to understand the need of these men to seemingly deny any impact HIV may have in their lives, and to explore the nature of the uncertainties these men experience, it is helpful to revisit aspects of Mishel's Uncertainty in Illness Theory and Bashers' Uncertainty Management Theory. According to Mishel (1990), uncertainty is the inability to determine the meaning of illness-related events. Specifically, uncertainty comes in four forms: ambiguity concerning the state of the illness, complexity regarding treatment and system of care, lack of information about the diagnosis and seriousness of the illness, and unpredictability of the course of the disease and prognosis (Mishel, 1988). In each of these four aspects of illness Mishel describes, uncertainty stems from a lack of understanding regarding information related to specific characteristics related to the treatment of disease. In Mishel's measure of illness

uncertainty (Mishel, 1981), items such as "My treatment is too complex to figure out," and "There are so many different types of staff, it is unclear who is responsible for what" address aspects of illness, that while they may indicate uncertainty, clearly deal with aspects of illness that could potentially have definitive answers. In this way, uncertainties of this type could potentially be resolved through scientific-based facts about disease, or in process-oriented descriptions of health-care workers' roles and responsibilities. In looking specifically at the case of HIV and relevant aspects of the disease to the HIV-negative men in this study, uncertainties regarding sex, transmission of the virus, and treatments for their partner are primarily concerned with these fact-based or objective aspects of the illness.

For Brashers' Uncertainty Management, the recognition of uncertainty and the appraisal of it as positive or negative elicits behaviors such as information-seeking or avoidance to keep feelings of uncertainty as levels deemed acceptable to the individual experiencing the uncertainty (2001). In this approach, there is no indication of how the source of uncertainty will affect the associated information seeking or avoiding behaviors. For example, if we take an objective aspect of HIV, such as the potential to lower risk of transmission of the virus, and the individual appraisal of that aspect of HIV is positive, the resulting information-seeking behavior may be affected in terms of where and how information is sought. However, if the source of uncertainty stems from a more psychosocial aspect of HIV, such as "what does HIV mean for my future," it may be difficult to predict how information-seeking behavior is influenced. Both Mishel and Brashers, in later conceptualizations of their respective theories, did begin to identify different sources of uncertainty as being primarily medical, personal or social (Brashers, et al., 2003; Mishel, 1990). However, further understanding the nature of the uncertainty's source has the potential to better increase the predictive power of these theories.

More broadly, other researchers within the field of communication have also identified a variety of sources of uncertainty in relationships; however, there is no agreed upon formal categorization or classification of uncertainty. Babrow, Kasch, and Ford (1998) propose a sorting of uncertainties according to their various meanings including complexity, quality of information, probability, structure of information, and lay epistemology. This classification scheme begins to look at uncertainty by type; however it primarily, like Mishel and Brashers, is concerned with sources of uncertainty. Other commonly identified sources of uncertainty include jealousy, relational dissatisfaction, illness, violations in expectancies from relational partners, and conflict, among others (Afifi, & Reichert, 1996; Babrow, Kasch, & Ford, 1998; Brashers, et al., 2003; Knobloch, & Solomon, 1999; Mishel, 1990). However, in fields such as economics, computer science, and health care, there has been a concerted effort to understand the varieties of uncertainty and the various psychological effects they may elicit to improve models of decision-making.

Han, Klein, and Arora (2011) have proposed a conceptual taxonomy of uncertainty specifically applied to health care. In reviewing the literature from the fields of communication, decision science, engineering, health services research, and psychology, the authors constructed a taxonomy of uncertainty having three distinct dimensions: scientific, practical, and personal (Han, Klein, & Arora, 2011). Scientific, or data-centered, uncertainty pertains to concerns associated with aspects of illness such as diagnosis, prognosis, causes, and treatments. Practical, or system-centered, uncertainty applies to the processes associated with care (e.g. patient concerns regarding a physician's competence). Personal, or patient-centered, uncertainty pertains to psychosocial and existential issues such as personal goals, the effect of illness on relationships, and the outlook on life. The Han, Klein, and Arora (2011) taxonomy is useful as a

basis for understanding the uncertainties HIV introduces into the lives of the HIV-negative men participating in this study. For the purposes of discussing their uncertainties, "objective uncertainties" serves as a label for the more fact-based or data-centered aspects of uncertainty while the label "subjective uncertainties" identifies the practical and personal aspects associated with the participants' uncertainties.

**Objective Uncertainties**

**Partner Well Being and Risk of Transmission.** At the moment when the partner's HIV-positive status is disclosed, initial questions and uncertainties for all the men in the study center on objective aspects of the disease itself. Initially, two simultaneous concerns arise. The first focuses on the well-being of the infected partner, while the second concern centers on personal risk of infection. For example, John describes these nearly simultaneous feelings upon learning that the man who would eventually become his partner was struggling with fears that he might be HIV-positive.

> So he finds out, and I'm like, like the next day or whatever, and internally I'm all sorts of confused and weird but I think…he might tell the story differently, but I think I was like, "I'm really sorry," and tried to be supportive. I might have been a little angry like, "you put me at risk."

Being concerned for your partner, as well as worried about your own health, describes Andrew's experience as well. Once he tested negative, the focus remained solely on his partner.

> It was more than a year of living here. We were in the apartment. I remember him coming home. He said that he had gone to the clinic to get tested. I don't remember if someone had given him a heads up, you know, he, [if] he was nervous about something, or if it was routine. He mentioned that he got the result and, [pause] I mean, [pause] you

> know the, the combination of being worried for him and wondering, "Oh my God, I need to get tested." That was a lot to deal with in that moment. I certainly…I certainly… I was a lot more worried, anxious than he seemed to be at the moment. He was trying to, I won't say "cheer me up," but he was trying to, trying to be supportive of me and what not. I went to get tested that afternoon and, you know, I was pleasantly surprised that the swab came back negative in about 10 minutes. And I felt good. I felt good in that moment, that I was probably good to go and more of the worry turned to just him.

For Carlos, it took six months of chatting online and talking on the phone for him and his partner to even first meet. On that first date, Carlos discusses how he first expressed support and concern for his partner when his partner disclosed his HIV-positive status.

> Yeah, I was the one that, um, because he was, he couldn't touch me. He felt that he was not worthy, and I could see that, now that I know about what people with HIV feel. I do remember him acting that way, like he wasn't worthy of me touching him. So, I grabbed his hand, and was walking with him, and even though he was going way above the level that I was used to [by holding hands in public], I … I …I felt safe.

This story of their first time meeting in person and their first kiss is interesting in that the negative partner is the one initiating intimate contact. In his partner disclosing his HIV status, Carlos sensed his partner's feelings of being unworthy of touch or intimacy. Social support involves behaviors that are responsive to another's needs and function as an expression of caring or comfort (Gardner & Cutrona, 2004). As Carlos demonstrates, holding his partner's hand and giving him a kiss helped to convey messages of support to his partner.

**Impact on Sexual Behavior.** After these initial concerns for the partner, the HIV-negative participants' worries then turned to issues relating to the transmission of the virus. What

sexual behaviors are safe? What sexual behaviors are not safe? There is an element of managing uncertainties around the instrumental or "objective" aspects of the disease, concerns related to the facts associated with the disease. How can it be transmitted? What is going to prevent transmission? What are the particulars of how this disease progresses? Carlos goes on to discuss how concerns for his partner quickly returned to concerns for his own health and well being.

> The HIV and me protecting myself but, um, but with him actually telling me about the HIV … I… I think it was more about the HIV at that time, because I was like, a man I can always find if I have a need, but this right here is stepping over, and if something happens or something goes wrong, that's something else I have to deal with.

Carlos and his partner did not engage in sexual activity for the first few months of their relationship as Carlos struggled with the uncertainties associated with the risk of contracting the virus. Carlos' partner was HIV-positive when they met, and HIV, along with the accompanying concerns for sex slowed the progression of intimacy in the relationship.

Generally, the men in this study fall into one of two groups. The first group consists of those men who whose partner was HIV-positive before they entered into a relationship; the second group includes men who were already in a relationship with their partner when he was diagnosed as HIV-positive. Regardless of whether HIV enters the relationship at initiation or after the relationship is more established, all of the men in this study experience similar objective uncertainties related to HIV. However, for the men who were already in a relationship when the HIV infection was diagnosed in their partner, HIV represents a disruption to the norms and routines of their relationship. While the men who entered into a relationship with an HIV-positive man approached a progression to sexual intimacy much more slowly, the men who have HIV enter their existing relationship also experience definite changes and disruptions to

intimacy. One very obvious area of change was to sexual practices. Andrew describes a shift in the types of sexual practices in which they would engage.

> Mechanically things changed. Certainly, and I think he was also very reluctant to do much sexually just… just to protect me. You know like I said. He certainly took it better than I would have. There was certainly a period of time where he was, "I don't want to do anything yet to put you at risk." But other than that nothing, nothing else changed.

For Andrew and his partner, the focus on sexual activity centered on minimizing Andrew's risk of infection. Caleb also mentions similar changes to sexual activity.

> Um, I guess, "the how" sexually. How we should behave, not knowing, only knowing at that time, at that time knowing mostly the, most, how many believed stuff about transmission of HIV and what you have to be careful of and, you know, so, um, the whole, um, the mechanics of it I guess. You know. How are we going to go forward through this?

David also describes the struggle he and his partner had with determining what this virus meant for the sexual aspects of their relationship.

> I just didn't know what it meant for us. I remember thinking well it shouldn't mean anything for us, but it did. And, um, [pause] it primarily concerned me from a sexual standpoint. It concerned me, what that meant for our sex life. I don't think I had concerns, at least conscious concerns, at that point. I wasn't concerned with him dying or anything like that. I knew enough about it to not be scared of that. Um, but it was around intimacy and how could we now be intimate, and now that we would always have to use a condom if I didn't want to become infected. And those are huge concerns.

These quotes hint at a larger concern growing out of the uncertainties regarding sex. Sex is one aspect of intimacy, and, as these men discuss concerns with the mechanics of sex, they also reveal broader concerns regarding overall intimacy, not just sexual intimacy, within the relationship.

**Subjective Uncertainties**

As the uncertainties associated with the mechanics of sex morph into concerns regarding relationship intimacy, uncertainty takes on a more psychosocial aspect for these men. Knobloch and Solomon (1999) identify uncertainties associated with relationships as a particular type and source of uncertainty. Relational uncertainty pertains to questions people have regarding their own attitudes and behaviors related to the relationship. Specifically, uncertainty within a relationship may find its source in self-uncertainty when an individual is unable to make sense of his own attitudes and behaviors related to the relationship, partner uncertainty when an individual is unable to predict the partner's attitudes or behaviors, and relationship uncertainty which relates to questions concerning the state or status of the relationship (Knobloch & Solomon, 1999). Because these uncertainties are concerned with attitudes and beliefs, they relate to the psychosocial and existential uncertainties identified in the Hans, Klein, and Arora (2011) taxonomy and therefore can be labeled as more subjective in nature. Having more psychosocial and existential uncertainties regarding their partner may well place the uncertainties of these men within the definition of relational uncertainty. However, the uncertainties experienced by these men, as they relate to HIV, are primarily concerned with intimacy suggesting a more specific uncertainty construct exists within the realm of relational uncertainty.

As Peter continues to discuss sex and the risk of transmission, it is apparent that these concerns are shared by the HIV-positive partner and represent an overall threat to the connection these men share with their partners.

> I don't think I was ever concerned that I'd get HIV from him. One of my concerns was from a perspective of being in a relationship…was how he felt about being in a serodiscordant relationship and whether he would feel…some of what I hear as I read is that some folks don't want to be in a relationship with someone who is negative because they fear they would give them HIV, and that would be devastating. And I, obviously, I can't relate to that perspective, because I'm on the other side of things. So that's something we talked about, whether he would be okay emotionally, being in a relationship, was he going to feel like he was always, potentially responsible for infecting me. I had a couple conversations with him, "If I become HIV-positive, it's not going to be from you, and I wouldn't blame you for it." You know, I make decisions about what I'm going to do. I know what… I believe I know what the risks are. Just like getting on an airplane, nothing is risk free. And, I think he feels good about that. I hope he does. That's the one thing that I do worry that it might be a, um, create distance, that worry about infecting me.

All of the men participating in this study discussed their HIV-positive partners' fears regarding transmission of the virus to their negative partner and potentially giving them HIV. This fear is in opposition to, or in conflict with, the negative partners' desires to be close to the positive partner. This tension, then, becomes a source of uncertainty threatening intimacy within the relationship. As Peter's quote above demonstrates, this fear of passing along the virus also involves an additional thought. It is one thing to fear passing the virus, it is another to fear being

in a relationship because of being afraid of passing the virus. While Peter's partner fears passing the virus, Peter has an uncertainty about his partner's commitment to the relationship because his partner fears transmitting the virus. This demonstrates how uncertainty surrounding intimacy takes on a subjective nature and is approached slightly differently from each of the partners' perspectives.

After the initial awareness that HIV is present and the HIV-negative men cycle through concerns for their partner and face questions regarding sexual activity, there is the broader realization that HIV may have intimacy-related implications beyond sexual activity. As such, uncertainties immediately experienced at the moment of initial awareness of the presence of HIV start as more objective-based uncertainties, or the more scientific or practical as the Han, Klein, and Arora (2011) taxonomy would suggest. However, as the men discuss concerns related to overall intimacy within the relationship, it is apparent that these objective uncertainties quickly evolve into more subjective uncertainties, or uncertainties that fall within the psychosocial and existential concerns of the personal realm within the Han, Klein, Arora taxonomy. Specifically, these subjective uncertainties are primarily concerned with overall intimacy within the relationship.

### Intimacy and Uncertainty

As David continues to discuss the sexual difficulties he and his partner experienced, he reveals the realization he had of the threat to overall intimacy between himself and his partner. He also discusses how the uncertainties associated with the mechanics of sexual intimacy turn to broader concerns of intimacy within the overall relationship.

> Well I think with… I think that had an impact on non-sexual intimacy. I think there was a shift. It's really hard to put into words, but there was a palpable shift for me in terms, um,

> [pause]. I'm trying to remember if I had questions at that point of when and how he had acquired HIV. I don't remember having that. I might have though. But it was around. I don't know it seemed to have some kind of significance in how we would then be with each other. So I …so with intimacy, it was about both sex, but that also filtered into just connection. Um, so, it's really hard to put that into words. I kind of just remember that time as feeling a bit shell shocked around it all, but I couldn't tell you what was shocking.

David describes a very definite shift in their relationship after his partner's HIV diagnosis, particularly as it relates to intimacy. In addition, David's quote also describes the difficulty in making sense of this shift in intimacy. David and his partner had been in an on again-off again-on again relationship, and his partner contracted HIV in the few months when they were not together. When they got back together, his partner had not yet been diagnosed, and the shock of the diagnosis took a toll on the connection they had established.

While relational uncertainty is defined in terms of the uncertainties partners engaged within a relationship have about themselves, their partner, and the status of the relationship (Knobloch & Solomon, 1999), the men participating in this study describe uncertainties that are much more focused. Specifically, the intrusion and disruption that an HIV diagnosis brings to a relationship gives rise to uncertainties related to intimacy. Intimacy, as a construct, is comprised of the following five components: Closeness, a feeling of union between two people who spend time with one another and influence each other's behaviors and beliefs; Openness, the willingness of partners to reveal private information about themselves to each other; Trust, the feeling that a relational partner will keep us safe; Affection, the positive feelings we have for another person that are communicated to that person with various actions; and Mutuality, when relational partners acknowledge and value the bond that exists between them (Solomon &

Theiss, 2013). For the men in this study, HIV introduces uncertainties that are related to these components of intimacy.

While the heroes and heroines of our fairy tales often overcome dangerous situations and risk potential death from pursuing their partner, never does that risk of death come from the object of their love. Gay men in general, and HIV-negative men in particular, must deal with this very situation. It becomes vital, then, to be knowledgeable regarding the effects and history of HIV as the disease has progressed from an almost certain death sentence to a manageable chronic illness.

**HIV Slows the Progression of Intimacy**

For HIV-negative men, meeting an HIV-positive man requires them to stop and think. These men need to consider potential consequences that come with being in an intimate relationship with someone who has a chronic illness, particularly one that is contagious and potentially life-threatening. This is a unique case to consider when positioned against the popular fairy tale narratives of how relationships grow and progress. With some of the men in the present study, entering into a relationship with an HIV-positive man was a conscious choice. These men met their partners when their partners were already HIV-positive. In this way, HIV already had a starring role in the relationship when it began. Intellectually, they know that today HIV is treatable and survivable. People with HIV can, and do, live long healthy lives. However, HIV became the central, most salient point of consideration when these men were assessing their relationship options.

To understand the progression of intimacy within relationships, it is helpful to consider how relationships begin and develop over time. Knapp (1984) proposes a model of relational development that includes stages involving initiation, experimenting, intensifying, integrating,

and bonding. Each stage of the model represents increasing intimacy between the individuals involved in the relationship by following steps that reduce uncertainty, increase closeness and mutuality, and develop an identity as a social unit.

HIV was there with that initial sense of attraction, forcing a more considered approach to the idea of dating someone who is HIV-positive. For these men, it seems to take longer for the relationship to ignite and grow. They moved much more slowly at relationship initiation and intensification if their partner was already HIV-positive when they first met. HIV in this case served as a mechanism for slowing down the progression of intimacy within the relationship. For these men, HIV and the potential illness effects and issues associated with HIV were central features in the decision-making process to even consider a relationship with an HIV-positive man.

Tim and his partner met through mutual friends 11 years ago. His partner was diagnosed as HIV-positive nearly 30 years ago, but has never really experienced severe sickness from the disease, and is today on antiviral medication. Tim describes an extended, flirtatious courtship when they first met.

> We were both invited to a mutual friend's birthday party. This was about 11 or 12 years ago, and, uh, we ended up talking to each other then. I really enjoyed it. I thought he was a really nice guy, and handsome as can be, and he had a best friend …he was there as well, [Partner's friend's name]…and this is during the period of the time that I was in the middle of writing stuff… music, and recording it. And I'd written this song, and I'd taken a copy of the CD to [the bar] and ran into [partner's friend], and gave it [the CD] to him. I'm not exactly sure what happened next, but I guess they thought it was funny, and they were going to memorize the words and sing it to me the next time I saw them both. I'm

> not exactly sure what transpired, but I talked to [partner], and he said that he really liked it so I burned a CD with all the other songs I'd written, and found out his address and mailed him the CD. And he liked it, and invited me over for dinner. I kept writing, and sent him another CD with more new songs. He invited me for dinner again.

Tim explains this exchange of the CD and dinners with his future partner all preceded them actually dating. Their first date, dinner and a movie, came later. Deciding to date this man was, for Tim, a very considered decision. He knew this man was HIV-positive, and felt there was quite a bit to consider before entering into a relationship.

> I wasn't sure at the moment, at that point in time. He was very open about being HIV-positive, and I had to think a lot about whether I wanted to get involved because I'd been involved in [City, State] with somebody in the 80s who, when the test first came out, found out he was positive, contracted AIDS fairly early on, um, and passed away. And I drove him to the hospice, and went through the wringer. And then had a few friends here in [current location] in the early 90s who passed away. A guy that I was dating…there was a lot of … I just questioned myself, do I, you know, want to get involved with someone who is HIV-positive, and, because I don't want to lead anybody on. I just had to weigh everything, the costs and benefits of this, and am I prepared to deal with possible events in the future? Illness, just like I had to deal with in the past. So there was, I did a lot of soul searching about that stuff.

Throughout the description of how they met, and the questioning of whether he could enter into a relationship with another HIV-positive man, Tim struggles with whether he should make himself emotionally vulnerable to such a relationship. Trust is defined as a psychological state comprising the intention to accept vulnerability based upon the positive expectations of the

intentions or behavior of another (Evans & Revelle, 2008). In assessing the emotional risk involved with initiating a relationship with another HIV-positive man, the aspect of intimacy Tim shows the most difficulty with is trust. Tim's uncertainty centers on the question of whether entering into a relationship with this man will protect him from the emotional harm he has experienced in the past as former lovers succumbed to HIV. As Tim demonstrates, past experiences and conceptualizations about HIV directly affect his decision to pursue a relationship with an HIV-positive man. In Tim's case, it is not just stories about people's experiences with HIV or even his past understanding of the potential course of the disease in the other person. Tim's considerations about a potential relationship were based on his own past relational experience where HIV was a factor.

While HIV presents an issue to be considered when deciding to pursue a relationship, it also affects the pace at which the relationship intensifies. In Tim's relationship, he says several months went by before there was any kind of sex.

> We waited a couple of months actually before we had sex which is weird in the gay community, too. A lot of people kind of have sex, and then introduce themselves afterwards. [laughs] For us it was the other way around. We got to know each other.

With Carlos, HIV was an ongoing consideration as they negotiated their relationship. All relationships move through periods of intensification that may involve relational turbulence, but HIV was consistently at the center of this relational model for Carlos and his partner.

> [Interviewer]: Do you think this testing his persistence or this patience that you saw in him, do you think HIV plays into that at all?
>
> [Carlos]: I was always thinking, 'What would the family say? What would my friends say?" And, "How would I fit into my social circle?" I was basically a semi-popular kid

> here in downtown [City] and, um, and then my family had me as the Golden Boy. They had me on a pedestal, and every move I made was the perfect one. I never made a move without thinking about three, four times, and now only twice and…I always had a backup plan for whatever I had. Um, I was thinking about all this stuff…literally got me thinking. For a while there, we didn't have sex, because I was just, like, too much… too much pressure, and so little time for me to learn all this stuff, and for me to feel comfortable. So, to answer your question at first, yes. It had to do a lot with the HIV, and somewhat with me protecting my heart from not being broken again.

In this quote, Carlos is describing how he struggled with HIV and what it would mean for him. He worries about the stigma associated with the disease, but his mind goes to a place where he imagines or questions what his friends and family would think if he became HIV-positive. He mentions that he is seen as perfect, so contracting HIV would damage that image of perfection. This seems to be overwhelming for him, and so sex is out of the question until he can figure out how to deal with these uncertainties. Abstinence is a pretty effective method at keeping disease away, and when there is no disease, he only has to deal with the effects of the disease in his partner without any personal repercussions associated with being sick.

Sex, in relation to intimacy, is a behavior that is used to express affection for the relational partner, and it works to form the bond that results in those feelings of closeness. For both Tim and Carlos, waiting to have sex also had the effect of slowing down that progression to feelings of closeness and mutuality. In this way, HIV sits at the center of issues salient to conceptualizations of intimacy within the relationship, causing these men to both reflect on their past experiences and understandings of the illness, as well as contemplate both their personal future, as well as the future of this relationship. In this way, the progression of intimacy is

slowed while these men work to resolve the uncertainties they have about intimacy with an HIV-positive man.

**HIV Disrupts Existing Intimacy Norms and Relationship Functioning**

While the presence of HIV slowed the initiation and progression of intimacy for the partners where HIV was present at the start, the men who experienced the intrusion of HIV in their already existing relationship describe similar disruptions to intimacy. After HIV became an issue, these men, despite initially saying HIV was not an issue in their relationship, have found it difficult to find new relational norms after HIV was introduced. Caleb and his partner have been together for 17 years and his partner was diagnosed as HIV-positive nearly 15 years into their relationship. As of this interview, Caleb and his partner are still working through some of the intimacy-related difficulties brought on by his partner's HIV diagnosis.

> So, it did cause, I think some problems between us as far as that goes. And it's taking some time for us to try to figure out where we're going to go with it, and we're still kind of figuring that out, two plus years later. We're still trying to figure out where we're going to go with, with, with how we're going to have sex, how we're going to do it. The sex between us has always kind of been a point of contention. It's just the differences we [have] with our sexual energies and our sexual desires and everything. It's always been one of these things where it's almost like, we've got to plan it out.

According to Caleb, the couple has very different personalities that drive very different needs, desires, and approaches to sex and intimacy. Because of this, the couple has spent quite a bit of time working to develop agreed upon norms around initiating sex. When HIV intruded on the relationship, those agreed-upon rules suddenly changed.

> So, the first couple years of our relationship, he got to the point where he was like, "I'm always initiating. Why are you never initiating?" So, then we got to the point where he's like, "I'm not going to initiate. So, if you want to have sex, you have to initiate. So, if we go a week not having sex, it's your fault because you didn't initiate." So, we still have those kinds of things sometimes, but uh, it's hard for me I guess, being more the reserved person, to be the initiative person, so, so, we still have that area to go. And I think the HIV may have, let me go back to old behaviors a little bit because, okay, how are we going to have sex now? What are we going to do? If we're only going to do this little quick thing then it's easier to kind of do that kind of thing and so, um, so we have to kind of come back to where we were before which has taken a little bit of time to do that.

As Caleb describes, HIV allowed him to fall into previous relationship patterns that the couple had already discussed and worked to change. Specifically, the responsibility for initiating sex became a point of contention in their relationship. With Caleb having difficulty taking responsibility for intimacy and the partners struggling with issues of mutuality regarding sexual practices, Caleb and his partner worked to change that. Caleb became more comfortable initiating sex, but when HIV then came along, it brought with it uncertainty about sex and intimacy. The previous agreed-upon rules had not taken into account HIV. With HIV now a factor, reverting to the old patterns where a different kind of uncertainty was present was easy to do. Because of this, HIV affects how the partners seek to reinforce the bond between them.

Andrew and his partner have been together for a total of 11 years, and his partner was diagnosed seven years into their relationship. Here, Andrew discusses uncertainties and changes to sexual practices brought on by HIV, but it is apparent that the disruption to the couple's existing intimacy patterns has been difficult to address.

> Well, I mean, you know, just sort of fooling around not, not going, not going the full distance, just for, just for safety's sake, slam on the brakes, or something like that… especially when he wasn't on meds. Um, but, I mean, we weren't completely abstinent just… just limited our activities to some of the less risky things. But, yeah, it was definitely work still, uh…maybe a year ago… still sort of thinking maybe we don't know… we don't want to do that… I don't just want to do that to you… not cause he didn't want to do it.

In this quote, Andrew notes that even up until a year ago, they would not engage in certain sexual practices. His partner was diagnosed four years ago, but it has taken three years to get comfortable with certain things. This speaks to the problems of developing new patterns to intimacy when older intimacy patterns and norms have been disrupted. In these established relationships, the HIV-negative partner discusses the difficulties in re-establishing or maintaining intimacy because HIV was introduced after patterns and norms were set.

In another aspect related to their intimacy, Andrew describes how having an open relationship just kind of happened for the two men. They started the relationship with expectations of monogamy, but they did not really have set relationship rules until after his partner was diagnosed.

> Obviously… especially being men…have trouble staying monogamous, you know, that was an issue for both of us at times, and tried to…tried to be monogamous and both ended up cheating on each other and opened things up a little bit. And…. Yeah, I think it's been now mostly at this point just sort of unspoken, but sort of understood that, if there's an occasional thing, then that's, you know, that's fine, especially him. Especially now that he's positive, and I'm not. You know, I certainly don't begrudge him wanting to

> do some things that we can't at the moment. You know, I'm not crazy about that idea. I'm not going to drive him to the guy's place, but at the same time, it doesn't bother me terribly.

For Andrew and his partner, being monogamous was an understood aspect of the relationship, even though they had never explicitly discussed it. Once HIV came along, they felt the need to formally recognize the relationship as open. Andrew actually first characterizes sex outside of the relationship as "cheating." Andrew also acknowledges that HIV prevents some sexual activities between himself and his partner because those activities raise the risk of transmitting the virus. Andrew does not "begrudge him wanting to do some things that we can't at the moment." Within their relationship, Andrew and his partner had trouble with openness in relation to their attitudes regarding sexual activity and sex with someone other than their relational partner.

David always insisted on a monogamous relationship even though his partner had expressed an interest in an open relationship. However, with HIV being introduced into the relationship, David describes a change to their agreed upon relationship rules.

> "I… I… prior [to the HIV diagnosis], he had always been interested in that [an open relationship]. I insisted on it not. So, then I said I want that [after the HIV diagnosis]. I need that in order to keep this relationship going. I think, at the time, I felt, um …[pause] I needed to go out and meet other people, and I needed to experience sex. I don't know why exactly. I don't think there's a rational reason I can give you other than maybe it was simply I needed or wanted a, [pause] venue to express my stress or frustration, [pause] whatever emotions I was feeling at the time.

David earlier described the shift in intimacy within his relationship. Once HIV became a part of his relational reality, David's shift away from monogamy was his way of dealing with the changing dynamics around the closeness and mutuality he had shared with his partner. Sex prior to HIV was associated with intimacy. After HIV disrupted the relationship, sex became an emotional release. The presence of HIV changed the role played by sex in the relationship. Prior to the HIV diagnosis, David associated sex with intimacy. After the HIV diagnosis, he needed to work through a change to the role sex had in the relationship.

With the intrusion of HIV, aspects of intimacy changed, and for these men that had already established relationships, HIV had the effect of forcing them to leave behind or change the path they had already established toward fostering and reaffirming intimacy between themselves and their partner.

**HIV Creates Barriers to Intimacy**

In close relationships, sex functions as an arbiter of intimacy (Sternberg, 1986); the threats and restrictions that HIV places on the sexual practices of these men also threatens to negatively impact the overall intimacy within the relationship. In addition to disrupting the pace and path of intimacy progression within these relationships, HIV also presents barriers to intimacy that create difficulties for the relational partners. Carlos describes how condom use becomes a barrier to intimacy.

> Even though you don't think about it, but you can see the reaction, the way they move, when they're reaching over for the condom. You can see they're like, "oh, we have to go through all this process just to get something."

In relating this difficulty with condoms, Carlos is identifying the intrusion to intimacy that is HIV. It directly attacks the partners' affection and closeness, and causes the partners to interrupt an intimate moment to make accommodations for the unwelcome third party that is HIV.

As Peter discusses, sex is important to these men and plays an important role in establishing the connection between the couple.

> I think there's no more intimate thing than letting someone inside you, and I got to a point where I was just very much in love with this man. I wanted to experience that. I wanted him inside of me. I wanted a piece of him. It might sound odd, but that's kind of how I feel.

Peter's quote is part of a larger discussion regarding the decision to not use condoms with his partner. The decision to use condoms has always been, for Peter, an easy decision when having sex outside of a committed relationship. However, in his comments regarding sex with his partner, he discusses the downsides of using them. It seems that the difference here is that before, when it was "an easy decision to make" it was outside of a committed relationship. However, all the downsides to condoms came when he entered a committed relationship. Condoms, then, represent both a physical and psychological barrier to intimacy.

John also describes the barriers to intimacy that result from the intrusion of HIV. Like Peter, having to use a condom represents a barrier to intimacy within the relationship.

> But your question was, why unprotected sex? Why is that important? It's an intimacy thing. Condoms, I'm sometimes, I'm most frequently the bottom, and they're uncomfortable, and I can tell a difference. I disagree with Dan Savage on this point 'cause he always goes on and on that you can't tell a difference with condoms or no condoms. You can tell a difference. I can feel a condom inside of me, and sometimes it

> burns. They, like, bunch up, and it's, like, weird ribs. I don't want to deal with that. It's just better [without condoms]. Um, and it's more erotic. There's a lot of fantasies around barebacking. Um, I think that kind of covers it. It's also easier if you don't have to worry about condoms. I would say [partner] and I are pretty kinky individuals, so, like, randomly having sex somewhere that isn't our home could happen, and if you've got to kind of like whip out condoms it can kill the mood. It really can. It's nice to just not have to worry about it. Well…it's, it would be nice. The best thing would be if no one had to worry about it. I still have to worry about it. But, with [partner] I'm at a point where I don't worry about it.

It is interesting to note that John describes the problems with condoms as intimacy related, but rationalizes the decision to not use condoms with his partner because of physical reasons associated with discomfort. This hints at several potential problems associated with condom use. John feels the need to justify not using condoms based on easily understood qualities of condom use. However, John also recognizes that the issue is really about intimacy, or that feeling of closeness with his partner. HIV and condoms threaten that closeness; yet, it is more difficult to explain and rationalize.

The barriers to intimacy brought on by the uncertainties associated with HIV contribute to additional barriers beyond the restrictions HIV places upon performing particular sexual behaviors. Because closeness and a sense of union are also components of intimacy (Solomon & Theiss, 2013), Steve describes how the effects of illness have created other physical and emotional barriers to intimacy.

> Lots changed since then. And, um, now we're in a relationship. I love him, but you know, um, ah, we've not had sexual relations probably for about a year and a half. Because of

> his medical conditions, he sleeps upstairs and I sleep downstairs. You know, that's hard, so you know you go from, moving from that attraction of, of lust to, you know, that kind of thing, to you know, caring for that person. How do I look at him now? [Sighs] That's a whole deep long conversation, and this isn't a counseling session, but ah, the last two years have been "let's just get you well. Let's just get you well." I don't really have time to think about my feelings or our relationship.

With Steve and his partner, the overwhelming nature of the complications related to his partner's condition act as a barrier making the progression and maintenance of intimacy difficult, if not impossible. As the quote shows, Steve sees a barrier in the necessary sleeping arrangements, and, at this point, illness has completely taken over their lives such that nothing else can be thought about, and certainly not the emotional aspects of intimacy and a relationship.

**HIV Creates Doubts Regarding Commitment to the Relationship**

As Peter's quote above highlights, Peter questioned whether his HIV-positive partner could commit to a relationship when he carried fears of transmitting the HIV virus to Peter. In this way, HIV creates doubt in the HIV-negative partners' minds as to the stability or the mutuality of commitment each partner has to the relationship. In addition, the negative men participating in this study also recognize the doubts their positive partners' may have regarding the negative partners' commitment to the relationship. For example, Steve explains, "I think his concerns are then with me. I think he probably is concerned if I'm going to leave him." Because Steve's partner has experienced so many overwhelming and debilitating effects of illness, he knows that Steve also experiences the overwhelming nature of disease, and Steve recognizes that this instills a fear in his partner that he may decide one day that dealing with disease just involves

too much to stay in the relationship. This is not an unfounded fear. As Steve relates in the following quote, relationships can just be too difficult to deal with.

> It's draining. Yeah. Because you know what happens? After all the lovey-dovey stuff like that, it's, ah, truly it becomes, are you going to be there for that person? You know. Are you going to truly be there? And I don't know if the reward is worth, if there's, the reward is worth the work to get to that. What I'm trying to say is, where I am right now, do I have enough of that fulfillment from the relationship I have with my own kids, or with my friends that I ***need*** [emphasis added by participant] a relationship? Probably not. It may change. And that's another thing I've learned. Your opinions change very quickly in life. What I thought five years ago is vastly different than what I think so now. And, and, and I'm sure it will evolve. So, if I've learned anything, just don't say, "Well, this is the way it's actually going to be," because you change. You just, you know, people change. And that's why you stop being judgmental because you don't know where people are on that cycle. But, I can tell you right now, that yes I would. I would not, I would not look at somebody…I think that's a valid question after you've gone through it if you've experienced it. Um, I don't think [partner] ever allowed me being negative to consume him or be a problem. I don't know what his answers will be, but from what we've talked about, it never has been. But um, but where I am is, I would never be in another relationship. It's draining. It's totally draining.

Steve and his partner have battled through years of debilitating side effects from his partner's illnesses, including illness beyond HIV infection. The overwhelming nature of disease at this very acute stage completely destroys intimacy, and with it, the sense that there is much of a relationship at all.

For Carlos' HIV-positive partner, there was a reluctance to delete his profiles on websites and smartphone apps designed for meeting and dating other men. Carlos describes how he interpreted this behavior.

> At first I think he just thought that I was going to like leave him. He had the websites still open because he thought eventually I was going to go, and he would have to have a rebound or something. But once I assured him that I was with him, that I was getting comfortable, that I was comfortable … now he doesn't worry about that.

Carlos describes his partner's previous struggles with feelings of being tainted and not worthy of a relationship because of the HIV infection. Because of the HIV, Carlos' partner had difficulty believing that Carlos could actually commit to a lasting relationship with someone who was HIV-positive. To combat his partner's feelings of unworthiness, Carlos goes on to describe how he has to work continuously at reassuring his partner of his commitment to the relationship.

> What I mean by responsibility is that you have to always maintain the relationship. You have to make sure that he, that individual, feels loved. That he feels that you appreciate him, and I, like, on that, on that area, I have to admit, but I do let him know that I care about him, and he must understand that Latinos, that we are not used to, um, to basically show too much emotion. I mean we show emotion but not when it comes to …see here in the states…when someone is dating someone…even in the straight world…. Um, they'll be holding hands or kissing in public. But I come from a family that that is private. That is personal. That is not something to be displayed.

For Carlos, demonstrating to your partner that feeling of mutuality, that you both are committed and involved in the relationship is a duty that is essential to the health of the relationship,

particularly when HIV creates uncertainties in the HIV-positive partner about how committed the negative partner is to the relationship.

Tim describes similar experiences where he must work at reassuring his partner that he is committed for the long term. According to Tim, the source of his partner's uncertainty regarding Tim's commitment to the relationship stems from the side effects of the antiviral medication he takes.

> The main problem is the side effect of the meds he takes is lipodystrophy. He's very conscious about body image, um, and, um, he had to basically kind of have liposuction done. I supported him, helped pay for that, uh, so that's more of an issue is his …his self image because of that. One of the things that I try to reassure him is that I'm okay with that. That doesn't affect my attraction to him at all. Um, I know it is something that bothers him, so I try to, um, make that not a concern if I can.

Tim goes on to describe how he has learned over the years that comments regarding this particular side effect made by his partner represent fears his partner has regarding Tim's commitment to the relationship. While this side effect is related to his partner's body image issues, it also speaks to the fear his partner has with feeling unattractive and the uncertainty of what that could mean for intimacy within the relationship. Tim explains how he allays his partner's uncertainties.

> I think I've done it a number of times. I've heard him say I hate the way my body looks and that's a cue. When we were in …and I think when we were in Florence we were having a dinner cause the uh… and I brought it up again and said, "I know that you're concerned about this but I'm telling you I love you and it makes no difference to me. You're no less attractive to me. I still think you're hot and I still love you and don't

> worry about it for my sake or in terms of our relationship." I don't know if he worried about me… well he…he was very grateful that I said it so I suspect probably on some level he probably did worry. I don't think I ever gave him reason to—it was more you know just his own you know thought about it looking in the mirror and not fitting the ideal. Who does? You know? So yeah I think that he … I think that he probably did worry about that.

With Tim addressing the mutuality component of intimacy the two men share regarding their commitment to one another, he works to both address the uncertainties of his partner and also foster intimacy.

**Intimacy Uncertainty**

These data indicate the men participating in this study experience uncertainty in a more specific way than what is described in the more general notion of relational uncertainty. As was previously noted, relational uncertainty encompasses those uncertainties that people in relationships have regarding themselves and their partner as they relate to the relationship overall (Knobloch, & Solomon, 1999). While the men participating in the present study may have uncertainties related to their relationships, the uncertainties they experience associated with HIV and illness are directly related to the various aspects or components of intimacy. In addition, the intimacy uncertainties experienced by these men are associated with sexual behavior and practices. The facts associated with transmission of the virus and sexual behaviors that may increase the possibility of transmission may be seen as the information needed to successfully manage uncertainties related to how the virus is transmitted. In this way, their intimacy uncertainties are of an objective nature that is based on observable phenomena and factually presented. As was discussed, initial concerns regarding the mechanics of sex and the factual

nature of HIV then lead to uncertainties regarding feelings of closeness and connection between the partners. At this point, their intimacy uncertainties become subjective in nature, or based on attitudes and beliefs held by the men that are more psychosocial or existential in nature. Knobloch and Delaney (2012) identify disruptions to sexual activity, emotional intimacy, and openness as themes associated with relational uncertainty among couples facing depression. Findings from these data in the present study also support the presence of disruption to intimacy-related constructs within relationships facing illness; therefore, it is proposed that intimacy uncertainty is a subcomponent within the broader construct of relational uncertainty. Therefore, intimacy uncertainty is the state individuals occupy when they are unsure about the objective and subjective behaviors and feelings relational partners have regarding closeness, openness, trust, affection, and mutuality that exist between the partners.

Because HIV represents an intrusion into the intimacy of the couple and sparks intimacy uncertainties, these men addressed the management of this uncertainty in several ways. The goal of their intimacy management efforts is designed to accomplish two particular goals. First, the men seek to banish HIV and illness from the more intimate aspects of their relationship. These men work to try and push HIV off to the margins and not allow it to affect certain intimate aspects of their relationships. Second, when HIV and illness cannot be pushed completely out their relationships, the couples work to maneuver around the effects of the disease by modifying or creating new relationship rituals designed to help them create and foster a more intimate, shared connection.

**Establishing Rules and Norms Regarding Sexual Behavior and Condom Use**

As has been noted previously, sex is an important arbiter of intimacy, and, due to the nature of HIV, sexual behaviors are a point of intimacy the couples in this study had to negotiate

in such a way as to foster a sense of closeness and unity within the overall relationship. For these men, condoms, like HIV, represent an intrusion into the relationship. For example, John compares the use of condoms in homosexual relationships to their use in heterosexual relationships.

> I dated this guy that was a biochemist and he feared viruses. So he would say things to me when we were dating, like, even if they cure HIV you can't have unprotected sex because you never know what the next virus that could mutate and pop up could happen and I was like, true. Factual. But if you're dating someone and you're in a trusting relationship and you've established some rules and regulations and enough time has passed to trust each other some new, mutated virus isn't going to spawn between each other. And if you end up in a relationship you have conversations about that. Like I said I'm just very trusting and I also would eventually like to be in a relationship where I can have unprotected sex. Straight people have unprotected sex all the time. They made birth control which some doctors says isn't great for women just so men could have unprotected sex with their wives. I don't know. I think it's too hopeful that people will use condoms 24/7.

For John, having unprotected sex within his relationship is important. By stating, "Straight people have unprotected sex all the time," he is suggesting that condoms present a barrier and that they can be managed away in trusting relationships. As an earlier quote from John describes, both HIV and condoms represent a barrier to intimacy. He goes on to describe in further detail the intrusion that condoms represent, saying the he does not want to have worry about using them. John's attitudes regarding condom usage are especially interesting given his comment that he "is frequently the bottom." By assuming the receptive position with regards to sexual activity,

John is taking the riskier role when it comes to disease transmission. In order to mitigate that risk, he describes how he now takes antiviral medication as a prophylactic to prevent the possibility of HIV infection.

> I didn't go on Truvada until [partner] and I started dating. I'm sure we talked about it that very first night we had sex. It's like in May, after, when I was like wrapping up my degree, we finally decided to hang out all the time. I think we had mentioned it, and I think within a week I was like, find a doctor that will prescribe it, and I'll get on the drug because it takes some time to build up in the system, and we were pretty clear that we wanted to have unprotected sex.

In this quote, not only is John describing his decision to take antiviral medication, but it is also important to note that he, as the receptive and HIV-negative sexual partner, is driving the decisions regarding condom usage, even directing his partner to find the doctor that will prescribe medication.

For Carlos, having unprotected sex was also important, and, like John, Carlos typically assumes the more receptive role in the relationship. To feel comfortable about having unprotected sex, Carlos describes the negotiation and evolution of the rules the couple adopted for their sexual practices.

> Yes, the negotiation about that was, "Look," I told him… [partner]. "Whenever I'm going to, we will have to … and when you brush your teeth, we're going to use Listerine, but that's a powerful mouthwash, and we have to wait 30 minutes before we kiss. Or when we shave, let's be sure you put your name on your shaving stuff, and I'll put my name on my shaving stuff." And then I was like, "Whenever you cut yourself, whenever you clean, clean it with bleach or whatever. And when it comes down to sex, there's not

> going to be any sucky-sucky without a flavored condom." And I was like, "There's not going to be any penetration without a condom." So, and for him, I was like, and I mean to me, uh, we used to give oral but I would rarely put a condom on, but when it came down to being with [partner], I was super, like, literally, like I said I had more rubber around. Basically, it was kind of like a bubble, living in a bubble, but he was okay with it, because he knew that I was like, just not yet knowledgeable about it. And when we did it, it felt normal, just like screwing any guy that is negative, but it's still a condom. It's still rubber that you feel, but it's still a normal screw. You have to be more careful about it. After we had that first screw, I remember he was like, "How do you feel?" He was very, he was always asking me how I feel, and that was one thing that I realized; he really did care about me. I wasn't just a person that he wanted to screw with.

At this point in the relationship, the rules around sexual activity between himself and his partner involved a variety of activities (with condoms at the heart of it all) designed to prevent any transmission of the virus. However, as Carlos engaged in more information-seeking, he became more comfortable with relaxing the couples' rules around using condoms.

> But, with time I went from like, I said, once I educated myself, um, I went from condom, condom, condom all the time to okay. Since you're basically undetectable, and I spoke to my doctors, literally, I spoke to so many doctors, and they were like, "Well, it's really safer if you use a condom, but, um, if you want to go that route, as long as he doesn't ejaculate in you, you're good. And I was like, "Really?" And even though I knew that information, I still went another month without feeling comfortable, and one day, we were just laying there, and I was like, "Screw it." I'm not going to always be like, he has to want to do the barebacking, and I was like, 'cause Lord knows I would get tired of

barebacking. I mean, not barebacking, but using condoms, if it was me.

Carlos goes on to describe then having sex for the first time after making the decision to forgo a condom.

> My whole body was shaking, because I was like, and he was like, "You don't feel comfortable, [Carlos]." And I was like, "I do, to certain degree, it's just that my body is like, ehh." But my mind was feeling comfortable. We did it the first time, and he, of course, ejaculated outside. He was like, "How do you feel? How do you feel?" And, for that one day, I thought that I should go and get tested for some reason, because I was petrified. I thought I was like, "What was I thinking?" Of course, I had to wait more time, so I was like, "Okay. Fine. I'm going to wait," and I was like, "[Partner], let's use condoms now to see if everything is still okay." Everything came out fine, and I was negative, and he was like, "Are you comfortable? Are you okay? We can use condoms if you still want to." I was like, "I feel more comfortable. I feel more safe. I feel like you will respect the one thing that we agreed on, that you will ejaculate outside when we bareback, and if you want to ejaculate inside, you will always use a condom. And so he's respective of that, and for that, I am truly grateful to him.

While Carlos is now on antiviral medication as part of a clinical study on HIV prevention, it is important to note that Carlos' decision to have unprotected sex as the receptive partner was done prior to him going on antiviral medication for prophylactic purposes. Carlos mentions several times about how his partner expresses concerns for him, wanting to know how he feels, and letting him set the rules around intimacy. Everything around condom usage (or non-usage) is dictated by Carlos, but his partner is completely comfortable with that. The partner's expression of compassion and concern seems to set Carlos' mind at ease, and helps him deal with his

uncertainties and concerns about sex. The partner, by continually asking if Carlos is OK, instills a sense of trust in Carlos that allows him to feel more comfortable about sex and the couple's rules on condom usage and non-usage. For Carlos, he gets to dictate the terms of sex. Being in charge helps him to manage his uncertainties, while the positive relational communication from his partner also allows him to manage his uncertainties and promote intimacy between the partners.

In the following quote, Peter talks about his decision process to go without condoms. This happened in stages, and it is similar to Carlos' situation in that there were very specific steps Peter and his partner went through. It is interesting to note that, in contrast to John and Carlos, Peter was primarily the "top" in their relationship, and he made the decision to go from being solely a top to also taking on a receptive role in the couple's sexual activity. This is something he wanted to do, and again demonstrates the negative partner's role in driving the decision-making regarding sexual behaviors.

> Uh, one of the things the doctor and I talked about is, you know, there's far less risk as a top, so if that's primarily the role you're playing then, that's um, you know, that your risk is very, very low. Um, he did say there's no zero risk, and the big challenge is, you know, if your partner forgot to take a dose or if the viral levels spike above undetectable, um, then you could be at risk, particularly if you're bottoming. And you know, I thought a lot about that, and I decided it was something that I wanted to do. And, in the early going, I was always the top. Um, I think it was emotionally easier for him in particular, and it certainly was for me. There came a point in time, um, I guess it was over the summer, maybe late spring, or early summer where I wanted him to, I wanted to be the receptive partner. And we've done that, um, fairly regularly. And I'm not really worried about it,

> because I see him take his medication every day, and I've seen his blood work. It's just he's very healthy. All that said, yeah I'm putting myself at some risk. I, we've even talked about, do I consider going on Truvada which is the PrEP, um. So that's [pause], again, this is one of those things where I don't think it's a done conversation actually, certainly not for a while anyway.

For Peter, he clearly sees that taking on the role of being the receptive partner during sex as something he is doing for his partner. He also mitigates the risk by telling himself that he sees his partner taking his meds everyday (and the doctor says there's little risk if he is doing so), so it's OK. While he also mentions the discussions he and his partner have had about going on the antiviral medication himself as a prophylactic, he currently is not taking any medication as a preventative measure.

The decisions regarding sex and condom use are not driven by the availability of medication by any of these men. The desire to have sex without a condom is a decision around intimacy and the desire for the feelings of closeness and unity with their partners. Condoms, for these men, are an intrusion similar to HIV. Rather than allow condoms to intrude on the couples' intimacy, condoms are, for the most part, banished from the relationship. This also reflects the couples' desires to banish HIV and prevent HIV from disrupting their intimacy. Not wanting to use condoms and having to use medicine would both seem to be something indicating a reminder of the illness. However, they serve completely different functions for these men. For the negative partner, taking medicine is liberating. It makes it so they don't have to restrict themselves when it comes to sexual activity. Medicine is a remover of illness. It gets rid of the interloper into the relationship that is HIV.

In addition to fostering intimacy by developing rules around unprotected sexual activity,

the men participating in this study also adopted new sexual practices altogether. As Tim describes, the questions he and his partner have related to intimacy were centered on constraints to sexual activity.

> So we did talk about it I guess. It was more… it wasn't, "Should we have sex?" It was more, "What are the constraints? What's okay, and what's not okay." I know we had those sorts of discussions. I have gum disease, so I didn't want to do oral sex, and I'd given up anal sex in 1980 and '81 when I'd gotten a case of warts which was horrible to go through, and I didn't want to start that up again, because I knew that condoms can break. I taught Human Anatomy and Physiology and birth control stuff to students. So, basically, we don't do insertive sex, but, uh, we're happy. We're compatible. We have sex you know every Friday. We have date night. We go to our favorite Thai restaurant, and come back and …[laughs].

Tim, because of certain health issues he's had, has just decided to give up certain sexual practices. Interestingly, he discusses later in the interview how they have developed and opened up their sex lives to other kinds of experiences. In a way, their constraints sent them in a direction to be more creative and more satisfied with their sex life.

> How has it changed? Um…[pause]… it hasn't changed a whole lot. Um. [pause] Um… [laughs]. It's gotten a little more adventurous in some aspects. Um. We're both interested in leather, sort of, in general, which we didn't do at first. That's almost another coming out, when you're interested in BDSM [Bondage & Discipline; Domination & Submission; Sadism & Masochism]. Um, so it took us a while to open up about that and those interests to each other. Yeah, and, and, you know, doing and experimenting more stuff with what we wanted to do together. And that [pause]. So, it's different more in that

sense. We do more stuff than we used to. Um, but I'm still, we're monogamous, which is apparently another weird thing.

For Tim and his partner, they solved the problem of HIV intruding into their intimate moments by being creative and opening up to each other about their sexual interests. In this way, HIV serves as a mechanism to promote the openness component of intimacy within their relational lives. It is also interesting to note that, like the examples provided by John, Carlos, and Peter, Tim and his partner have also chosen a route to sexual activity that does not involve condoms. For all of these men, using condoms is, in a manner of speaking, acquiescing to the intrusion of HIV. Rather than give in to condoms, and by extension HIV, affecting their most intimate moments as a couple, these men choose to engage in sexual behavior that still fosters intimacy, but pushes out the intrusion that is HIV.

**Incorporate HIV Treatments into Relationship Rituals**

In addition to establishing intimacy-related behaviors that seek to push back on the intrusion of HIV into the relationship, the men participating in this study report behaviors that are designed to promote intimacy between the couple while at the same time, neutralizing the effect of HIV. While the HIV-negative men in this study may or may not take antiviral medication as a preventative, all of their HIV-positive partners take medication to treat their HIV infection. Medication serves as a rallying point for these men to both demonstrate commitment and closeness, while at the same time, working to remove the effects of illness.

As Tim describes, one ritual he and his partner have developed involves his partner's medication.

The one thing that I do every week is that he has, uh, a set of meds that he takes. And a little box for every day of the week, morning and evening and so every week, every

> Sunday, I do his meds. So I dole out all the pills in this thing. He asked me to do that very early in the relationship. Um, I thought okay I'll do this. It kind of …in a way, I don't forget that he's HIV-positive, and it's one of the ways, drudgery sort of things that he doesn't like to do. I think he wanted me to, [pause], and we didn't talk about it. I think he wanted me to have some type of part in his healthcare. Um, we're sharing a life together, and part of that is taking care of each other, and being there for each other. I see doing that as, uh, sort of symbolic of that.

In this quote, Tim says that the reason his partner asked him to do this is so that he doesn't forget that his partner is HIV-positive. He goes on to say that he thinks his partner wanted him to be involved in his health care, and that is part of sharing a life together, taking care of each other, and being there for each other. In this way, getting the negative partner involved in the process of treating HIV not only makes him demonstrate his commitment to the relationship, it also serves to remove intimacy uncertainty by fostering more openness and promoting closeness and mutuality between the men. This behavior may also provide a glimpse into the relationship between intimacy uncertainty and relational uncertainty. The sharing of responsibility for medication serves to promote intimacy, but may also remove some relational uncertainty in the process. If your negative partner is willing to take part in this process, he is communicating his willingness to stay in the relationship.

As Carlos describes, he and his partner also developed a ritual around taking medication together. The ritual started with Carlos taking medication for Attention Deficit Disorder, but grew to include medication he takes as part of his participation in a clinical trial studying the use of antiviral medication as a prophylactic.

He knows that now, with him, I feel like I'm in a regular relationship. That doesn't even cross my mind anymore as much as it used to. I know that the best way to help him out, to make sure that he feels comfortable and that I'm okay with it, is to take, um, my medicine at the same time with him. And, that we semi, what, feel that we are both taking care for each other, and that we are comfortable with each other. And that's how I know that he's comfortable way more than what he used to be at first. At first I was taking Vyvanse a lot because I could not focus on one thing, and I was like doing… I was jumping from one thing to another, and all over the place, and I was like everywhere. For ADD. Um, so with, um, him, he basically, just he was, I would take my medicine, and, basically right now, I'm in a study to see how meds will affect me since I'm a negative person. So, I'm taking a cocktail, but I don't know what it is. He can look at a pill and tell you what it is, and I'm like, "Damn, he's such a geek." But, um, but, um, like I told him, some could be a sugar pill, because we don't know. So, um, so right now, I'll be taking my pills, and my vitamins, and that'll be my little cocktail, and he will have his. So, basically, we'll be helping each other, reminding each other. You know, did he take his? Did you take your medicine? Did you take your medicine? So, we'll be helping each other, because the one thing I found, I realized is that if I keep him healthy, then I'll be healthy. That's how I saw it. 'Cause if I'm helping him to be healthy, then I'll be healthy, so why not?

For Carlos, taking medication is not only good for their individual health, it is also important to the health of their relationship. By setting aside time to take medicine together, it makes them both feel like they are taking care of each other, that they are in this together. This idea of taking

medicine every day helps the negative partner understand the experience of the positive partner and serves to create a sense of union. In this way, they are managing their intimacy uncertainty.

Andrew and his partner present an interesting counterpoint to the experience of taking medication together as an act to remove intimacy uncertainty. As Andrew relates, asking his partner about his medication represents a line that is difficult to walk.

> It was still a big concern, but supporting him as best I could whenever he needed the, um, you know, not getting too involved. It's one of those things you don't want to smother him with concern, or you know, make him feel like he's all alone. That was, it still is, a bit of a difficult line to walk. You know, do you remind him to take his pill at night? You don't want to, "Take your pill? Take your pill?" That is still a challenge, but immediately afterward, it was still a concern. There were some times like I mentioned before when I'd get on him about taking his meds. Just making sure …getting ready to go to bed… have you taken your pills? Stop reminding me.

Andrew and his partner had been together for over seven years when HIV was introduced into their relationship. HIV represented a disruption to relational norms rather than being something that was incorporated into the overall development of the relationship experienced by Tim and Carlos. For Andrew, when he asks his partner about taking his medication, it is seen as nagging. In this case, Andrew and his partner have not incorporated medication as part of a relationship ritual that promotes intimacy and removes the influence of HIV. For Andrew and his partner, medication serves in a similar capacity as condoms. It is a reminder of the presence of both the illness and the source of intimacy uncertainty within their relationship.

While condoms represent an intrusion to intimacy, medication is a remover of illness. Taking medication, rather than a disrupting behavior, is a source of assistance in pushing HIV

out of the relationship. Couples participating in this study, in an effort to promote intimacy, form a relationship ritual around medication as a time they can both share in neutralizing HIV's impact while at the same time, promoting closeness, affection, and mutuality.

**HIV Influences Relationship Talk**

In popular culture, gay men are often stereotyped as being promiscuous, and having many sexual partners outside of committed relationships. While there are men for whom the stereotype proves true, the difficulties for these men come when one of their casual sexual partners evolves into a committed partnership between the men. "Hooking up" is a social phenomenon that does not fit the socially accepted and expected relationship development stories involving a sequence of events along the lines of meeting, dating, committing, and marrying. With many of the men in this study meeting their partner via "personals" web sites and apps designed for finding casual sex partners, the move from casual "hook up" to committed life partner is often difficult to explain to friends and family. Moving from casual sex to friends to committed partners was the situation that Peter and his partner navigated. Once they became friends and participated in other activities besides sexual activity, Peter describes how it was difficult to categorize their relationship.

> I think that he and I started out as biking buddies, and we would go out to dinner, to social functions together some before even his partner passed away, because his partner got to the point where he couldn't go out. But certainly after his partner passed away, we were doing that a lot more, and people were wondering are you friends, are you fuck buddies? Are you a couple? People didn't really know what to make of us which is understandable. People like labels. They like to know where to put people. And we kept saying for the longest time, "We're not a couple. He's healing." For the longest time, and

> you know, we kept saying we don't fit into any box and it got to a point really over the summer. There were two things that brought this to a head. We acknowledged, okay. We're spending every other week together, we'd spend every day together if you were living with me. Maybe it's not the best time, but neither of us wanted to walk away from it, because it felt right. He was also struggling with, he'd kept the [type of] job, and it had a commute, and it became really hard to deal with the estate. And, he has a house that needs a lot of repairs, so it can be put on the market and sold. So, I said, well, we got to the summer so I said, "I can put you on my health plan, but that would mean we'd have to register as domestic partners." And I left it out there as an option, but I said, "You know, that would mean we're moving forward as a couple." And I didn't know if he wanted that, but he did. So he moved in and quit his job to focus on getting the estate, and part of it was, yes, we want to move forward as a couple. So we did all of that in August, and as we were doing that we were like, "Okay, now we really have to kind of come out and tell people." I actually went and told my kids and my ex, and we told some of our close friends, and we came out on FaceBook to sort of the rest of world. And there was this, "Well, duh, we've known this for months. You're not telling us anything that we don't know."

Peter here is talking about how they identify as a couple and how they got to that point. He mentions that people like labels, and part of the decision to identify as a couple was to deal with the constant questions. Saying they were a couple makes it easier to explain to other people, even though they didn't feel they had an established, socially appropriate box to put this in. Interestingly, part of the issues here are with the fact that they first got together via a "hookup" site for only sex. Individuals hold culturally-specific and shared notions of normative relational

scripts (Holmberg, & MacKenzie, 2002), and the "boy meets girl" narrative is one of these scripts. It is difficult to explain where a relationship starts when it does not follow one of society's established, socially acceptable methods for relationship development. The way they met does not follow the established boy meets girl, dates, and then gets married "happily ever after" narrative of our society. Peter and his partner are not alone in attempting to negotiate the transition from casual sex partners to committed relational partners. While commonly held narratives may follow the relational development script as outlined above, men often define the casual "hookup" in such a way as to leave open the possibility for the development of deeper levels of intimacy and commitment (Epstein, Calzo, Smiler, & Ward, 2009). However, this narrative is not seen as socially acceptable, and the couple struggles with how to characterize their relationship. There seems to be a reluctance to label the relationship as well. This idea would be rooted in the fact that they started the relationship with one set of rules (quick hookups, sex only), and then progressed to "friends with benefits." However, because their relationship rules have changed, they are reluctant to name themselves a couple. It is yet another evolution in their intimacy they have had to negotiate.

In this situation, the HIV status of Peter's partner had an interesting role in helping to move along the discussion about relationship status. Part of what helped move them from sex partners to committed partners was the need and availability of healthcare to treat HIV. To clarify where they were at, there was this option to talk about health insurance that eased them into the discussion of moving forward as a couple, essentially being able to label themselves as a couple. This was important because so many outside people were asking, and because Peter has children, it helps him explain the relationship to his kids. For Peter and his partner, this was a way of managing intimacy uncertainty. The couple used these relationship talks as a way to cut

through the ambiguity and uncertainty associated with how to navigate the progression of intimacy and explain their overall relationship to the outside world. This seems to be a way to use relational talk to reduce or manage intimacy uncertainty. HIV may also help this along. Cannold, O'Loughlin, Woolcock, and Hickman (1995) found that HIV acts as a catalyst within the relationships of HIV-positive men by promoting behaviors designed to achieve further relationship clarification and intimacy. If the pair can successfully use discussions of health care to clarify their intimacy level, their relationship status falls into place. This is another example that hints at the connection between issues of intimacy and the overall relationship. Health care becomes the topic of discussion, but in a way, becomes the object of discussion that stands in for the relationship. The talk is all about health care, but the talk is really about the relationship status.

Relationship talk involves communication with a partner that involves discussing the status of the relationship between the partners (Knobloch, Solomon, & Theiss, 2006). As has been discussed throughout these findings, the disclosure of an HIV-positive status brought with it much uncertainty regarding sex and intimacy. To navigate and manage these uncertainties with their partners, the men in this study resorted to relationship to address their intimacy uncertainties. Several of the men participating in this study were in long-established relationships with their partner prior to the partner becoming infected with HIV. These men certainly had to manage intimacy uncertainties brought on by the intrusion of the virus. However, as time moved on, it is apparent that prior to the HIV diagnosis, there was much about the relationship that was not discussed. The HIV diagnosis changed that. For example, Caleb and his partner didn't really talk about the opening up of the relationship.

> Now, having said that, the reason I understood [partner] going outside of the relationship is that, because I know that related to my fetish there were some things that he wasn't getting in the relationship. Some things that he wasn't getting in the relationship, he needed to get that elsewhere. I understood that. What I kind of, what we've gotten better with since he was diagnosed is that, um, it was always that in the background, not knowing, you know, not that I wanted to know all of the details or anything, but not knowing how frequently or anything like that, but it was kind of you know, I'm at work and he's at home, you know, is it, is it seven days a week is it, you know that kind of thing. Not knowing the logistics of it caused a little bit of an anxiety for me as far as what's really going on. But since he's been diagnosed and it's more kind of a, open about the whole thing, um, and we've had more of those dialogues about how he finds and meets people and goes about the hook-up.

They didn't talk about sexual preferences, needs, desires, until after his partner was diagnosed. It seems as though Caleb has a lot of guilt about his role in the relationship, sexually speaking. He is more reserved, he has a fetish his partner doesn't share, so his partner going outside the relationship for sex is, for him, kind of his fault. HIV forced the couple to talk more about their personal needs and desires. Caleb feels more comfortable knowing some details rather than not. If it feels sneaky, it's wrong. His partner was dealing with guilt associated with having sex outside the relationship, and that guilt led to not talking. The HIV broke down these barriers to discussion around this issue. This is an important turning point for Caleb in terms of intimacy within his relationship with his partner. Gay men in non-monogamous relationships that openly discuss extradyadic sexual encounters report higher relational satisfaction, greater satisfaction with their sexual relationship, and more consensus on important relational issues than men who

are secretive regarding outside sexual encounters (Wagner, Remien, & Dieguez, 2000). Caleb is not uptight about monogamy; anxiety came from not knowing what was going on, in effect, being on the outside, and when he now knows, he is on the inside and where he should be with his partner. Dealing with these uncertainties led to the couple being more open with one another.

In this section, Caleb is talking about the impact the diagnosis had on the disclosure of their open relationship, not only to each other, but also to their friends and family. At that point, no one knew they had an open relationship, and as partners, they hadn't really talked about it. His partner was feeling guilty about it. The diagnosis forced them to both talk to each other, and it became obvious to family and friends what was going on. This was especially difficult because Caleb's family doesn't really talk about these types of things. Caleb continues to discuss how HIV opened the dialogue between himself and his partner.

> So it's always been a point of, kind of, in our relationship of trying to figure it out. So this just added a different component but in some respects it added a component that forced us to talk about it more, and forced us to maybe work out some things that we had kind of let go by before. So, it opened the dialogue a lot more than we'd had in the first seventeen years of our relationship.

It's interesting that he moves directly from discussing these disclosure issues into a discussion about the problems they have had in negotiating sex. Even two years after the diagnosis, they still haven't worked out all the particulars around how sex will proceed. Talking about HIV, for this couple, is standing in for talking about the relationship. Questions regarding where are they going as a couple, how do they proceed with sex and the relationship; those questions could be said certainly about the HIV, but also about their relationship in general. The couple seems to have been dealing with issues around trust and guilt, and it seems that the HIV has forced them

to confront those issues. Today, they are now still working it out. These quotes from Caleb represent a whole exchange where he is discussing his thoughts, concerns, and, in his words, anxieties about his partner having sex with others. This is another instance where it seems that the HIV diagnosis wasn't devastating to the relationship, but, in fact, allowed them to talk more openly about the relationship. In effect, the couple has better relational talk and more frequently discusses the needs of each partner. As Caleb presents this story, it would seem there is potentially an issue with trust. He didn't want his partner being sneaky, potentially a trust issue. They do not do some things sexually because there is a trust issue. Although they are very committed to one another having been together for 19 years, HIV helped them to talk about some facets of their relationship they had not discussed previously. HIV highlighted potential trust issues, a component of intimacy. By talking about these issues, the men were able to approach those aspects of intimacy uncertainties that existed between them.

For David, his partner's HIV diagnosis set off a chain of events that the couple struggled through. For context, David had moved to a northern state for graduate school, and the plan was for his partner to remain at his job in a city in the south. However, because of several factors, David's partner moved to be with him; while working through the various personal and financial issues, the couple turned to therapy for help.

> I had been to a therapist myself to deal with my issues around [my partner] being HIV-positive, and that therapist, after a few sessions, thought that we should see a couple's therapist. And I talked him into it. At the time, he was not crazy about it, um, and so we did see a couple's therapist, but even then it wasn't talking about HIV, it was talking about us and what we wanted in a relationship.

David goes on to discuss how the diagnoses played into the relationship discussions with the therapist and with his partner.

> I don't think it [my partner's diagnosis] changed what I wanted. I think it, [long pause] I don't know that it's fair to say that it changed, perhaps it's better said that it caused me to evaluate what I wanted out of the relationship. I don't know that it was a change as much as it was that I need to think about this more than I have. And so [pause] I think it prompted an examination of that. Um. Not a very good one I will admit. Um, I think I handled that mostly through, then, becoming very sexually active at the time. I don't know if that… it helped some in terms of actually finding myself no interested in the men I was with outside of some sexual encounter but I also think it was not a reflective method of dealing with it so much as it was venting whatever the subconscious wanted.
>
> The therapy was thinking out what we wanted and what we wanted for each other, and so I will say that started a very long process that went past therapy and extended into other experiences that has that kind of simmered until this past year with his unemployment situation and me having a very bad roommate situation and us kind of leaning on each other because that whole situation brought him to Ohio. Otherwise he would have stayed employed in Charlotte so when I find something he was going to move with me then. Coming to Ohio was kind of an accident. It was a way out of financial situation. A bad financial situation but so we have … that really tough experience crystalized some things that started way back then. Thinking about how we wanted to be together that started way back then. I don't know if we could have what we have now which feels very good and very strong if we hadn't. I don't know that we

would be strong now if we hadn't undergone real pain back then. I don't know, but that certainly prompted us to do things to explore things that made us realize what we value in each other and where we're good and where we're not good for each other and where we conflict.

While the decision to engage in couples' therapy was not made precisely because of the presence of HIV, David does acknowledge that he began therapy on his own to work out his feelings about HIV. He goes on to say that his partner's HIV status did cause him to evaluate what he wanted out of the relationship, and the therapy served to help the couple identify those needs and wants while working through a variety of complex issues. In this way, HIV provided the impetus for the couple to engage in relationship talk designed to focus on several components of intimacy including those feelings of closeness and mutuality.

**Minimize Their Conceptualization of Risk Regarding HIV**

As the men participating in this study indicate, minimizing the risks presented by HIV is another way they manage uncertainty regarding intimacy within the relationship. For Peter, entering into a relationship with an HIV-positive man involves the ownership of risk. As Peter describes, taking ownership of that risk is important to fostering intimacy and promoting the overall health of the relationship.

I think it's really important to make sure that both partners accept that they're, the decisions they make and the risks they take are their own. And, you have to be very, very sure that, as a negative partner, you're never going to say, "You did this to me." And as the positive partner, you have to make sure that you can let go, and not feel responsible. I …I think that that plus, just being very open and honest and really saying what you want and what you need … not only about HIV, but about everything. Whether it's the sex you

> want, or what you like to do. That's true in any relationship. I do think you have to be able to, just from my perspective, I've felt it's been important to say I don't… I would never say to him, "This is your fault. You did this to me." I'm going in with eyes open. I know what I want, and I know that means there maybe some risk, and that's okay.

In this quote, Peter is talking about how each of the partners needs to approach the relationship. This relates to the previous section on relationship talk, but this particular quote indicates that ownership of risk is an important topic of relationship talk. HIV becomes the reason to talk about the relationship if HIV were absent, they might not be talked about or brought up. To have a conversation about how you feel about responsibility in the relationship and to the relationship happens because HIV is present.

For Steve, he has adopted the attitude that having unprotected sex is inevitable, and because of this, it does not do the couple any good to worry about the possibility of HIV infection.

> Um, I'll be very blunt with you, honest, since I think this is a study, and I think…we have had unprotected sex. It's going to happen. Not a lot. He's never actually came inside of me. But, there were times without condoms. I can honestly….I meant to go back to tell you this when we were talking about intimacy a little bit later….even then, I never freaked over it. I never did. Um, probably one, because of the whole being undetectable and, um, the fact of passing it on when he's on the antivirals is virtually impossible kind of thing. Um, and then it wasn't….and then, we said, yeah, it probably wasn't the best thing. I think we did have a discussion about that. And we said, "Yeah, we probably don't need"…and then it ended, you know. Um, 'cause I wanted to be honest about that, because I think that's important with a lot of couples are going to think, "uh, oh

(sounding huffy & judgmental)…you know, there are risks." There are risks, and, um, but there are risks when you get in a car. And there are risks when you eat food. And there are risks in life, and I guess that's how I looked at life, 'cause I'm like, I am not living my life worrying about all this stuff. Life is just too much to worry about every single day. And I am just not one of those people. I just don't freak out over it.

Steve deals with the uncertainty that HIV brings to sexual intimacy by first getting educated about the risks, how transmission occurs, and how his partner's medicine works. From there, Steve conceptualizes the risks of HIV infection with other everyday risks people live with. In a sense, his attitude toward HIV and the risks associated with it are normalized as being similar to the risks associated with driving a car. There is a relationship between risk and uncertainty associated with sexual practices; by conceptualizing the risk as a normal everyday phenomenon, Steve's uncertainty regarding intimacy with his partner is kept under control.

Caleb expresses sentiments regarding the risks associated with HIV similar to Steve's sentiments. For Caleb, knowing the risks and not buying into myths associated with HIV are important for the relationship's long term health.

I guess I would just say, get to know what the real risks are. Don't, don't buy into this you know, these kind of myths that have been around since 1980 when people thought, you know, drink on, sipped out of the same straw, you did now I've got to go, you know. Just know the real facts, know what the real risks are, know, and then figure out, and then for the negative person figure out where you're comfort level is with the risks. And that, I think, is more support part, because you know there's going to be risks no matter what. Um, there's also risk of getting hit by a car tomorrow, you know, so understand the risks and the fact that I can mitigate a car wreck is to look both ways before I pull out of an

intersection, that doesn't prevent anyone else from ramming into me when I'm not looking or from behind or anything. So, know what the risks are, know what you can do to mitigate those risks and then also just understand that there's risks in everything you do and if you, if you make that a factor then it's going to impact the relationship and potentially end the relationship, how, is it really worth it? I guess everyone is different. For me, having a relationship, the one thing that always bothered me growing up being gay and being in the closet was never about the sex it was always about the relationship, wanting to be in a relationship with someone and it just happened that someone was a man. So the relationship was important to me and that's just, you know, you're a early riser and I'm a late riser, that's about the level of the issue it should be. How do you work around that? Uh, kind of thing, so, I think just educate themselves and just be very realistic about, you know, this doesn't have to be the center point of your relationship.

As Caleb describes, the risks associated with HIV are compared to other normal, everyday risks. Because the risk associated with HIV is somewhat mundane, it can then be conceptualized as a small, minimal factor in the relationship akin to the small, unimportant differences that exist in all relationships. Steve echoes Caleb's feelings on the minimization of HIV as a factor in the relationship.

Um, and I guess in the last two years, I've learned, man, we are a lot more capable of dealing with heavy duty stuff than we thought. You just do it. You just do it. So, if I had to give any advice, it would…and the reason why I even brought that and why I wanted to share that especially for your study 'cause I think it's important, is when you are with, being somebody who is negative, one, know your status. Be tested. That's important no matter what. I always tell people to do that. I get tested, you know, once a year. Um,

probably should be more, but I do it once a year. Um…is when you go into it, just, if you're going to make it an object of your relationship, if it's going to be an issue, then don't be in the relationship. Because you are making something that really shouldn't be there. And, as if it could be anything such as, I don't like your breath. Or I don't like your hair color. If you make something an issue from the beginning, not to say this isn't a big deal, don't get me wrong, but people have broken up relationships for a lot less than that. So what I'm saying is work through it. Know if your own mind what it's going to be.

This conceptualization of risks as small and insignificant seems to be an attempt by these men to redefine what it means to be at risk given the situation. They also seem to be denying HIV any power over their relationships. HIV is certainly an intruder to intimacy, and presents a real threat to the overall health of the relationship, but for these men, the risks associated with HIV can be so effectively managed that HIV will have no power over the ability to establish and foster intimacy between these men. While these men deny the intrusion of HIV and adjust their attitudes and behaviors toward that goal, HIV is having a profound influence on the relationship.

# CHAPTER FOUR: IDENTITY FINDINGS

## Relationships among Uncertainty, Intimacy and Identity

Alongside intimacy uncertainties associated with HIV intruding on their relationships, the men participating in this study also struggle with what this intrusion means for their sense of identity. With the presence of chronic illness, patients often struggle with a variety of identity issues. For example, the change in health status from being considered "healthy" to being diagnosed with a chronic illness can disrupt a person's self-image (Corbin & Strauss, 1988). Other research has found that uncertainties associated with chronic illness result in identity dilemmas for patients which, in turn, results in difficulties in managing illness (Charmaz, 1994). For men specifically diagnosed with HIV, they may feel less able to define and manage their identities due to the uncertainties associated with HIV infection (Brashers, et al., 2003). In addition, HIV-positive men may have competing goals in managing their uncertainties associated with their illness that conflict with their identities (Brashers, 2001). While the men participating in this study have not been diagnosed with a chronic illness, it has been argued that being involved in a committed, romantic relationship with an HIV-positive man does result in the HIV-negative man experiencing illness along with its associated uncertainties and, specifically in the case of the present study, intimacy.

Relational uncertainty can be the result when individuals experience difficulties and disruptions to their sense of identity, or when going through an experience where their identities are in a state of flux (Knobloch & Delaney, 2012; Knobloch & Solomon, 1999). As it relates to the present study, research has shown that illness and identity management can impact components of intimacy. For example, Goldsmith, et al. (2007) discuss how openness between couples is affected when chronic illness is present. In exploring the intimacy uncertainties

experienced by the HIV-negative partners of HIV-positive men, it becomes apparent that the HIV-negative partners struggle with identity issues, similar to how previous research has shown HIV-positive people struggle with identity management as they contend with the uncertainties associated with the illness.

## HIV, Intimacy, and Identity

With HIV playing such a prominent central role in the relationship of these mixed-status couples, HIV also then affects the HIV-negative partners' conceptualizations of the couple's relational identity and how their sense of personal identity lives in accordance with that relational identity. As intimacy progresses to deeper and deeper levels within the relationship, boundaries are pushed, trying things that are not only potential risks to transmitting the disease, but also risks to the relationship. The men in this study adopted different behaviors related to sex and intimacy as they worked to manage their intimacy uncertainties. The couples deal with questions and choices regarding using or forgoing condoms, adopting specific sexual acts that could result in transmission of the disease, and experimenting with specific sexual acts that may be considered outside the norm or move into the realm of fetishes. As the couples attempt to manage intimacy uncertainty with these types of behaviors, additional concerns are raised that quickly move into relational uncertainties and have the potential to conflict with the partners' deeply held sense of identity at both the relational level as well as the individual or self level. Will the partners have the same sexual preferences? Should the relationship be opened up to outside sexual partners? If those preferences are different, is that a threat to the relationship?

As the men continue to deal with the changes to intimacy initiated by the intrusion of HIV, it becomes clear that making sense of how this illness fits with their own sense of self becomes a struggle. For the men in this study, there is a clearly struggle with concerns regarding

HIV and how they make sense of sex and intimacy. For example, it was previously noted that David struggled to even make sense of his feelings regarding that change in intimacy. This struggle with how the self makes sense of relationship-related uncertainties represents an identity struggle. Sense-making regarding their attitudes toward intimacy are at odds with what these men thought they knew about their attitudes associated with relationships. This struggle with intimacy connects the uncertainties regarding the relationship to uncertainties regarding the self-concept. It is this self-uncertainty that challenges the self-concept of the men participating in this study. In this way, HIV is the agent that leads these men to enact behaviors to not only deal with the intrusion that is HIV, but also to reinforce or buttress their sense of self. If making sense of this illness and assigning it meaning in their lives is a process involving identity work, it is helpful to understand the nature of identity formation, development, and maintenance.

## Identity Theory

Identity, as a construct, is a product of both self-reflection, as in asking the reflexive question, "who am I" as well as performing behaviors designed to demonstrate the answer to that question (Vignoles, Schwartz, & Luyckx, 2011). In other words, identity is an internal process that involves making decisions about one's self-concept and then behaving in such a way as to demonstrate that identity. In this definition, identity is, in part, the result of a conscious and considered process on the part of an individual. Research seeking to understand identity typically conceptualizes identity as existing on three different levels: individual, relational, and collective (Vignoles, et al., 2011). Theories associated with these levels of identity tend to focus on the processes leading to identity formation and change. At the individual level, these processes tend to be viewed in terms of the sense of agency an individual has in creating or discovering his own identity (Vignoles, et al., 2011). At the relational level, the processes of identity formation and

change are concerned with the interpersonal aspects of identity. Identity, at this level, is developed through interactions with others and based upon the roles, along with their definitions and interpretations, an individual takes on in connection with other people (Vignoles, et al., 2011). At the collective level, identity is based on memberships in social groups or categories along with the meaning the individual assigns to these groups and categories (Vignoles, et al., 2011). For all three levels, identity is more than the definitions and categories associated with each level; identity is also the result of the attitudes, beliefs, and feelings associated with those definitions and categories.

From a theoretical perspective, these different layers of identity intersect and interact with one another. At any given moment in time, the various characteristics that make up an individual identity are at work and may be enacted based on a variety of circumstances and social contexts. While the definition of identity seems to favor the conscious and deliberate nature of identity building, the different aspects of identity are enacted across time and social context. Because of this, an individual's sense of identity is also shaped through implicit processes that occur without the individual being consciously aware of them (Vignoles, et al., 2011). For example, if an individual feels a threat to his self-esteem, the processes to defend against that threat serve to also shape the individual's sense of identity.

Identity, then, is multi-faceted, developed and maintained through processes that are both implicit and explicit, occurs as a product of personal efforts at defining the self as well as using social processes to define the self, and is influenced based on circumstances and social contexts over time. Entering into a relationship, then, is an exercise in identity formation, development, and extension. When forming a relationship with a romantic partner, individuals are both actively and subconsciously making adjustments to their sense of identity on multiple levels

including their own personal sense of identity and the ideas about the relational identity they share with their romantic partner.

With so many factors influencing identity, various aspects within a single individual may prove incompatible or contradictory. It is this situation that much of the identity research investigates. Theoretically, there is the potential for these contradictions among an individual's various aspects or layers of identity to negatively affect the individual's sense of unity. Indeed, one view within the field of identity research looks at the problems associated with a multi-faceted view of identity where the different facets could pose a problem for unity (Vignoles, et al., 2011). To reconcile these competing or inconsistent identities, individuals enlist a variety of processes to construct narratives that reconcile the inconsistencies across time and situations, or they create personalized redefinitions and meanings of identity (Vignoles, et al., 2011). Additionally, identity construction involves the interplay between the individual's sense of agency in constructing identity and the contextual constraints (Vignoles, et al., 2011). Problems may arise because while the individual may have agency in personally constructing identity, one may face constraints arising from the social construction of identity. Contextual constraints can be challenged but not ignored.

## Relationship between Uncertainty and Identity

One useful theory for understanding the relationship between aspects of identity and constraints on identity is the Communication Theory of Identity (CTI). CTI characterizes four interpenetrating layers of identity: the personal layer, the relational layer, the communal layer, and the enactment layer (Hecht, Warren, Jung, and Krieger, 2005). The interpenetrating nature of the layers is an important aspect to identity; characteristics of identity associated with each layer can be identified, but the layers work together as a whole (Hecht et al., 2005). Within CTI, the

overlapping nature of the layers creates the conditions where conflicts between the layers might arise. These conflicts are also described as identity gaps.

In the present study, having both initial uncertainties surrounding the objective aspects of HIV and concerns for the positive partners' emotional well-being as well as the subjective aspects associated with broader intimacy uncertainty, the HIV-negative partners fluctuations in intimacy with their partners serve to highlight disruptions to the HIV-negative partners' identity management at both the personal and relational levels. The presence of illness in their HIV-positive partners represents an intrusion at the relational level. Whether they embrace it, HIV and intimacy uncertainty are part of the relational level identities of these men. However, this illness identity at the relational level sits in conflict with the HIV-negative partners' identities at the personal level.

## Relational Identity

As HIV and the associated intimacy uncertainties become a significant factor in these men's lives, exploring the relational identities they hold can provide insight into the behavior they use to manage their uncertainties. Conceptualizations of the relational self can be understood by looking at four key assumptions: 1) the relational self consists of knowledge individuals have about themselves in relation to their significant others; 2) the relational self exists on multiple levels of specificity that encompass relationship-specific knowledge, generalized knowledge regarding domains of relationship such as family or specific groups of friends, and global knowledge regarding the self in relation to all significant others; 3) the relational self can be accessed from memory; and 4) the relational self contains positive and negative evaluations of the self in relation to a specific significant other along with goals and strategies one uses in interactions with that other (Chen, Boucher, & Kraus, 2011). Because HIV

brings with it threats to intimacy that directly affect the HIV-negative partners, the men participating in this study activate specific aspects of their self-concepts when deciding how to communicate and other behaviors to manage their intimacy uncertainties. In the following section, relevant aspects of identity enacted to establish and maintain the bond between the couple, along with the associated behaviors used to define and manage those relevant aspects of identity at the relational level are discussed.

**Importance of Commitment**

The participants in the present study see themselves as firmly ensconced in a committed relationship. Part of their self-concept is built around the idea that they are one-half of a couple, and certainly they define much of themselves in relation to their HIV-positive partner. In defining their commitment, these men tell stories that clearly delineate the point they became a couple as well as stories that discuss their future plans, hopes, dreams, and desires. Constructing and telling these types of relational stories are the means by which couples link themselves to one another in a relationship and how they characterize their joint relational identity (Burleson, Metts, & Kirch, 2000).

An important milestone in the development of these couples' sense of relational identities can be seen in how they relate the story of when they first became a couple. As Caleb discusses, he and his partner agreed to the specific event where they moved from "dating" to being in a relationship.

> I was 28. This was, I met him in the summer, June of '94. I'd only really started coming out at 28 in March. So, uh, I was living with a couple, uh, straight people, friends of mine from college, that we all had an apartment together. It's kind of rotate apartments, people moving in and out. But, um, but it was near the downtown area of [city] so the bars were

near to my house, and I would go. As I started going out, I met a few people, I developed a circle of friends. We were going out a lot, and most weekends going out at the bar and, um, I, I noticed my partner, uh, out at the bars a couple of times. But um, I just um, I didn't um, I didn't talk or anything, I just, but probably about the third time I saw him, I was with one of my friends I guess, he also noticed. So, he, uh, came and started talking to us and then uh, and he, at the time, he told me later thought that I was with, that I was with that guy. We were we were friends but we were not. And so um, we just talked a little that night, and a couple of nights later that same friend uh, we all went to the drive-in movies. And, and uh, yeah. There are a few of those left up there. And of course that evening, my partner started talking sat down next to me started talking to me and we just kind of talked and at the end of the night we all say goodbye and he kind of saddled up to me and said… so we ended up planning going on a date, a couple dates, and we started seeing each other and it was fairly, I would say fairly, I would say this was probably July when we started going on a couple dates. I always, we always mark the anniversary date of us getting together as in August of '94 because that's when the weekend that we went to Provincetown together. So, I just always mark that as the, as the time in which we kind of officially were dating, and so um.

In this quote, Caleb is marking the date of getting together as officially when they took a weekend away together. However, they had actually been dating for a month or two at that point. So, this particular date seems to be the time they officially recognize they are in a relationship. Marking the point the men identify as being in a relationship takes on a special significance when thought about in terms of identity. In relating this story, Caleb is invoking historical events in his relational trajectory. In invoking the past through storytelling, relational partners are able

to lend continuity to their relationship, even as the relationship changes over time (Burleson, Metts, & Kirch, 2000). For Caleb and his partner, HIV became a part of their lives nearly 15 years into their relationship, and, as has previously been discussed, the couple has struggled with uncertainties regarding intimacy both before and after the introduction of HIV. HIV certainly marks a change to the relationship, and telling stories of how they first became a couple helps to provide continuity to the relationship, even as the couple struggles with intimacy.

Both attitudes and laws regarding same-sex marriage are slowly evolving; however, marriage for same-sex couples still has not acquired the same level of stature as heterosexual marriage. As Andrew discusses, public validation that he and his partner exist as a couple would complete the picture he has of his relational self.

> Obviously, I'd like to make it official, and, you know, have family around, um, you know? Fully make him part of the family, I guess. I mean, I don't think my folks consider him to be anything but part of the family anyway, and I don't get the impression that I'm anything other than his family, but still….

In expressing his desire to get married, Andrew attempts to downplay the significance of marriage somewhat by saying that he and his partner are family regardless, but he still would like to "make it official." This public recognition is important to maintaining the sense of identity that Andrew holds regarding the type of relationship he has with his partner. Andrew goes on to further explain his position on marriage.

> I think that's just the final indication that, uh, at least to other people. I don't think it makes a difference to us. I think it's more just a, you know…whether you're talking about straight people or not you always just kind of think, "You've been together 11 years and not married? You know, that's a fine arrangement, but it's just kind of like,

> what's that little piece that we're not seeing. You know, are you opposed to marriage?" So, you know, I think if it were possible to get married we'd do it just to, not that I'm morally concerned with what other people think, but just to demonstrate publicly. It's, you know, we've been together 11 years, and we would have done this earlier if we could. This is who I want to spend the rest of my life with. [pauses] I think it's just sort of the final step. The final indication, [pauses], plus, it's just a big party.

For Andrew and his partner, marriage would make them both formally part of each other's family, whereas they are now informally part of the family. This is an interesting distinction in Andrew's mind. After being together for 11 years, there is still something about their relationship that remains incongruent with Andrew's sense of self. He says being married would be a message to other people, and that it doesn't make a difference to the couple, but of course, it does matter. When Andrew says, "You know, are you opposed to marriage?" he is recognizing society expects people that are committed to one another to enter into legal marriage. He feels the need to make the statement to others that we are committed, together, and a family. He also mentions "that little piece that we're not seeing." In that statement, "being married" is seen as an identity that is off limits to Andrew and his partner. There is an allure to marriage where people seem to be experiencing something in that public validation of their relationship that Andrew and his partner currently cannot.

Carlos and his partner have been together for three years, and, like other men in this study, also talk about the importance of marriage.

> I do perhaps want to get married some day, but I feel like in the, just like in the straight world and gay world, marriage should be considered something very serious, not just something to play around with. I'm not a religious person but if you make such a vow or

> a nuptial like that, I feel that it has to be sacred. It has to be something that you agree, and you're both really, really on board. And, he's like, "If we were ever able to get married, I would like for us to have a simple wedding." And I'm like, "If I'm going to get married, I want an all-out wedding. People are going to fly from all over to our wedding I'm sorry. None of that simple shit." He's like, "You're so materialistic." I'm like, "No. It's my day, your day, we're going to make it our day." But really, if it comes down like that, in the years to come, I would be okay with it. But, he has to understand that we're still in the process of knowing each other, and some people get married in the course of one year, but then I also see what happens when people rush into it. I saw that with my brothers, but I just want to make sure that we're on the same page. That we both understand that we are both there for each other, and there's a lot of tests to come in the future. But, I want those to come and go and then we'll be okay with it.

As Carlos' quote demonstrates, there is a seriousness that he sees in marriage and relationships. While barriers to same-sex marriage are quickly falling around the United States as well as the rest of the world, Carlos does not necessarily see that as an opportunity to jump into marriage quickly. In accordance with his self-concept (partly shaped by his family members' experiences), Carlos sees marriage as something that is potentially in his future with his partner, but they need to spend time further developing the relationship. However, as Carlos explains the meaning of the ring he wears, it quickly becomes apparent the importance he places on his relationship with his partner as well as the depth of commitment he shares with his partner.

> It is basically a promise ring to each other that we'll be together. No matter what comes, we'll be there for each other. Well, actually, I had both of the rings, and one of them was a little too big, so I'd wear it on my middle finger. I was sitting down, because his parents

are both reverends, and I was in church, in his parents' church. And I was looking around. I'd never been inside, because the outside was kind of ehh. But, when I went in, I thought it was so beautiful, and it was very humble. It wasn't like one of those glamorous churches that you see, and, for some reason, I just felt, just felt like taking my middle finger ring off. And it so happened that it fit him perfectly on his, on his finger. And he was like, "Just keep it, and know that every time you see it, just know that I love you, and I'm always going to be here to back you up." And then he was like, he took the other ring that I had on my other hand, and took it like, "Here, I'm not giving you a ring but this is one of your favorite rings." It's my favorite one because it's an HRC [Human Rights Campaign] ring, and it says, "Believe, Love, Be, Live." So, and his only has the HRC little logo on it. Ever since then, we've been wearing it. And we will not leave the house without for some reason. One time, I did leave the house without it and he's like, "Where's the ring, where's the ring?" I was like, "I still love you, I'm still here. Come on. I'll put the ring on when I get home." I will take it off when I'm at work, not because I don't want people to know; it's just because I deal with a lot of ink sometimes. And I don't want ink to get on it because this is a ring that actually evolves, and I don't want it to get in it and for it to get stuck and not move anymore. But, it's basically our way to say that we're together and for people to know that he is taken. That's how I want them to see it. [laughs]

In re-telling these stories of commitment, the men participating in this study demonstrate the depth of their partnership. Marriage is an enduring commitment that, because of its legal nature, is not easily undone. For those getting married, it imparts a premier, coveted status to the partners, and in reaching for that identity through the exchange of rings or taking part in

commitment ceremonies (as Caleb and his partner did), these men are demonstrating the depth of their commitment to one another. This is not just any close relationship. This is the most important relationship they have. Because HIV represents a threat to intimacy in these relationships, the stories highlight how disruptive HIV actually is to these men. The behaviors employed by these men to manage their uncertainties regarding intimacy are undertaken with goal of minimizing or denying HIV's influence on the relationship. These men do not see themselves as being sick. Illness is outside of their self-concept, and as such, the presence of illness within their relationship is difficult to make sense of at the relational level. As Chen, Boucher, and Kraus (2011) suggest, the relational self constructed by the HIV-negative men in this study works to define the goals and self-regulatory strategies that characterize the self when relating to their significant others. These goals and strategies then play out as various behaviors to deal with the identity dilemmas presented by HIV and the associated intimacy uncertainties.

**The Educated Identity**

In describing themselves and what is necessary to deal with HIV, the men in this study consistently discuss education. As Carlos describes, valuing education is something these men share and helps them bond as a couple.

> But when I got to talking to him he was very smart, and we …very educated, and I was like, I was afraid that someone was going to throw that I did not go to college. And I was always one of those type of people that I would never admit to certain things in my life just to be judged on. So with him, I told him that I never did college. I attempted to go, but with life, um, I never actually went to college. But, he had a Master's, and he went to college all these years. So he understood my background. He knew how to be

> compassionate when I opened up about my father, and the poor stuff that we went through, and my family not being permanent residents. He understood that.

Being educated, and using that education to thwart the intrusion of HIV into their intimate moments with their partners is a consistent strategy described by the men in this study, and is certainly part of the personal identities of each of these men. It is interesting to note that these men see themselves as educated despite widely different levels of formal education. Participants' formal education ranges from only a high-school education through all levels of post-secondary education including Associates degrees, Bachelor's degrees, Master's degrees, and Doctoral degrees. However, education takes on additional meanings beyond level of education attained. For example, Andrew describes himself based on an assessment of intelligence.

> I do take pride in my intelligence not that I'm not particularly creative… I'm not an artistic type. I recognize my limitations there although I do have good ideas from time to time like everyone does. I'm not a complete dummy in that regard.

For Carlos, education and its importance within this self-concept is rooted in achievement. As he describes, education helps you accomplish your goals and attain success.

> So my parents', um, point of view towards me and my brothers, not to basically throw this to myself but to them, I am like the golden boy of the family. The one who actually tries to achieve. The one who actually travels outside of the country. The one to, uh, to always be curious about educating myself that they will never…The one who knows how to speak three languages, and they barely know how to speak one. And, um, my brother's English of course and to them… Carlos is like… he's not even part of us. He managed to be someone that is way more than… and even though when I'm with them I try not to… I try my best to humble myself even though I'm still myself; but, whenever I'm with my

> parents I try my best not to brag about the trips I take. I try my best not to, to dress too nice in front of them because they were used to… the most expensive clothes we probably got when we were kids and them themselves… were from yard sales or the Dollar General store… so but… to them I'm considered the Golden Boy.

As Carlos demonstrates, education for these men is not only a trait or characteristic of their self-concept (as in "being educated"), but it is also a pathway to success and achievement. Because education is a process, they see it as fulfilling different functions at different points in their relationship.

**The Functions of Education**

**Efficacy in Information-Seeking.** Because these men see value in education, see themselves as educated, and see education as the means to accomplish goals, they describe various ways these attitudes play out in the way they manage their intimacy uncertainties. As John describes, one function of being educated involves these men having the ability to conduct research on HIV, and understand various aspects of the virus and how it is treated including how it is transmitted, how antiviral medication works, and advancements in HIV-related research.

> Do you know about pre-exposure prophylaxis? I'm sure you do. It was approved I guess August of last year, so in all my research of post-exposure prophylaxis, and just my general research about safe sex, I research everything. I'm a huge Reddit user. I'm on… I subscribe to, like, not just funny Reditts. I subscribe to, I research everything. This versus that. You know I just got meds yesterday from my dermatologist, and I'm, like, Googling which ones are most effective for anti-aging. I just…I don't know. I research everything. So, I've been researching HIV and safe sex for a long time. And, I think the reason I was so interested in HIV and safe sex was because I have a really high sex drive, and I'm a

> fairly kinky person, which I'm not really ashamed of, so it's always been this research. How you can have this lifestyle but be safe or as safe as you possibly can be. And so I tend to, I tend to feel more safe in relationships because you can have conversations and have unsafe sex, versus one night stands where I would never feel comfortable without a condom. But, in my research the idea of going on post-exposure prophylaxis… pre-exposure prophylaxis popped up back when I was dating [ex-partner] in Jersey just because we were open. We had had the incident of me going on post-exposure prophylaxis the first time. We were still having sex with other people even though it was safe so we decided [to go on pre-exposure prophylaxis]. And, I had decided in my head it might be a good idea to go on this drug. You know, and then my concerns were side effects, and was I going to have fat redistribution if it was an older med. I just didn't know what it was going to do to me.

For John, managing his uncertainties related to HIV and intimacy center on information-seeking behaviors as postulated by theories of uncertainty management. However, John's information-seeking behavior stems not only from his desire to manage his uncertainty, but also from his sense of efficacy in executing effective information-seeking behaviors. In this way, John's sense of efficacy in his research ability follows from his self-concept of being educated.

**The Mitigation of Risk.** In addition to feeling that they are "educated" individuals able to find the information they need, education also functions to help mitigate the risk associated with HIV. In addition to John feeling that he has the ability for effective information seeking, he is confident in using the information he finds to make decisions. Because of this, the risks associated with the transmission of HIV from one partner to another in the course of sexual activity are mitigated. Peter, as he describes discussions he's had with doctors regarding HIV

echoes John's sentiments at being able to effectively make decisions regarding the risk associated with sexual activity, and in particular with this quote, the decision to have sex without condoms.

> We actually… I had been doing some reading on my own, and I had changed doctors to one in DC that had primarily LGBT clientele, um, and …had talked to him about… I was … I explained my partner's medication and so forth, and, you know, and the conclusion was… well the doctor basically said that there is… long-term serodiscordant partners … the negative partner is not contracting HIV from their primary partner. In cases that the negative partner, sort of converted, there are other things at play.

As Peter describes the discussions with his doctor, it is clear that his efforts at information seeking and becoming educated about what being undetectable means is all about conceptualizing risk to facilitate decision-making regarding condom use. The information seeking behavior here is kind of interesting in that he first changed doctors to one that had primarily a gay clientele. He then gave a simple view of the risk...just that it's very low in long-term serodiscordant partners. Peter provided very little detail justifying the decision to go without condoms other than to say that he did some reading and checked with a doctor familiar with LGBT clients. His information-seeking behavior focuses primarily on finding an authority figure to confirm his desired behavior (going without a condom) is acceptable and safe. Because he sees himself as "educated," Peter seeks out an educated authority to confirm his conceptualization that there is minimal risk associated with having unprotected sex.

**Fostering Changes in Attitudes.** In addition to assisting with the conceptualization of risk and bolstering efficacy and agency in information-seeking skills, having a self-concept that incorporates an identity associated with "being educated" facilitates attitude change. In this

sense, being educated allows individuals to rationalize a change in their beliefs and attitudes. Before Steve came out as gay, he had been to Bible College and had a career in the ministry. As he discusses, his ability to educate himself was a key part of the process of accepting himself and people with HIV.

> I guess I just looked at disease as disease. That I just never….I had read up on it. I knew what it was. I understood about, you know, medications and being undetectable, and I had learned about it, and so I, and I was just not…I can't really answer other than it was just never an issue for me. I didn't sit down and go through some seminar. I didn't have some class. Nobody gave me brochure. Obviously, you hear stuff on TV. I loved Jerry Falwell. So, you know, during all that, I used to hate people with AIDS, and you know they were all that. [I was] taught…programmed to be that way…..and then, you know, when I started realizing, "Oh man. I'm gay, too!" I had to understand what that was about. So, you know, I had read, and understood. And it never became a factor.

In Steve's case, moving from hating people with AIDS, to reading and becoming educated lead to where "it never became a factor." It is important to remember that realizing he was gay does not guarantee Steve would be accepting of people who are HIV-positive. Education helped facilitate that attitude change.

Carlos also exemplifies how education helps to change attitudes regarding the disease. As he discusses, it was more than just an issue of dating someone who is HIV-positive. Carlos did not want to be around anyone who was HIV-positive and actively pushed people away.

> Like I said, back in the day, I was an ass, and before they were to say something, I had a suspicious…I would literally back out immediately, because I was petrified. I wasn't educated about it, and, um, and the first thing that I thought about when I heard HIV was

> death. I was never, like, basically putting people with HIV down, I was always just staying away from them. But still, that's even worse probably than putting them down. But I had a friend, and I saw what it did to him, and he was a person that … he was not a citizen, so therefore, he could not get the proper treatments even though he was poor. And I saw that it was so hard for him to get treatment and for you to buy medicine, like, if you had money it was very expensive, so when I saw what it was doing to him, and I tried my best to just stay away from him, and I know …well, what I noticed with him with that came a lot of pain, rejection, just a lot of stuff that will make anybody feel depressed and miserable, like they're tainted… like they're not worthy for being around anyone just because people have that stigma. I was one of those that had it. That, um, they were not worthy to be around you. But, when I met him [his partner], finally I picked up a book… a brochure, a pamphlet because I wasn't even willing to have sex, like, immediately.

For Carlos, getting educated about HIV, and seeing it from a more personal perspective, makes a big difference. Carlos talks about avoiding and pushing away anyone with HIV. It is as though the pushing away he talks about is in both the physical sense, and the emotional sense. The fear he has about HIV drives these feelings, but, in gaining a new perspective, a form of being educated, as well as reading about the disease, Carlos' attitude changed, and he went from being an "ass" to being an advocate. Education changes attitudes and identities.

**Redefining What "Safe Sex" Means.** Education plays an important role in the lives of these men as they deal with the uncertainties wrought by their partners' HIV status. From an identity perspective, these men see themselves as educated. This identity gives them agency regarding HIV. Illness is intrusive. No one asks for illness. No one makes a conscious choice to

be sick. As HIV enters these men's lives and brings with it uncertainty relating to the most important relationship they have, being educated gives these men the feeling that they have some level of control and instrumentality over this unasked-for intrusion. They have confidence in their ability to find and use information regarding HIV to accomplish their goals of marginalizing HIV in their relationships.

An interesting outcome of becoming educated regarding HIV is that it allows these men to redefine what constitutes safe sex. The terms "safe-sex" and "safer-sex" are somewhat ambiguous. The website AIDS.gov recommends a variety of safer-sex practices designed to reduce the risk of HIV transmission. All of the recommendations for safer-sex involve the use of condoms or sexual practices that do not involve intercourse (U.S. Department of Health and Human Services, 2012). AIDS.gov also provides the following information targeting the HIV-negative partner in mixed status couples.

> You may also want to stay up-to-date on developments about pre-exposure prophylaxis (PrEP). Though researchers are not recommending PrEP be immediately used to prevent HIV infection, recent research findings suggest this may someday be another prevention method to be used with – not instead of – condoms, safer sex practices and other HIV prevention methods (U.S. Department of Health and Human Services, AIDS.gov, 2012, "Is It Safe for Mixed Status Couples to Have Sex," para. 5).

Current safe-sex recommendations from the U.S. government do not necessarily advocate the use of antiviral medication as a prophylaxis even though the U.S. Food and Drug Administration has approved HIV medication for that purpose (U.S. Food and Drug Administration, 2012). In addition, the use of the drugs as a preventative measure also comes with the recommendation to

continue to use condoms. However, as these data show, the men in this study are actively seeking out ways to eliminate condoms from their relationship.

As both Carlos and Peter talk about their decisions to go without condoms when having sex with their partners, it is clear that the information they have found and the discussions they have had with healthcare providers give them the information needed to make them feel as though it is safe to have sex with their partners without a condom. In their minds, they do not see themselves as engaging in risky or irresponsible behaviors. In earlier quotes from John, he talks about doing research into safe sex. The information he is looking for is related to the use of antiviral medication by HIV-negative men as a preventative measure. However, as it has been shown, safe sex recommendations still involved the use of condoms. As John rationalizes, however, he is engaging in safe sex practices.

> And his viral load has been undetectable now for months. In my research, I found that the Swiss government released a statement for heterosexual couples that, if the man has been on the same meds without any kind of switch for six months or more, and the viral load has been below zero for six months or more, then they… it's … I can't remember the wording, but it basically says you don't have to use condoms. You're not going to transmit HIV to your wife or girlfriend or whatever. If your viral load has been undetectable, you're not going to get it. So the fact that I'm on Truvata is really an extra precaution. Even though that research was done on heterosexual couples, some doctors think that it's the same for homosexual couples even though you know the rectum is more prone to transmission. And then I read about it, you know, on forums, I've read accounts of gay men who have been negative for 25, 30 years with a positive partner and they don't even take Truvada, and they have unsafe sex even though their partner is

> negative. So the more research I did, the safer I felt being with [my partner], um, and having unsafe sex or unprotected sex with him. In my mind, we are having safe sex. It's just a different precaution. I picture little condoms in my blood stream.

As John notes, he feels he is having safe sex with his partner, even though they do not use condoms. This is related to John's sense of identity. In both his formal education and his intelligence level, John feels confident in his ability to use this information he has found to justify his behaviors, even though this behavior is contrary to the guidelines put out by the U.S. government. In John's case, he just found other authorities (the Swiss government) and other situations (recommendations for heterosexual couples) and applied that information to his situation. In this way, John is representative of the men in this study. While authority figures define safe sex in relation to condom use, the men in this study have used their intelligence and education to redefine the meaning of safe sex and maintain their identity of being HIV-negative.

Overall, identity at the relational level for these men is concerned with marginalizing HIV as much as possible. Their partners are HIV-positive, and they know they cannot completely ignore the realities associated with HIV. Therefore, these men, in having a sense of self that values education, incorporating intelligence, and being educated as components of their self-concepts, use that identity to guide their strategies for achieving their goals associated with intimacy uncertainties.

### Personal Identity

As they discuss HIV and its presence in their lives, the men participating in this study reveal much about how they view themselves, and how that self-concept informs the behaviors used to both manage intimacy uncertainty and manage their sense of self. At the personal level of identity, HIV does not exist as part of their self-concept for the HIV-negative men as it does for

their HIV-positive partners. They are not HIV positive; even though their relational identity deals with HIV, as part of their self-concept, it does not exist. To understand the impact this perspective has on their behaviors, the Model of Narrative Identity is a useful theoretical perspective on self-concept construction. As the model puts forth, "narrative identity is the internalized and evolving story of the self that a person constructs to make sense and meaning out of his or her life" (McAdams, 2011, p. 99). The stories people construct are autobiographical in nature, represent a selective reconstruction of past events along with an anticipation of future events, and explains, both for the self and others, that person's life (McAdams, 2011). For the men participating in this study, the stories they tell provide insight as to how they see themselves and also serve to explain how HIV fits within their lives.

**The Healthy Identity**

Because HIV is a chronic illness, the HIV-negative partners of HIV-positive men are very conscious about their health and very intentional about being healthy. As HIV threatens that health, they define and manage their self-concepts with the goal of denying the intrusion of HIV into their personal sense of self. HIV not only intrudes on intimacy, but it is also restrictive. Certain behaviors are off limits. Precautions have to be taken in even the most mundane, everyday situations. Generally, gay men, and HIV-positive men in particular, cannot give blood. If an HIV-positive man is preparing a meal and accidentally cuts himself, there is an instant threat to his HIV-negative partner. For example, Steve describes the simple problem of his partner needing to scratch an itch.

> So that, I mean, like today, as I was telling you, he went to physical therapy. And he said, "Well, I went down to scratch my leg, and when I did, I started bleeding." And he said, "I

had to get it patched up, and skipped that [the physical therapy]." Because his skin, you know? I hate that for him.

For an HIV-positive man, a simple gesture of scratching his leg becomes a big disruption that results in cancelling their plans. For the HIV-negative partners, this reality is part of their relational identity. However, at the personal level, the perspective on illness is very different.

In telling their stories, these men portray themselves as active, independent, and capable, in contrast with the restrictions within which HIV-positive individuals must live. For example, Andrew describes himself as active and athletic.

> I was, played basketball, baseball, track, cross country in high school. Even, even up through college. Played a lot of intramural sports, and after college played a little semi-pro baseball. Kind of, kind of was disappointing though. Most of my friends and coworkers starting having kids and families that …you know the team sports started coming…being harder and harder to come by. Don't do a lot of that anymore. It's more golf, tennis, and pretty much working out and running to keep me from getting large.

In this quote, Andrew expresses a thought related to fitness. His sports activities will keep him from "getting large." Andrew seems concerned about his health and fitness, and certainly those ideas are part of his self-concept. As an interesting counterpoint to his self-concept of being healthy and athletic, he also does not want to hear about others' health issues.

> You know one of my friends… I'm glad I'm not on Facebook…because he's got some medical problems, and he's like, "Oh, it was a rough day." And, you know, I…I do feel bad for him, you know. I'm certainly willing to give him my support and everything else, but at the same time, there's plenty of things I don't want to know. There's this… there's quite an over-share that people seem to have gotten in the habit of on FaceBook. That's

> why… I don't want to say that I'm not interested in people, but I'm not interested in all of your problems.

This quote from Andrew was in response to a question of what types of social media he uses. It is interesting that in talking about why he does not use a particular social media platform, Andrew defaults to using examples related to sharing medical information. Illness is something that he has to be concerned with in his daily life with this partner; he does not want to have to hear about it in other venues.

For Steve, his self-concept is related to being healthy in that he sees himself as very independent and capable. As he describes, part of his attraction to his partner is rooted in his own self-concept of being strong and independent.

> Um, he has always been the strong one in his family. The one they went to. The one that took care of everybody else. Um, probably that's why I was so attracted to him, because I was always that person. So, we were always very independent. You know, I took care of mine. He took care of his. And you know, even from the very beginning, we never meshed our bank accounts, or they….we bought stuff together, and one day he'd buy dinner, and I'd buy dinner and we'd split the house and stuff like that….but we never mixed our monies only because we had kids, and stuff like that. Um, so in all aspects, we were always so independent.

In this quote, Steve describes his partner as "the one that took care of everybody else," and he then talks about his attraction to his partner because "I was always that person." Steve sees himself as independent and capable; rather than needing to be taken care of, Steve is the one whom others can rely on—an identity that incorporates being healthy as part of the self. Healthy people do not need care or others helping them, caring for them, supporting them. Healthy

people are independent. In contrast, Steve's partner, as he describes, is suffering debilitating, life-threatening complications from his illnesses.

> Good pastures syndrome [the non-HIV related disease his partner has]. So, bottom line, he lost complete use of his kidneys. He is on dialysis. We do dialysis at home. He's been in and out of the hospital for that last two years. I'd say, 15 times. Um, the last one back in, um, this year in June. I thought I had lost him, and he almost died. But, um, got, his knee got septic from an injury, and he couldn't lift his head. They were going to put him in a nursing home, and we said "No, we're taking him home." His daughter is a LPN, and then going to get her RN, and so she, um, helped out a lot. So, we just suffered through, ah, it was a fun summer, but he's doing great. He's walking now, starting to become a lot more independent. We were hoping for a kidney transplant soon, so….anyway, so our story is, is just, it's been, the last two years have been very, very tough. But, oddly enough, it has absolutely zero to do with HIV [laughs]. It is crazy. What's funny, though, the first year after we got together, he was diagnosed with Hodgkins cancer. Um, ah, Hodgkins, what's that called?
>
> [Interviewer] Lymphoma?
>
> Lymphoma. Thank you. And, um, worked through that. Now that was related [to HIV], but came out wonderfully. Beat cancer. Was cured and everything and then this disease. So, he has had a lot of medical problems in the last eight years, so…he keeps it interesting, I'll tell you that.

Steve's self-concept involving capability and independence is in stark contrast to the image Steve paints of his partner and the debilitating effects of illness. Illness takes away being healthy, independent, and capable, but, for Steve, that is his partner's reality, and in juxtaposing

descriptions of themselves next to one another, Steve calls attention to the differences in their individual identities. Steve is healthy. His partner is not.

The HIV-negative men in this study are very concerned with their health and keeping themselves healthy. While this may be somewhat obvious considering the infectious nature of the disease, having a healthy, disease-free self-identity creates a conflict between the personal self and the relational self. The relational self must consider disease, and this particular disease threatens intimacy, the process at the very heart of building a sense of unity in the one relationship that is more intimate than any other these men have.

**Behaviors Associated with a "Healthy" Self-concept**

Because these men have incorporated concepts of health and independence into their self-concepts, keeping HIV from invading their personal sense of self is a priority. To that end, these men engage in behaviors designed to set themselves apart from the disease.

**Performing or engaging in "healthy things."** Prior to the following quote, Steve has just mentioned that he needs to, at times, leave his care-giving role behind, and go do healthy things. Here, he describes what "healthy things" means.

> I guess I….um…some buddies of mine, um, went to, um, it's a couple, they went to Chicago, and he was at a medical conference. He's a nurse practitioner. His partner had never been to Chicago, and he said, "Why don't you come with us?" And so, I can't look at [my partner] and say, "Hey, why don't come, let's all go together." He can't walk. You know what I'm saying. That's what I mean. In that sense. Um, so, you know, um, my son plays football for [college] in [city]. So, I've been going there like every other weekend when they have home games or whatever. And, you know, he can't weave in and out of the stadium to get to the seats and, or handle the heat sitting in there. And so it's

> all….and there are times I don't need to be a caregiver. There are times I need to just not worry about a sick person. I don't need to worry about, do you have the cane, do you have all the medicines, and I just go, um, and so, yes. So that may be going out, and if I get sloshed, I get sloshed, and I only take care of [myself], you know? I can be the dumb one, and somebody's going to take care of me, you know. All I've got to worry about is remembering to have cab fare, you know. That kind of thing. Um….but it's not just the, you know, going and having cocktails or enjoying that kind of stuff. It just has to do with truly being physical or active or doing things. You know, um….everything I do with him is very managed…because it has to be.

This is an interesting notion of being physical and active as a way to escape his care-giving role temporarily. In needing to escape from the restrictions brought on by HIV, Steve has to do more than just socializing, or just getting away. It must be physical. In this way, he is seeking to further distance himself from illness, and attempting to prevent HIV from intruding on his self-concept. Doing "healthy things" is a way to manage his identity and continue to define and reinforce that he is able and not sick. His relational identity involves illness and he needs to cling to a piece of identity that says "I am not sick" at the personal level.

Peter relates the story of his partner's previous relationship, the effects of illness on that relationship, and how escaping to do something physically active was important to being healthy.

> So in full disclosure…several years ago we met on Man Hunt. We were obviously both looking for someone to have fun with. At the time he was in a long-distance relationship and his partner was suffering really from severe Alcoholism and was slowly killing himself. And it got to the point where my partner said to him I'm here for you, you need to get well, you're not meeting my needs though so they had an agreement um and so

> that's why he was out there. So he and I met, had some fun together kind of continued chatting and saw each other and realized that we both had a common interest in biking. At the time um he was working a full-time job and whenever he wasn't working he was home caring for his partner because at that time his partner was unemployed. He had lost his job in the recession and begun really spiraling down, drinking constantly and was in and out of the hospital um with a variety of illnesses related to the alcoholism. Biking was a way for him to keep emotionally healthy so after the first couple of meetings we were talking about what we enjoyed and I was looking to get back into biking for a variety of reasons so we started biking. First it was once a week, Saturdays and then it was Saturdays and Sundays and over the course of 9 months biking…you spend three or four hours on a bike side by side and you start talking about a lot of stuff and especially his case he had a lot he was dealing with and I would listen and give advice and we became very close. We became very close friends. Uh so we spent a lot of time together outside of biking.

This is another interesting comment on the idea of doing healthy things. In this case, Peter's partner, because of his previous relationship, used biking as an outlet to escape illness and its debilitating effects, and be healthy. Peter refers to this as emotionally healthy, but similar to Steve, this is a very physical kind of activity that is undertaken to be away from the illness identity associated with their relationships. This relational identity exists in conflict to the "healthy" personal self-concept.

For HIV-negative men, being healthy and active is certainly part of their personal identities, but it also serves to give them a method for escaping an illness identity. Illness, as an identity for the couple, is intrusive, restrictive, and overwhelming. These men entered into these

relationships not really considering the restrictive aspects of illness. Being active seems to be a rejection of the debilitating aspects of illness. Illness makes you less able to do things, less able to be active. To maintain their individual identity, they need to engage in active pursuits because their sense of relational identity is at odds with their personal sense of self.

Identity construction occurs within contextual constraints that cannot be ignored, and an individual may challenge these constraints while also attempting to reconcile the inconsistency presented by a having relational identity involving illness and a personal identity that is healthy (Vignoles, et al., 2011). In the situation of the HIV-negative men, their partners' HIV cannot be ignored, and the illness identity that accompanies HIV cannot be ignored; however, the negative partner can continually challenge or push back against this identity from intruding into their sense of self. Illness is fundamentally disabling. The reaction then is to manage a disabling identity threat with active behaviors designed to reinforce ability and agency. The problem arises when personal agency and ability are found within a relationship and that relationship also represents a disabling threat. Due to the nature of illness, they cannot just redefine it to deal with the inconsistency. It isn't a cognitive phenomenon that can be dealt with by thinking it through. Rather, it is a physical presence (in the form of the debilitating aspects of disease) that can only be reconciled be expressing themselves physically.

**The Role of Disclosure.** From the moment that it is diagnosed, HIV is seen as the issue of the positive partner. There are certainly some initial concerns over what that means for the negative partner, but it is primarily seen as something that the positive partner has to handle. Concerns about self are quickly eclipsed by concerns for the partner. As David discusses a visit from a social worker reinforced that the virus was causing an intrusion, and the focus from all involved is on the HIV-positive person.

> I honestly don't remember when we found out or when he told me but at some point after that, um, he was, um, he was concerned. So he had taken this test and, uh, at some point after that, you know, he told me that he was HIV [positive]. And so I, kind of the next memory I have of that is the state caseworker coming to the house because [state] required a caseworker to come to the house. It was an African-American woman. She was very nice, but I felt very intruded. It felt very intrusive to me. I hated it. Um, and she did ask if he wanted me there, and he told her yes and, you know, I had told him if he wanted me there, I'd be there. It was up to him if he wanted me there, and she asked him things like, "Is there any sex partners we need to contact or anything." It was so…it felt demeaning to me. It felt dehumanizing to me, um, way beyond what I felt the scope of the state should be. That's kind of the next, very strong memory that I have of that time.

For David, everything about HIV is intrusive into his life, and, yet, he is not the owner of any part of the situation at all. In his quote above, he says his partner wants him there during the state's social worker visit, but he clearly feels the situation is demeaning and intrusive. He is not the one who is HIV-positive, and, as the interaction with the state caseworker shows, he has no say or ownership of what transpires. There is an identity dilemma here for David. With HIV being present at the relational level, it is part of the relational identity. However, at a personal level, even though David does not have an illness, he almost has a guilty identity by association.

Tim also demonstrates this inconsistency in ownership of HIV. At the relational level, HIV is a reality, but personally, HIV is not, and the status of the disease within the relationship is not his to own. As Tim describes, there ends up being a tension between Tim feeling the need to disclose his partner's HIV status and the realization that it is not his story to share.

> I didn't tell my father. My father liked [my partner]. They overlapped for about four years. Uh, and my father was, well he was old, late 80s, and I didn't tell him because I was afraid he would just worry. He was a physician, so he wasn't ignorant about it but still you just worry about your kids … you know is he going to get infected? My father already knew that I had lost a significant other to AIDS, um, back in the early 90s. So, I didn't want to worry him, so I didn't disclose status for that reason. Other people… I think it's [my partner's] choice. It's not my choice to out his health status just like he wouldn't for me… I don't want to take that choice away from him.

For Tim, disclosure of his partner's HIV status is clearly controlled by his partner, and Tim takes no ownership of that. However, as Tim goes on to describe, there have been times where he will disclose his partner's status.

> I have told a couple people, yes. Well, my brother, [clears throat], my step sister [clears throat], my work wife, uh… I told her um, but generally I don't. For some people that I'm close to I've mentioned it, but people at work, I don't. He has a much larger social circle than I do 'cause I'm... he's more gregarious. So, you know, there's… um… So there have only been a handful of cases where I've told people. Uh, when we have mutual friends, a lot of time [my partner] will just you know… out himself. And we know another couple that is serodiscordant or whatever you call it. Um, and he's not, you know, he's not uptight about it. I think in certain situations, like with coworkers or something he wouldn't want probably to disclose, but as far social situations, you know his family, all of his relatives know...are aware of it. He's been positive since the early 80s, so that's a long time. Um, so we let people know.

Tim's last statement is interesting here. He slips into "couple mode" and says, "We let people know." This is immediately after he has first said it is up to his partner, and that he generally doesn't tell people. His partner, having been positive for a long time, is not uptight about disclosing his status according to Tim. It seems that Tim is more reluctant to share the information and does not claim any kind of ownership. This, again, points to an inconsistency between personal and relational levels of identity. As previously noted, the participants' relational self is concerned with their HIV-positive partner, and their generalized relational self is another level of identity concerned with other relationship groupings such as family relationships (Chen, Boucher, & Kraus, 2011). For Tim, this seems to explain how HIV operates as part of his identity. At the relationship-specific level with his partner, HIV is a reality that must be dealt with. At the general relationship level, Tim feels obligated to share with his family relationships which include not only actual members of his family, but also relationships he identifies as family such as his "work wife." However, at the personal level of identity Tim is more reluctant to disclose his partner's HIV status. He does seem to feel he owns that information, and may not want to take ownership of it. HIV status is part of an illness identity, and illness is not part of Tim's personal identity.

Carlos' experience regarding the disclosure of his partner's HIV status is similar to Tim's experience. Carlos discusses HIV as if the couple is very open about it, and yet, there are people Carlos has not told.

> Believe it or not there's been people, our friends I mean, that know us both…they see us as a perfect role model. And when they put that pressure on me to be honest, I feel like I have to watch everything I do carefully. Be more careful about it. Take more precaution about what I do or say. For instance, last year, not this year's gay pride parade but last

year's gay pride parade, I did the one thing that, um, my cousin, he was at his house watching TV, drinking tea, and his house is literally an hour away from where I was. But they were having…I was in the gay pride parade, so here I was wearing… not wearing … holding a big sign that said, "HIV-negative and I'm with him." And he had a sign that said, "I'm HIV-positive and I'm with him," and an arrow was pointing toward each other. That day, literally when it hit the news, it was all over the news in [State], and I was like, "Thank god my mom watches another station!" She doesn't watch English media, but my cousin said he was watching TV, with tea, and he dropped his cup, and was like, "What the hell are you doing? This is broadcast!" But, um, that day we, like I said I was, I was not afraid anymore and wanted to let people know that it's okay.

The participation in a Pride Parade and having his mixed status relationships "outed" on television sits in contrast to Carlos' desire to not disclose his partner's HIV status to his parents. As he describes, it would make them worry.

My mom has a little mini farm in her back yard, and [my partner] has to watch his step because he might step in poo… chickens, rabbits, and whoever… but they are basically okay with it [his relationship with his partner], but when it comes to the HIV status, I haven't told them. I'm like, "[Partner]…this is something that they don't need to know, because if I tell them now that they're finally comfortable with you around, the first thing that they're going to think of is, 'My son! Oh my god, my son!' because my mom, literally, when I told her about my, about being gay, the first thing that she threw at me, other than the Bible of course, is that people that are gay die of AIDS and all that stuff. And I was like, "Holy crap!" And at that time I wasn't even as educated about the issue as I am now. But, um, I was like, "[Partner] let's not tell, um, my mom. Let's not tell my

family." There's only one in my family that knows, and that's my sister. And I told her that because I needed someone that I knew knew. And that way, if my parents ever say anything why I didn't, I did! It was my sister but not with you. [laughs]

There are two ideas here....the first is that he felt the need to let someone in his family know, but the second is that he also did this as a preventative measure against family feeling like he was keeping something from them. He can say that he was not keeping anything secret and that he did tell the family. In thinking about this quote in relation to the one above it, there is an interesting disconnect between discussing the couple being role models because they are a discordant couple and Carlos not telling his family. There is some pressure being felt here to be honest, but also be careful. Their status as a couple became very public during a pride parade that was covered on the news and a relative saw it. There is still some reticence to telling family, and he will not tell his parents about his partner's status. This seems to point again to the inconsistencies at the different levels of identity. As part of a mixed-status couple, HIV is a daily reality for him and his partner, and that relational identity involved telling people about it. In fact, being proudly open about his partner's HIV status is a way to help others overcome the stigma associated with HIV. However, at the personal level, Carlos does not want to tell his family, primarily, he rationalizes, because they will worry. However, it could also be that, while HIV is part of his relational identity, he does not want it intruding on his personal identity.

Peter echoes Carlos' comments regarding disclosure to his mother. Peter has not told his mother his partner's status, even though she has asked him specifically about his HIV status.

Primarily, because her knowing would just make her worry, and tell me that I'm an immoral person. She's fairly judgmental. And that would lead her to ask questions about who gave it to me and… and… to be honest my thought is, you know, um, even if I was

positive, her knowing… she's not going to be able to do anything to change it or help me, um, and …it doesn't have any impact on her life, so I don't feel like she has the need to know.

However, Peter and his partner have talked about the rules of disclosure around his partner's HIV status. As Peter discusses below, they have discussed when and to whom his partner's status can be revealed, and the general rule is that it is his partner's choice. This also supports the idea that both the HIV-positive partner and the HIV-negative partner have a vested interest in this information in that it says something about them both; however, the HIV-positive partner is the owner of the information and makes the rules.

He and I talked about that. In general, it's up to him to disclose. There are like, so there are times where, um, somebody comes up to me, and is interested in playing with both of us [both he and his partner engaging in sex with a third person]. So usually, I'll check with him to see if he's interested, and I'll ask, "Do you want me to broach the HIV topic?" And so far, the answer is always, "Yes, see what he thinks." So, what I'll do is, I tend to start the conversation with, "Are you okay playing with someone who is HIV-positive?" And I generally don't say, it's him or me, and what's interesting is you get one of three reactions. You get the, you know, either the, "Hell no!" Either they block you, or they go silent, or they'll tell you, "Hell no!" Or, they'll be okay with it, but they'll want to use protection, which is fine. Then there's the reaction, "It depends. How hot is he? Send me some pictures." You'll be surprised how often I get that, and in that case, I'll say, "Well, that's a no." And they'll get mad at me, and I'll say, "Look. If you're, you need to either to decide, you're willing to take the risk, or you're not. Don't tell me you want pictures, because then I'll think you're a picture collector, and it just sounds really

> bad anyway." That's, so far, the only context I've shared his status. I suppose if I ever had to take him to the hospital or that type of situation that would be another reason, but we haven't had that situation. I think we prefer to be private about it unless we feel we need to share his status with somebody.

At the end of this comment about the rules of disclosing his partner's status, Peter refers to "we." He becomes the go-between in terms of negotiating back and forth between disclosing his partner's status to the third person and running back and forth to his partner. In a sense, Peter is taking the responsibility for disclosing, or taking on the responsibility for feeling the effects of disclosure for his partner. As the caregiver, he is, in a way, potentially buffering his partner from negative reactions to disclosure and saving his partner's feelings. Collectively, they want to keep it private; they may or may not feel the need to share. The rules of disclosure and responsibility for disclosure are decided by Peter's partner, but Peter feels some ownership. He feels as if there is a "we" in this situation. Again, this also seems to support the idea that the HIV-negative partner has this illness relational identity to deal with, but he has little control over it. The HIV-positive partner decides how it is managed, and the HIV-negative partner has responsibility in the relationship to deal with it.

Throughout all the interviews with the study's participants, the HIV-negative partners do not see themselves as owning the information about their partners' HIV status. They all make it clear that it is something the HIV-positive partner owns and chooses to disclose. This is interesting in that the HIV-negative partner, by being in the relationship, in many ways is the co-owner of the information. Having an HIV-positive partner certainly says something about the HIV-negative partner; therefore, they choose who to tell or not tell in their family. Carlos told his sister, but not his mother. Tim did not tell his father, a physician, but he has told his brother,

step-sister, and "work wife." Steve did not tell any of his children until his partner was very sick. In the way they discuss the issue of disclosing their partner's HIV status, the men in this study seem to gloss over the inconsistency between their personal and relational identities presented by the presence of HIV. This may be yet another way that illness as an identity is thrust upon the HIV-negative partners and they can do little to manage that identity other than attempt to escape it or partition it off. They are very selective in disclosing to the people that have close associations with their personal identities, and they follow rules set down by their partner when dealing with relationships closely associated with their relational identities. This maintains the illness identity at the relational level, and prevents HIV from intruding to the personal sense of identity.

# CHAPTER FIVE: DISCUSSION

The present study addresses a significant gap in the literature regarding specific aspects of the illness experience as well as contributes additional insight to theories and concepts associated with uncertainty, relationships, intimacy, and identity. In previous research on illness, uncertainty, and identity, the investigations have focused on the illness as experienced by the primary patient. However, building upon previous research identifying illness as an interdependent phenomenon and showing the influence of close relationships on illness (Afifi, Hutchinson, & Krouse, 2006; Goldsmith, 2009; Goldsmith, et al., 2007; Westman & Vinokur, 1998), the present study addresses the gap in the literature and focuses on exploring the illness experience of the non-ill partners of patients experiencing a chronic illness. Because there is also a dearth of research investigating health issues faced by the LGBT population (IOM, 2011), the present study, by focusing on the HIV-negative partners of HIV-positive gay men, also contributes to the body of literature exploring the illness experience of the LGBT population.

HIV, because it is an infectious disease transmitted through close, intimate contact, presents both objective and subjective uncertainties for the HIV-negative partners. Objective uncertainties faced by the men participating in this study include concerns related to their personal health and risk of contracting the virus, concerns for their partners' health and wellness and risk at both the physical and emotional levels. Subjective uncertainties faced by these men are psychosocial or existential in nature and represent uncertainties associated with intimacy within the relationship between the HIV-positive and HIV-negative partner. Overall, these men face intimacy uncertainties brought on by the presence of HIV in their lives. That is, they experience disruptions to both the typical modes for the negotiation of intimacy (such as sex), and to the pre-established relationship routines they use to reinforce and maintain intimacy

within their relationship. Specifically, intimacy uncertainty arises when these men are unsure about those objective and subjective behaviors and feelings relational partners have regarding the aspects of closeness, openness, trust, affection, and mutuality that exist between themselves and their partners.

To address these uncertainties, HIV-negative men use a variety of behaviors to help them achieve coherence, or reach a level of acceptable uncertainty where their lives feel structured, ordered, and predictable. The behaviors involved in managing intimacy uncertainty include: 1) establishing new rules and norms regarding sexual behavior, 2) incorporating HIV treatments into relationship rituals, 3) engaging in relationship talk, and 4) minimizing their conceptualization of the risks associated with HIV. Specifically, this study was designed to address the question of what role uncertainty plays in the formation and maintenance of the HIV-negative men's identities. To that end, the following describes the role HIV plays in the relationship of these men as well as reviews the nature of the relationship between uncertainty and their identities. Additionally, both theoretical and practical implications, limitations, and recommendations are discussed.

## HIV as Intimacy Regulator

HIV intrudes on the couple's sense of intimacy and causes uncertainties in ways that make it more difficult for the couple to share aspects of their lives that contribute to a close, intimate relationship. Because of this, the couple engages in behaviors designed to push illness out of the relationship by ignoring it, downplaying its presence, taking control of it on their own terms, or creating new ways to maintain and increase intimacy given its presence. In the field of clinical psychology, clinicians often treat clients, both couples and individuals, facing intimacy issues by helping clients find ways to regulate intimacy (Prager, 2000). According to Prager

(2000, p. 241), "Effective intimacy regulation seems to involve a rhythm of intimate contact alternating with more separateness in which partners' needs are fulfilled and in which conflict and recrimination are minimized." Each couple possesses an optimum mode where they determine the timing, pace, and depth of intimacy-promoting behaviors. There is a time and place to create a separateness to minimize conflict that may arise from attempting to create too much closeness. Key to effective intimacy regulation is the control partners exert over behaviors designed to promote intimacy. For couples experiencing the intrusion of HIV, HIV appears to take control of intimacy regulation away from the partners. HIV demands specific behavior changes to the intimacy between the couple, affecting the timing and type of intimate behaviors the partners engage in, the pace at which intimacy is developed over the course of the relationship, and the depth of intimacy between the partners. HIV, in a sense, becomes the intimacy regulator between mixed-status couples and the uncertainties associated with this intimacy disruption propel the men to choose behaviors that minimize the disruption and HIV's power over the relationship.

## Uncertainty and Identity

Because HIV intrudes on intimacy, the men participating in this study experience uncertainties that not only challenge intimacy development between the couple, but also challenge their sense of identity. At the relational level, an individual's self-concepts are concerned with their interpersonal interactions and their roles in those interactions (Vignoles, et al., 2011). By intruding on intimacy, HIV calls into question the assumptions these men hold regarding their relational roles, leaving them with the need to resolve inconsistencies between how they view their self-concepts involving relationships, and the need to deal with an illness-related role that helps define their relational identity as they make sense of HIV. At the personal

level, the presence of an infectious, chronic disease at the relational level threatens to impinge on the "healthy" self-concept these men have developed as part of their personal sense of self. To manage these inconsistencies between the personal and relational levels of identity, these men engage in behaviors designed to marginalize HIV as an intrusion into their intimate lives and sense of self. To that end, the men participating in this study call upon their personal sense of being educated to allow them to perform information-seeking behaviors designed to minimize the risk of HIV infection, redefine the meaning of safe-sex within their relationship, and foster a change in attitudes directed at removing the stigma associated with HIV. In addition, these men engage in behaviors designed to reinforce their self-concepts as healthy individuals. To do this, these men engage in active, physical pursuits designed to allow them to reject and escape the debilitating effects of illness. Additionally, these men refuse to accept any level of ownership of HIV and abdicate any responsibility in disclosing their partners' HIV statuses. In this way, they seek to distance themselves from HIV in an effort to keep from becoming associated with the disease themselves.

## Theoretical Implications

The findings of the present study carry important implications for the study of uncertainty, identity, and associated constructs and theories. In addition, these data also provide practical implications for healthcare practitioners and public health advocates.

### Intimacy Uncertainty

One goal of the present study involved exploring uncertainties held by the HIV-negative partners in mixed-HIV status couples. While there is a considerable body of work focusing on intimacy and uncertainty in relationships, the findings from this study indicate the participants experience intimacy-specific uncertainties. The uncertainties these men hold center on the

various components of uncertainty, including: 1) the couples' feelings of closeness or union, 2) the couples' feelings of mutuality, 3) feelings of trust between the partners, 4) openness between the partners, and 5) affection between the partners (Solomon and Theiss, 2013). Uncertainties related to these components of physical and emotional intimacy have been found in studies where one partner is experiencing depression (Knobloch & Delaney, 2012). In developing a measure of relational uncertainty, Knobloch and Solomon (1999) identify measures of uncertainty related to self, partner, and relational factors with items that seem to address the various components of intimacy such as: "How certain are you about what you can or cannot say to each other in this relationship?" (openness); "How certain are you about whether you and your partner feel the same way about each other?" (closeness); "How certain are you about how you and your partner view this relationship?" (mutuality). In measuring intimacy, Solomon and Knobloch (2004) use a composite scale enlisting items from three separate scales designed to measure such aspects as affiliative need, willingness to help, and commitment to continuing the association. Intimacy coincides with relational uncertainty and heightened intimacy acts to increase the likelihood of positive outcomes from relational uncertainty management efforts (Knobloch & Solomon, 2002). This previous research, taken with the present study's findings regarding intimacy-specific uncertainties, supports the position that intimacy uncertainty is an additional, separate, distinct construct within the more broadly defined construct of relational uncertainty.

**Contributions to Theories of Uncertainty**

In addition to introducing the concept of illness uncertainty, these data contribute to Mishel's Uncertainty in Illness theory and Brashers' Uncertainty Management theory by extending the notion of illness-related uncertainty from primarily a patient-oriented perspective

to one that looks at the illness-related uncertainties of the partners of patients, specifically within the context of HIV in the current study. Previous studies investigating HIV and uncertainty have found that HIV-positive individuals hold uncertainties regarding unclear relational implications and unknown impacts on long-term relationships as a result of their HIV infection (Brashers, et al., 2003). The present study helps to shed light on uncertainty sources within mixed-status relationships by identifying intimacy as a primary source of uncertainty for the HIV-negative partner.

Uncertainty Management is often presented as a process where uncertainty is described, an appraisal of that uncertainty follows, and decisions are made regarding information-seeking behavior. While the authors of uncertainty theories do not necessarily promote a linear focus, the conceptualizations of these theories of uncertainty seem to lead to linear thinking. In addition, uncertainty management is conceptualized in terms of individuals grappling with, and making decisions about, uncertainty. However, findings from the present study suggest that similar to identity, uncertainty is a multi-faceted and layered construct consisting of several processes interacting and interrelating with one another. For example, participants indicate that both partners are working to address intimacy-related uncertainty, potentially via behaviors that are in conflict. That is, HIV-positive partners may perceive threats to the couple's intimacy because of fears regarding transmission of the virus. The HIV-negative partner may perceive HIV as a barrier or threat to intimacy. In working to resolve these threats to intimacy, the partners may enact, for example, competing behaviors regarding condom use and sexual activity. Thus, the present study brings an additional perspective to theories of uncertainty by introducing the perspective from the other half of the dyad involved in the relationship (the HIV-negative partner and possibly by extension, the partner who is not chronically ill).

**Contributions to Theories of Identity**

Illness is disruptive, but what makes it so difficult to deal with is the identity threat it presents. Treating illness can become routine, even seen as easy, but the desire to get back to a pre-illness, carefully constructed identity, and the impossibility of that notion, is where the problem lies. Unlike Michel's Uncertainty in Illness theory that discusses growth and changes to a chronically-ill individual's worldview and outward perspective, the non-ill partners focus inward on the view of self.

In making sense of their partners' HIV diagnoses and the intrusion to intimacy that HIV represents, the men participating in this study enacted several identity-defining behaviors in an attempt to marginalize HIV and deny it power over their sense of self. Serious illness presents situations that are restrictive and limiting. Because of this, the identity dilemmas and inconsistencies that are part of the illness experience are fundamentally where the HIV-negative partners find the real struggles. Certainly, the debilitating effects of illness present struggles that must be dealt with on a variety of levels. Treatments may be difficult, or carry unpleasant side effects. However, the aspects of illness that appear the most difficult to deal with are the psychosocial effects of the illness. In the case of the present study, those psychosocial effects come as the loss of intimacy, the loss of identity, and the loss of relationships.

In looking at the Communication Theory of Identity, the theory posits an "enactment" layer of identity where communication is the locus of identity and an individual's sense of self is seen as a performance expressed through a variety of messaging (Hecht, et al., 2005). When behaviors announce an illness, the real problem and the very real threat to identity arise. Taking a pill in the morning or the evening is invisible and enabling. This behavior does not announce an illness to the outside world. When assistance is needed to walk, activities have to be scheduled

around the illness and specific behaviors cannot be performed (i.e., having unprotected sex); it is this public behavior that challenges the sense of self and forces a public acknowledgement of identity that is trying to be avoided. It is at this point, Hecht's Communication Theory of Illness and Mishel's Uncertainty in Illness intersect. Until uncertainty is returned to a state of coherence, the forced enactment of illness-related behaviors will always cause problems.

The findings from the present study make several important contributions to the literature describing the relationship between illness and identity. These data support the formation of an initial conceptualization of illness and relational identity.

**A Theory of Relational Illness Identity.** In developing a theory of illness identity based on the findings of the present study, several fundamental tenets must be included. First is the notion that serious illness is restrictive. Illness brings with it, at a minimum, limits to the individuals' capabilities. Even though physical limitations may exist for the partner diagnosed with the illness, some form of restriction will have to be dealt with on a relational level, be it physical, psychosocial, or existential. Second, illness is an overwhelming, intrusive, unasked-for identity. When serious illness enters the lives of close, romantic partners, there is no choice but to take on an identity that involves illness at the relational level (for both partners) and at the personal level (primarily for the sick partner). For the healthy partner, that serious illness is overwhelming and a particularly salient identity that is thrust upon oneself. Dealing with a serious illness as the one not diagnosed with the illness presents a unique struggle for the healthy relational partner. Third, the goal of personal identity management efforts focuses on marginalizing the effects of the illness at the relational level to limit the power the illness wields over the relationship. In addition, the healthy partners, when facing illness at the relational level, work to manage their personal identity outside of the relational identity. Personal identity

management for the healthy partner focuses on efforts to reject or escape the illness identity's intrusion into the personal identity.

## Practical Implications

In addition to the theoretical contributions outlined above, findings from this study also carry important practical implications for public health and assisting mixed-status couples in managing their uncertainties. Specifically, these data indicate a relationship between uncertainty and identity that is important to consider when designing health campaigns and healthcare interventions. Uncertainty management is typically presented as a linear process and healthcare interventions have been designed to follow this linear way of thinking. For example, Neville (2003) suggests nursing interventions should address patient uncertainty and include an assessment of patient information needs, an assessment of the patient's appraisal of the uncertainty, and provide guidelines for assisting with information-seeking. However, this simple process neither considers the multi-layered nature of uncertainty nor mentions identity and relationships as considerations. Given the findings of the present study, practical implications are discussed for addressing intimacy uncertainties and the related identity issues arising from those uncertainties.

Sex is an arbiter of intimacy and the primary uncertainties experienced by the men participating in this study revolve around intimacy. In particular, these findings regarding intimacy uncertainties should be reviewed in light of the U.S. government's public health information targeting mixed-status couples through the AIDS.gov website. According to AIDS.gov, mixed-status couples should always use condoms during sexual activity, even if the HIV-negative partner is on pre-exposure prophylaxis medication (U.S. Department of Health and Human Services, AIDS.gov, 2012). However, contrast this messaging with quotes from

participants in this study. For example, Steve remarks, "Um, I'll be very blunt with you, honest, since I think this is a study and I think…we have had unprotected sex. It's going to happen." John also indicates that it is too much to ask that couples will consistently use condoms.

> Like I said, I'm just very trusting, and I also would eventually like to be in a relationship where I can have unprotected sex. Straight people have unprotected sex all the time. They made birth control which some doctors say isn't great for women just so men could have unprotected sex with their wives. I don't know. I think it's too hopeful that people will use condoms 24/7.

These men also talked about going without condoms to demonstrate commitment and advance intimacy with their partners. Targeting these men with a message that describes safe sex in terms of condoms, and recommends constant use of condoms, misses the mark. In addition, the AIDS.gov messaging neglects to understand salient identity aspects to these couples' relationships that steer them away from condom usage. These men consider themselves educated and this educated identity drives them to redefine what safe sex means for them. This is accomplished through information-seeking designed to help them minimize the risks associated with unprotected sex. Going without a condom doesn't necessarily mean they are practicing unsafe sex. They are practicing a form of safe sex that is in concert with their salient identities.

Taken together, these aspects of uncertainty and identity present many layers that should be addressed in public-health messaging. In addition, there are different functions for sex with regards to relationships and intimacy. Sex leading to intimacy is different from sex to experience passion (Marston, Hecht, Manke, McDaniel, & Reeder, 1998). As these data demonstrate, intimacy is a primary concern for the men in this study and condom use presents itself as a barrier to intimacy for the couples. From a public health perspective, safe-sex messaging,

particularly campaigns and interventions targeting mixed-status couples should consider these attitudes and behaviors to increase effectiveness. As people talk about health challenges and choices, the relevant layers of identity can be seen (Hecht & Choi, 2012). These layers of identity can then be used to evoke the target audiences' identity in an effort to combine the desired health behavior with an identity goal (Hecht & Choi, 2012). The key is determining the appropriate layer(s) of identity to target. For example, in terms of the present study, the participants see themselves as having the self-efficacy to research information regarding safe-sex practices and adopt behaviors outside of the guidelines recommended by AIDS.gov. In this instance, targeting the personal level of identity may prove an ineffective strategy to persuade the HIV-negative partners of HIV-positive men to adopt condom usage as prescribed. However, because much of the intimacy uncertainties and salient identity issues occur at the relational level of identity, messages targeting behavior change linked to their role in the relationship may prove more effective.

## Limitations

Despite the theoretical and practical implications outlined above, this study has its limitations. These data suggest intimacy uncertainty drives particular behaviors related to relationship development and maintenance. The presence of HIV acts to motivate relational talk that, in many cases, may not have occurred otherwise. Uncertainties related to intimacy and relationships drive relational talk (Knobloch & Delaney, 2012; Knobloch, Solomon, & Theiss, 2006; Solomon & Knobloch, 2004). However, based on these data, neither outcomes nor valence of that relational talk can be inferred.

A second limitation of this study centers on the nature of behaviors used to manage intimacy uncertainties. The presence of HIV seems to foster behaviors designed to develop or

maintain intimacy, while also attempting to navigate the risks associated with HIV. For example, changes to sexual practices were discussed as something that occurred because of the HIV diagnosis. While these behavior changes are undertaken to enhance intimacy between the couple, there is no way to assess if new behaviors that replaced old behaviors are less than, more than, or equally effective in achieving the desired intimacy outcomes.

Finally, the men participating in this study have achieved high levels of education, and represent mostly white, middle-class backgrounds. Education has been identified as a key component of the participants' self-concepts, which drive behaviors they use to manage intimacy uncertainties and define their relational identities. However, it cannot be known if that education level is associated with their sense of self-efficacy in finding and using information related to HIV to overcome risks associated with sexual activity or if their sense of self-efficacy is a prevalent identity characteristic of HIV-negative men entering into committed relationships with HIV-positive men.

## Future Research

Little work has been done to identify the nature of uncertainty or integrate various perspectives into an uncertainty taxonomy. Because uncertainty management is often discussed as process-oriented, specific behaviors in response to the presence of uncertainty suggest a decision-making model underlies uncertainty management. As discussed, the uncertainties held by the men participating in the present study indicate that uncertainties take on both objective and subjective qualities. By understanding these qualities associated with the various sources of uncertainties, theories could be refined to better predict the outcomes associated with particular types of uncertainties. This idea is not without precedent. Knobloch and Solomon (2002) discuss how information-seeking behavior is shaped based on the valence of uncertainties. Future

research should seek to refine efforts to identify the nature of uncertainty in illness to increase the theory's predictive power associated with uncertainty and improve clinical efforts to help patients and their families manage uncertainties.

These data indicate several facets of uncertainty and identity in relation to HIV and mixed-status couples that have not previously been considered in health interventions. Future research should investigate the potential of chronic illness, and in particular HIV, to determine if HIV can be used as a positive point of negotiating new intimacy rituals and increasing positive relational talk. This may be most difficult in couples where HIV was introduced to a long-standing relationship. Can they leave behind old intimacy rituals to form new ones that are satisfying and enhance the relationship? Are there ways to develop new relationship-enhancing norms that incorporate HIV or should new intimacy rituals that are completely separate from HIV be established? Research designed to answer these questions may improve health-care interventions and HIV patient counseling.

These data identified being educated as a salient identity factor that seems to drive behaviors related to sexual activity and redefining safe sex in an effort to mitigate the risks associated with sexual activity and HIV transmission. Neither Mishel's Uncertainty in Illness nor Brashers' Uncertainty Management theory addresses the relationship between uncertainty and risk. Is risk a driver of uncertainty and thereby embedded within uncertainty? Or, is uncertainty a component of risk? In considering the dyadic nature of intimacy uncertainties and the risks associated with the transmission of HIV, future research should seek to further understand how individuals and couples conceptualize risk and uncertainty in relation to one another, particularly within the healthcare environment.

While the data in the present study were collected from HIV-negative men with HIV-positive partners, the fundamentals of a theory of relational illness identity seem to be applicable to other serious diseases. Severely debilitating diseases and conditions, such as cancer, Parkinson's disease, spinal cord injuries resulting in paralysis, heart disease, diabetes, and even general aging all present limits and restrictions to the individual diagnosed with that condition that will, in turn, affect that individual's close, romantic partnership by placing physical and psychosocial limits on the relationship. While the present findings are concerned with HIV, it is reasonable to consider that the above conditions would also intrude on intimacy within other relationships.

These data suggest intimacy uncertainty is a separate and distinct construct apart from relational uncertainty. While the two constructs are related, future research should look at confirming the presence of different types of uncertainties within the notion of relational uncertainty, and seek to better understand the components involved with intimacy. Understanding the different types of uncertainties associated with relationships may shed light on different types of uncertainty management strategies and different communication behaviors, over and above information-seeking.

Finally, relational identity is clearly a dyadic phenomenon; however, the present study presents a view of relational identity encompassing only half of that dyad. While it is important to understand each partner's self-concept and the role that self-concept plays in the development of the couple's relational identity, identity also results from the negotiation of social processes between the couple. Future research should comprehend the self-concepts both partners bring to the relationship along with the social processes that occur between the partners influencing the co-construction of their relational identity.

## Conclusion

Intimacy is a relational marker that identifies a person's most important and valued relationships, as well as being a powerful determinant of health and well-being (Prager, 2000). As the present study demonstrates, HIV intrudes on the relational functioning of mixed-status couples serving as an unasked-for intimacy regulator; the HIV-negative partners experience a variety of uncertainties associated with the threat HIV poses to intimacy between the couple. The resulting intimacy uncertainty experienced by the HIV-negative partner is defined as the state individuals occupy when they are unsure about the objective and subjective behaviors and feelings relational partners have regarding closeness, openness, trust, affection, and mutuality that exist between the partners.

In addition to providing a definition of intimacy uncertainty, the present study also makes several other important contributions to both the body of literature addressing uncertainty as a phenomenon associated with chronic illness and relationships and to the public health campaign efforts undertaken by practitioners. These data suggest that uncertainty exists as a multi-layered, dyadic construct, and that couples dealing with one partner's chronic illness may invoke competing and contradictory behaviors in an attempt to manage one or more uncertainties. In addition, these data suggest that intimacy uncertainty exists as a specific, discreet construct within the more broadly defined construct of relational uncertainty. To manage their intimacy uncertainty, the HIV-negative participants in this study rely on identity-driven behaviors to minimize the intrusion of HIV into the process of intimacy-building between themselves and their partner and to deny taking any ownership of an HIV-positive status within their sense of personal identity. As identity-related factors emerge as behavior drivers, data from the present study indicate public health efforts designed to educate and persuade mixed-status couples in the

adoption of safer-sex practices should be mindful of the multi-layered and identity-driven aspects of uncertainty management.

Close relationships play a central role in our daily lives, and, as this study discusses, have a powerful effect on our health and well-being. Intimacy is at the heart of those close relationships. The social processes involved with developing and maintaining a sense of closeness within our most valued relationships are particularly vulnerable to the overwhelming and intrusive nature of chronic illness. Promoting healthy lifestyle choices has long been a primary goal of public health; however, as the present study suggests, it is time to incorporate the concept of healthy intimacy into our ideas of what it means to live a long and healthy life.

## EPILOGUE: ACUTE ILLNESS AND THE DESTRUCTION OF IDENTITY

Throughout the findings presented from these data, exemplars illustrating the various intimacy uncertainties, behaviors used to address these uncertainties, and the accompanying identity construction and dilemmas have portrayed the commonalities among the HIV-negative men participating in this study. However, Steve and his partner represent a unique case to this particular data set. As previously mentioned, Steve's partner, at the time of data collection, was suffering far more acute and debilitating effects of illness than any of the other HIV-positive partners. In this regard, Steve's experience as the HIV-negative partner of an HIV-positive man was somewhat unique among the men interviewed. While the experience of Steve and his partner regarding intimacy uncertainty is consistent with the other men participating in this study, Steve's experience also sheds light on how the progression of chronic illness to more acute phases continues to affect intimacy uncertainty and identity.

In the following quote, Steve relates a comment from his partner made during a counseling session. In this quote, Steve's partner questions what Steve was first thinking upon entering into a relationship with an HIV-positive man regarding illness and its role in their lives.

> When we went to counseling, he said, "You knew it was going to be like this at some point." He said, "You knew that I would get sick. Why now?" was his, "Why won't you just come out and say that you don't want to deal with this anymore?" And I never answered the question, and then we ended the session, channeling it off to something else. So. [Sighs] I thought about that a lot. Him saying that. And, I don't if it was just head in the sand or just didn't contemplate it, or didn't think about it, maybe because I didn't think that it would be, um, given advancements in science and the fact that people live to be normal life spans, and that we would die old together that we would not

experience this. But, what he was trying to say was, "Whether this was Goodpasture's disease or something HIV related, you know, did you not know?"

This quote speaks to how the men in this study approach their relationship. In the case of HIV, it slows the progression of intimacy. However, with the exception of Tim who had a previous partner die of AIDS, the men in this study do not consider the long-term effects of illness. The debilitating aspects of serious, chronic disease are not comprehended as part of a relational identity. Illness, as a contributor to identity, is later thrust upon these men. It is unasked-for, and, for the most part, difficult to escape. It is a contributor to the construction of identity unlike most anything else.

Steve represents a time when illness becomes acute. Steve's partner has suffered through HIV-related health complications such as lymphoma. However, his partner has also experienced acute, life-threatening illness unrelated to HIV. Steve's partner suffers from health issues that have caused kidney failure, require daily dialysis treatment, have resulted in several hospital stays, and are difficult to treat due to complications in prescribing medications that will be compatible with the antiviral medication he takes for HIV. As his partner's illnesses grew more serious and his partner's illness became more and more disabling, Steve describes the catastrophic effects his partner's health issues have had on intimacy and their relationship.

I'm actually on the end of dealing with the emotional stuff, so I could really sort of give you my take on it, but….you know, maybe six, seven months ago I couldn't, but, um, in essence, it is like, grieving your relationship every day. You don't have a relationship anymore. You can't. You know. You're not two healthy, independent people growing together. You're with somebody who is fighting to survive. Fighting to live. So you have moments where you enjoy one another, but you don't…you…that's where I go…I had to

> manage my expectations because I couldn't constantly live in a state…I had a cycle. I'd get mad. Then I'd be mean. Then I'd feel guilty. Then I'd get mad…you see what I'm saying? Then I'd get mean, and um, it was a vicious cycle. And many times I'd take it out on him. And I realized…I said, you're just going to have to accept reality. This is, this is your life now.

As this quote illustrates, illness becomes so overwhelming that an intimate relationship is impossible to comprehend. It feels as if he lets himself think about the relationship, it takes him to a place where he is afraid that he can't continue helping with the health issues.

Steve's quote above notes that, "you're not two healthy, independent people growing together." This seems to be an acknowledgement that intimacy is gone. Illness has nearly completely robbed the relationship of anything that helps to build closeness between the two men. He goes on to describe exactly those aspects of their relationship that illness has taken.

> Just a relationship that partners have. You know, the newlyweds, together building a life, and two independent people, um, you know, doing things that two healthy people do. Both sexually…even emotionally. Financially. Doing things. Being involved in each other's lives. Being more active, you know. Those kinds of things. Because you know, he's very limited only so many amounts of energy….but he's much better. So, I'm saying there are times he's with it, and there are times he has to sleep quite a bit. Um…..so I grieve the you know, "oh that was so sweet of you to make me dinner." You know, of course when he gets well, he does that once in a while, but it's not like normal, you know….um…waking up on Saturday, let's clean the house. You know, now I always have to think, ok gotta get the dishes done, gotta make sure the house is clean. You know, gotta make sure the trash is taken out. You know, um, physical, anything physical, you

know that it slows that. And, um, I grieve who he was. He was always…[My partner] is the butch one obviously, when you talk to him, and as you can tell from me, but he is the mister handyman, and remodeled, and, um, built shit and stuff like that. And I hate that for him, you know that he doesn't have the dexterity in his hands or the energy to do those types of things. You know, at his other house, he completely re-did the basement. Um, so I grieve the fact that, that, there's not that…I grieve that he was always the aggressor sexually, too. That was very interesting. I was always the one that had the headache, or I'm tired, or whatever. Um, you know, to see that that has waned, you know. So, yeah, that's what I mean. I grieve that. I grieve what are we able to do growing together as far as building a relationship.

For Steve, illness has become so overwhelming and intrusive that everything constituting intimacy and helping build a close relationship is destroyed. At this point, Steve no longer hopes for the relationship they once had. Instead, he grieves the loss of intimacy and the ability to share even mundane things with his partner like it was a death. Illness has completely robbed him of that relationship, and it will never come back. In grieving the relationship, Steve has had to turn off his emotions related to the relationship, accept that those emotions have to be turned off, and deal with the sadness that comes from the grief caused by illness.

With the relationship all but gone, Steve describes those small things that he is still able to share with his partner. In particular, Steve's partner has a young grandson, and it would seem the child is one of the few aspects of their relationship that continues to hold their personal bond together.

All my children are grown. Course it's now just paying all the fun tuition, you know. We, ah, got over our breeder tax, and we thought, woo hoo! We thought child support would

> end, but now tuition came along. Um, he has two daughters and a grandson, so we have, our house is full. [His daughter] was here just earlier. And he is our joy…and, we call him our "gayby". We absolutely love him and spoil him rotten. He is a great kid, and, um, so that's the story in a nutshell.

Outside of their family relationships, there is little else the partners can still share and use to create their sense of closeness. As such, Steve describes how he has to manage his expectations regarding the future.

> At the beginning I just kept thinking, "oh, he'll get well, he'll get well. We just gotta get through this. He'll get well." And then when we constantly put him in the hospital, and that's when I became very neurotic in my…and then, then, you know work became busy, our company just…we grew so fast, and I was just overwhelmed. Highly stressed, and very irritable. Um, what I had to come to terms with was that I'm living with a terminally ill person. Um, has like zero to do with HIV. I'm dealing with someone where we have to bring in fluids and do dialysis every night. Maintain that. Um, you know financially, he's on disability, and he had a great job. You know, more of that burden has been put on me, but not anything negative. It's just manage my expectations of what the future will hold. I don't have any expectations now. I'm just, day to day. I guess I've learned not to think about the future, just what's going to go on maybe this week. That kind of thing. That's a whole other deep conversation you probably don't even want to get into.

For Steve, the idea of managing expectations means he must give up a future orientation; if he doesn't, he enters an irresolvable cycle that makes the situation even worse. Steve's uncertainties, at this point, can only be managed by accepting they exist and trying not to think about them.

> I try not to think deep thoughts. Um, I have found they serve me absolutely no purpose. I used to be a deep thinking person, and then when I realized that they were vicious circles, and…I used to believe in absolutes. I don't anymore. I just got to…what..what..what difference does it make me answering that question? I mean, what is that going to change? I'm not going anywhere. This is where we are. Let's get through this. So that, that's, I guess, that's where I am with that.

This again speaks to giving up any type of future orientation. For Steve, hoping for tomorrow leads to too many unanswered questions, and dealing with those unanswered questions will attack and destroy your sense of self.

Steve represents the end point in the intrusion of illness on a relationship. Most of his efforts at this point are around preserving his own sense of identity because there is no relational identity anymore, and really, most of his partner's personal sense of identity is gone as well. They do cling to the relationship with Steve's partner's grandson as the one thing that they can share. That is their only point of intimacy, and something they can enjoy as a couple. Everything else is gone. Illness can no longer be denied in the relationship because it has become so acute. For the other men in this study, they can still deny the intrusion of HIV to an extent. Where they can't completely deny it has to do with sexual relations, but they still work very hard to push that intrusion out of that arena as well.

Illness continues to take away or attack his sense of self. There are issues of individual identities as seen by the negative partner, but also a view of the negative partner's sense of the couples' identity. They help others with problems; they don't need the help. They are independent, meaning capable. Illness changes that. When it comes to serious illness, a struggle

with identity brought on by intimacy uncertainty is the salient uncertainty, and managing the inconsistency between the relational and personal levels of identity is the ultimate goal.

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# APPENDICES

## Appendix A: HIV-Negative Partner

**Discussion Guide**

Thank you very much for participating in this interview. The purpose of this interview is to gather information that will help couples coping with an HIV/AIDS diagnosis. Because of your first-hand experience with HIV/AIDS, you are in a unique position to comment on how couples face this issue. I am looking to understand your personal experience; therefore, there are no right or wrong answers to my questions. If you have any questions as we are going through the interview, please feel free to ask. If you want to stop this interview for any reason, you are free to do so. Do you have any questions before we begin?

**HIV-negative Partner**

***Rapport Building***

1. Tell me a little about yourself. (i.e. Where are you from? What is your job? What is your family like?)
    a. What kind of person are you? How would your friends and family describe you?
2. Tell me a little about your partner. How would you describe him?
3. How do you think he would describe himself?
4. Why did you decide to participate in this study?

***General Health Information***

1. Tell me a little about your health in general.
2. Other than your partner's HIV, tell me about any other health concerns you may have.

***HIV-related Health Information***

1. Before you met your partner, what kind of knowledge and experience of HIV did you have?

***Relationship and Identity Information***

1. Tell me a little bit about your relationship with your partner. (i.e. How did you meet? What attracted you to him? What do you like about him? What do you dislike about him?)
2. How would you describe your relationship?
3. What do you think your friends and/or family think about your relationship? How would they describe your relationship?
4. What types of activities do you like to do together?
5. What types of things cause conflict in your relationship?
    a. How do you deal with conflicts? How does your partner deal with conflicts?
6. What kind of big decisions have you had to make as a couple? Walk me through the decision-making process.
    a. How does HIV affect big decisions in your life?
7. What concerns, if any, do you have with your relationship?

***HIV and the Relationship***

1. Was your partner HIV-positive before you met?
2. Describe for me how you found out your partner is HIV-positive.
3. How do you think his HIV has affected your relationship?
    a. Is there anything about your relationship that requires special consideration because of his HIV?
4. How involved are you in your partner's health care?

***HIV-related Uncertainty***

1. Given that your partner is HIV-positive now, what concerns do you have about the disease?
2. What kind of uncertainties and questions do you have related to the disease?

3. How do you deal with these uncertainties?
    a. What role does your partner play in how you manage your uncertainties?
    b. Do you discuss your uncertainties? Do you discuss his uncertainties?

***Relational, Partner, and HIV-related Uncertainty***

1. What kind of concerns do you think your partner has about his HIV?
2. What kind of concerns do you think your partner has about the relationship?
3. Think about discussions you have had about HIV and the treatment or management of the disease. Describe for me some of the discussions that stand out in your mind.
4. Are there some HIV-related things you don't talk about?
    a. Are there some HIV-related issues you wish you would discuss?
5. What role, if any, do you play in the management of your partner's HIV?

***Final Questions/Wrap-Up***

2. Is there anything about you and your partner that I haven't asked about?
3. What kind of advice would you give to other couples that have to deal with HIV?
4. Is there anything else you would like to add?

## Appendix B: Institutional Review Board Application

# FORM B APPLICATION

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All applicants are encouraged to read the Form B guidelines. If you have any questions as you develop your Form B, contact your Departmental Review Committee (DRC) or Research Compliance Services at the Office of Research.

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**FORM B**

**IRB # _____**

**Date Received in OR _____**

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## THE UNIVERSITY OF TENNESSEE

**Application for Review of Research Involving Human Subjects**

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**I. IDENTIFICATION OF PROJECT**

1. **Principal Investigator Co-Principal Investigator:**
   *Complete name and address including telephone number and e-mail address*


Scott A. Eldredge
PhD Candidate/Graduate Teaching Associate
293 Communication Building
Knoxville, TN 37996
865-974-0696
seldredg@utk.edu


**Faculty Advisor:**
*Complete name and address including telephone number and e-mail address*


Dr. Michelle Violanti
Associate Professor
School of Communication Studies
293 Communication Building
Knoxville, TN 37996

865-974-7-7072
violanti@utk.edu

**Department:**
Communication Studies

**2. Project Classification:** *Enter one of the following terms as appropriate:* **Dissertation, Thesis, Class Project, Research Project**, or **Other** (Please specify)

Dissertation

**3. Title of Project:**

Uncertainty and Identity in Gay Male Couples Dealing with HIV/AIDS

**4. Starting Date:** *Specify the intended starting date or insert* "**Upon IRB Approval**"**:**

Upon IRB Approval

**5. Estimated Completion Date:** May 1, 2015

**6. External Funding** *(if any):* N/A

- **Grant/Contract Submission Deadline:**
- **Funding Agency:**
- **Sponsor ID Number *(if known)*:**
- **UT Proposal Number *(if known):***

**II. PROJECT OBJECTIVES**

The purpose of this study is to explore the ways in which members of a gay male couple where one partner is HIV-negative and the other HIV-positive make sense of their interactions and experiences with respect to uncertainties and identity.

To date, there is little exploration of how family members are impacted by a loved one's chronic, infectious illness, and this study will begin to help fill in the gap in the available scholarly research done to date in the area of uncertainty and illness. This research will increase the knowledge of how communication and romantic partnerships play a role in the management of chronic illness, and has the potential to help uncover ways in which social support can assist in facilitating positive relational outcomes for the individuals and positive health outcomes for the patient.

**III. DESCRIPTION AND SOURCE OF RESEARCH PARTICIPANTS**

This study will recruit only gay male couples in romantic partnerships where one partner is HIV-positive and the other is HIV-negative and who are at least 18 years of age. In addition, participants will be recruited that:

a) Are both English-speakers
b) Where both members of the couple are willing to participate
c) Where both members are aware of each other's HIV status

Participants for the study will be recruited through four primary means:

1) Personal contacts made by the researcher at the Knox County health department and non-profit HIV/AIDS education and counseling organizations will be used to pass along information regarding the study to anyone who may have a potential interest in the study. The PI has come to know these contacts in a professional capacity through a previous IRB-approved research project. The contacts have agreed to serve as conduits for distributing the flyers.
2) Recruitment emails and flyers will be used for classified advertisements and listservs. (example attached) This email and flyer will be provided to the personal contacts known to the PI as identified above.
3) The recruitment announcements will include an incentive for participation of $25 for every individual ($25 per person, $50 per couple regardless of whether the interview is completed) will be given at the start of the interview.
4) In order to get the most information-rich cases, this study will begin with the resources and contacts described above, and then use snowball sampling to identify additional participants who agree to be interviewed for this study. Participants and the personal contacts identified above will be provided with recruitment flyers and be asked to pass them along to additional people they believe may be interested or know someone who may be interested in participating in the study. In this way, no one has to provide health information about potential participants; only those who are genuinely interested can reveal their HIV status upon contacting the researcher to begin the consent process.
5) While researcher aims to conduct interviews with between 15 and 20 couples, he will apply the principle of qualitative saturation until no additional new information or negative cases can be found.

**IV. METHODS AND PROCEDURES**

This study has been designed using well-established procedures for collecting and analyzing qualitative data. Long interviews will be used for data collection and will proceed according to guidelines set forth by McCracken (1988), Lincoln & Guba (1985), and Creswell (2007). Data analysis will follow procedures consistent with grounded theory techniques identified by Corbin & Strauss (2008) and Charmaz (2006). The questions being used for each participant (see interview guide) grow out of social identity, uncertainty management, and privacy management theories. The guides are meant to prompt the researcher to make sure that all topics of interest are covered. The likelihood is high that not all questions will be asked in all interviews or asked in the same order because the interviews are designed to be conversations with a free flow of give and take and the participant may answer a "later question on the interview guide" in the process of addressing an earlier question, telling a story, or relating an experience. With respect to the validity of the data, the protocols being followed encourage the researcher to assess the

credibility (akin to internal validity), transferability (akin to external validity), dependability (akin to reliability), and confirmability (akin to objectivity). The ultimate criterion for data are their trustworthiness.

Upon response to recruitment advertisements, flyers, and emails (see attached), respondents will be contacted by the researcher by phone or email to conduct a pre-screening and to coordinate an in-person interview including details on a time and location. The pre-screening will consist of a request by the researcher that each member of the couple separately confirms to the researcher meeting the following criteria:

a) They are both 18 years of age
b) They are both gay males
c) They are engaged in a romantic partnership
d) They are each aware of the other's current HIV status.
e) That one partner is HIV-positive and the other is currently HIV-negative to the best of their knowledge
f) They are both willing to participate

Meeting places will be private locations of the participants' choice, and where the interviews cannot be overheard by anyone; only the researcher and the participant being interviewed will have access to the conversation as it transpires.

Data will be generated via long interviews with the researcher using open-ended questions and conducting interviews of each partner. Each partner will be interviewed alone, separately where one partner cannot hear the other's interview, and immediately one after the other without any time in between to prevent discussion of the interviews before both interviews are completed. The interview for each partner will last approximately one to two hours in length. At the appointed meeting time and place, each respondent will be presented with the informed consent form (see attached). The researcher will review the informed consent form with the participant, and give the participant time to review the informed consent form on their own and ask any questions. The researcher will then obtain the participant's signature on 2 copies of the informed consent. The participant will keep one, and the researcher will keep the other to be filed with other project documentation and recordings (see section V of this document for specific security and protection measures pertaining to the informed consent forms). Upon completion of this process, the interviewee will receive the $25 incentive.

All interviews will be completely voluntary with no penalty for refusal or withdrawal. After informed consent forms have been signed, the researcher will announce the intent to begin recording, start the recorder, request the participant to choose a pseudonym, and proceed to conduct the interview. The interviews will be recorded via a digital voice recorder. Upon completion of the interview, the researcher will allow for any additional questions the participant may have, review the researcher contact information, and conclude the interview.

The recordings will be fully transcribed. An outside transcriber may also assist with transcriptions. The outside transcriber, if one is needed and used, will be required to sign a confidentiality agreement (see attached) prior to receiving any recordings for transcription. The verbatim transcripts will then be used for the final analysis. Pseudonyms will be used both in transcription of the interviews as well as when reporting the findings to protect the identities of the participants. Participants' names will not be stored with the recordings of their interviews with the informed consent being kept in the adviser's office and the recording being stored in the researcher's office and home.

Commonalities uncovered by prior research associated with similar phenomena will help guide the interviews to the point of saturation and redundancy while also providing a high level of information and detail about the participants' experiences.

**V. SPECIFIC RISKS AND PROTECTION MEASURES**

There is minimal risk to the participants of this study given the following protection measures:

Within 48 hours of a completed interview, the digital recording of the interview will be imported to Scott Eldredge's private, password-protected laptop computer. Both the digital recorder and the laptop will be held under lock and key and Mr. Eldredge's private residence, 1516 Greenbrier Ridge Way, Apt 1102 Knoxville, Tennessee 37909. The digital recording on the voice recorder will be immediately destroyed upon transfer to Mr. Eldredge's computer. As a backup, these recordings will also be saved to Mr. Eldredge's private, password protected university computer, housed in a locked office in 98 Communications Building. When a transcription is to be made, a copy of the digital interview file will be placed on a flash drive. The researcher or outside transcriber will then use the recording on the flash drive to make the transcription. The recording on the flash drive will then be destroyed by the transcriber immediately upon completion of the transcription. An electronic copy of the transcription will be placed on the flash drive. All other electronic copies of the transcription will be destroyed. The flash drive will be returned to Mr. Eldredge's private home office for future recordings. Electronic copies of the transcribed interview will be placed on Mr. Eldredge's private home and office computers within 48 hours of completion of the transcription, and the transcription on the flash drive will be destroyed.

Once transcription is completed, any hand written notes, any hard-copy transcriptions, and informed consent forms will be locked in Dr. Michelle Violanti's office (293 Communications Bldg., College of Communications & Information, University of Tennessee, Knoxville, TN 37996-0343). Consent forms will be kept for three years with only the researcher and his advisor (Dr. Violanti) having access to the forms.

The participants have the right to retract the information collected during the interview as noted in the informed consent form. The researcher will not transcribe any retracted information, and

any recording made prior to the withdrawal will be immediately destroyed. Participants in this study and their responses to interview questions will be kept confidential.

After transcription when quotations are being chosen for inclusion in the dissertation and subsequent academic publications, additional pseudonyms will be created to minimize the possibility that someone could identify a participant by virtue of the people to whom he refers in the interview.

Given the preceding security measures, and that interviews will be conducted in private areas where outside people are unlikely to hear the interview being conducted, there is minimal risk in conducting these interviews.

The researcher will not ask any questions related to, or intentionally seek to gather any information that may contain, the participants' protected health information (PHI). In the event that a participant chooses to relate PHI to the researcher, all information in this study is protected and kept confidential. PHI is subject to the same security measures as all other data collected. Therefore, there is minimal risk to the participant that any PHI would be shared outside of the interview.

Information in the recruitment announcements, the pre-screening of participants, and the informed consent all identify that questions regarding everyday interactions related to HIV will be asked. In addition, the HIV status of each member of the couple will be known to the other individual per the pre-screening questions. Given this, there is minimal risk to the participants of experiencing emotional distress during the interviews with respect to HIV status. However, the PI acknowledges that information related to HIV may be considered sensitive, and that even someone who is living with HIV may experience unanticipated emotional distress during the discussion of interactions where an HIV-positive status is present. Therefore, the PI will provide information regarding counseling services at the end of each interview to all participants regardless of whether they appear to have experienced emotional distress (see sample resources for Knoxville). Participants are also free to choose not to answer a question with which they are uncomfortable. Finally, prior to leaving the interview, anyone who has experienced a strong emotional reaction will be asked if he would like the researcher to contact medical or counseling personnel. These precautions should help minimize the risks associated with engaging in the actual interview.

**VI. BENEFITS**

There are several potential benefits to this study. To date, there is little exploration of how family members are impacted by a loved one's chronic, infectious illness, and this study will begin to help fill in the gap in the available scholarly research done to date in the area of uncertainty and illness. This research will increase the knowledge of how communication and romantic partnerships play a role in the management of chronic illness, and has the potential to help uncover ways in which social support can assist in facilitating positive relational outcomes for the individuals and positive health outcomes for the patient.

**VII. METHODS FOR OBTAINING "INFORMED CONSENT" FROM PARTICIPANTS**

The participants will each be presented with the informed consent form prior to the interview. The researcher will explain the topics of the interview; explain that the interview will be audio recorded, and that participation in the interview is strictly on a voluntary basis. The researcher will also explain that the participants have the right to retract the information obtained during the interview, and request the researcher protect the link between the information and the participant. The researcher will explain that the participant will not be asked about protected health information and will not be required to disclose protected health information. The researcher and the participant will sign the form, and the participant will be provided with a copy of the signed informed consent for their use and information. See attached Informed Consent Form.

**VIII. QUALIFICATIONS OF THE INVESTIGATOR(S) TO CONDUCT RESEARCH**

The researcher (Scott Eldredge) is a doctoral candidate entering his fourth year of study in the field of Communications Studies. He has conducted previous IRB-approved studies using similar interview methodology, including one about gay men's interactions with, and disclosures to, health care providers.

The faculty advisor, Dr. Violanti, is an Associate Professor in the School of Communication studies in UT's College of Communication & Information. She has her Ph.D. in Communication Studies from The University of Kansas; her M.A. in Speech Communication from The University of North Carolina at Chapel Hill; her B.A. in Communication Arts from Villanova University; and her B.S.B.A. in Finance from Villanova University. She is an established researcher in the field of communication studies. She has been with the department since 1995, and has taught 22 different classes. She is currently serving as chair of 4 different doctoral committees, and has previously chaired 10 other doctoral committees.

**IX. FACILITIES AND EQUIPMENT TO BE USED IN THE RESEARCH**

- One digital voice recorder.
- One flash drive.
- Scott Eldredge's university computer.
- Scott Eldredge's private home computer..

**X. RESPONSIBILITY OF THE PRINCIPAL/CO-PRINCIPAL INVESTIGATOR(S)**

***The following information must be entered verbatim into this section:***

**By compliance with the policies established by the Institutional Review Board of The University of Tennessee the principal investigator(s) subscribe to the principles stated in "The Belmont Report" and standards of professional ethics in all research, development, and related activities involving human subjects under the auspices of The University of Tennessee. The principal investigator(s) further agree that:**

1. **Approval will be obtained from the Institutional Review Board prior to instituting any change in this research project.**

2. **Development of any unexpected risks will be immediately reported to Research Compliance Services.**

3. **An annual review and progress report (Form R) will be completed and submitted when requested by the Institutional Review Board.**

4. **Signed informed consent documents will be kept for the duration of the project and for at least three years thereafter at a location approved by the Institutional Review Board.**

**XI. SIGNATURES**

ALL SIGNATURES MUST BE ORIGINAL. The Principal Investigator should keep the original copy of the Form B and submit a copy with original signatures for review. Type the name of each individual above the appropriate signature line. Add signature lines for all Co-Principal Investigators, collaborating and student investigators, faculty advisor(s), department head of the Principal Investigator, and the Chair of the Departmental Review Committee. The following information should be typed verbatim, with added categories where needed:

**Principal Investigator: _____**

**Signature: _____ Date: _____**

**Co-Principal Investigator:_____**

**Signature: _____ Date:_____**

**Student Advisor (if any): _____**

**Signature: _____ Date:_____**

**XII. DEPARTMENT REVIEW AND APPROVAL**

**The application described above has been reviewed by the IRB departmental review committee and has been approved. The DRC further recommends that this application be reviewed as:**

**[ ] Expedited Review -- Category(s): _____**

**OR**

**[ ] Full IRB Review**

**Chair, DRC: _____**

**Signature: _____ Date: _____**

**Department Head: _____**

**Signature: _____ Date:_____**

**Protocol sent to Research Compliance Services for final approval on (Date): _____**

**Approved:**
**Research Compliance Services**
**Office of Research**
**1534 White Avenue**

**Signature: _____ Date: _____**

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**For additional information on Form B, contact the Office of Research Compliance Officer or by phone at (865) 974-3466.**

# Appendix C: Verification of Informed Consent

**INFORMED CONSENT STATEMENT**
Uncertainty and Identity in Gay Male Couples Dealing with HIV/AIDS

**Introduction**
Thank you for taking time to participate in this study. The study's purpose is to explore gay couples' interactions when one individual is HIV-positive and the other is HIV-negative. During the interview, you will be asked to recall your personal experiences including your interactions with your partner and people outside the relationship, your thoughts about your partner and your relationship, your usage of online/social media, and advice you would give to others in a similar situation.

Your participation is voluntary. You may change your mind later or stop participating even if you've already given consent without penalty. If you provide information that you would like to later withdraw, the information you choose to withdraw will not be transcribed or used in any way in this study, and any recording associated with that information will be immediately destroyed. If you have any questions regarding the consent form, please do not hesitate to ask.

**Participant Involvement**
During the interview, you will be asked several open-ended questions regarding your personal experiences. You will be asked to think about specific instances, events, times, people, and places, and describe these instances. Depending upon your answers, the researcher may ask additional questions designed to get more detail on a particular situation you describe.

Each partner will be interviewed alone, separately where one partner cannot hear the other's interview, and immediately one after the other without any time in between to prevent discussion of the interviews before both interviews are completed. The interview for each partner will last approximately one to two hours. A recording will be made of the entire interview, and that recording will later be fully transcribed. You will be asked to identify yourself using a pseudonym on the recording to keep your answers separate and distinct from other participants. To maintain your privacy, when reporting this information, pseudonyms will be used, you will not be personally identified, no specific geographic or workplace information will be named, and no link will be made between you and the answers you have provided. Your name will not be stored or associated with the recording of your answers. Your identity will be known only to the researcher and his adviser. While your voice is considered personally identifiable information, only the researcher and an outside transcriber who has signed a confidentiality agreement will actually hear your voice.

**Risks**
Given the nature of your responses and the steps being taken to ensure confidentiality and protect the information, including your protected health information, you provide, participation in this study carries moderate risk of a breach of confidentiality and emotional distress. Because discussion of issues related to HIV may be potentially distressing to some individuals, information regarding counseling services will be provided at the end of the interview to all participants, thereby making counseling information readily available should you experience emotional distress during or after the interview.

_____ Participant's initials

**Benefits**

To date, there is little exploration of how family members are impacted by a loved one's chronic, infectious illness. Although this study will not be of immediate benefit to you, this study will begin to help fill in the gap in the available scholarly research done to date in the area of families and chronic illness. For your participation, you will $25 regardless of whether the interview is completed or not.

**Confidentiality**

The information in the study records will be kept confidential. Pseudonyms will be used in both transcribing the interviews as well as reporting the findings to protect the identities of the participants. Even with the use of pseudonyms, it is possible that references to others during your interview could identify you; to minimize this risk, pseudonyms will also be used for those to whom you refer in any published quotations from your interview. Within 48 hours of a completed interview, the digital recording of the interview will be imported to a private, university office computer kept within a locked office and having restricted access to a single researcher. The digital recording on the voice recorder will be immediately destroyed upon transfer to this computer and not stored with your informed consent signature. Once transcription is completed, any hand written notes, any hard-copy transcriptions, and informed consent forms will be locked in Dr. Michelle Violanti's office (293 Communications Bldg., College of Communications & Information, University of Tennessee, Knoxville, TN 37996-0343). Consent forms and other study documentation will be kept for three years in locked storage with only the researcher and his advisor having access to the this information.

**Contact Information**

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of participating in this study,) you may contact the lead researcher, Scott Eldredge, (865) 974-0696, seldredg@utk.edu, 293 Communications Building, University of Tennessee, Knoxville, Tennessee. If you have questions about your rights as a participant, contact the Office of Research Compliance Officer at (865) 974-3466.

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**Consent**

I have read the above information. I have received a copy of this form. By signing below, I confirm that I am at least 18 years of age, and I agree to participate in this study.

Participant's signature _____ Date _____

Investigator's signature _____ Date _____

UTK IRB Approval:
SEP 24 2013 - SEP 24 2014

# Appendix D: Institutional Review Board Approval

THE UNIVERSITY of TENNESSEE
KNOXVILLE
Office of Research & Engagement
INSTITUTIONAL REVIEW BOARD (IRB)

1534 White Ave.
Knoxville, TN 37996-1529
865-974-7697
fax 865-974-7400

DATE: September 24, 2013

IRB# 9211 B

TITLE: Uncertainty and Identity in Gay Male Couples Dealing with HIV/AIDS

Scott Eldredge
Communication Studies
293 Communications Bldg.
Campus - 0324

Michelle Violanti
Communication Studies
293 Communications Bldg.
Campus - 0324

The points of clarification you submitted to this office regarding the above-captioned project satisfied the concerns of the reviewers and the IRB thus, your project has been granted approval.

Approval is for a period ending one year from the date of this letter. Please make timely submission of renewal or prompt notification of project termination (see item #3 below).

Responsibilities of the investigator during the conduct of this project include the following:

1. To obtain prior approval from the Committee before instituting any changes in the project.
2. To retain signed consent forms from subjects for at least three years following completion of the project.
3. To submit a Form D to report changes in the project or to report termination at 12-month or less intervals.

The committee wishes you every success in your research endeavor. This office will send you a renewal notice on the anniversary of your approval date.

Sincerely,

Brenda Lawson

Brenda Lawson
Compliances

Enclosure

# VITA

Building on a background involving a 20 year communication-focused career in the private sector, Scott Allen Eldredge entered the University of Tennessee in the fall of 2010 to pursue a doctoral degree in Health Communication. As a relational scholar, Scott's research interests focus on those significant interpersonal relationships that are involved in our healthcare and overall well-being. Scott is an active member of the National Communication Association and the International Communication Association, and has presented his research at numerous regional, national, and international conferences. With two journal publications to his credit and several more under review, Scott has conducted research studies exploring nurse-patient interactions regarding pain management, the social experience of LGBT people when visiting the doctor, and health care experiences as triadic interactions involving the patient, the health care provider, and the patient's close family members. Scott's dissertation focuses on close relationships and chronic illness specifically exploring issues of intimacy, uncertainty, and identity in mixed HIV status, gay male couples. In addition to his research, Scott teaches courses in interpersonal communication, organizational communication, public relations, and communication theory. Scott earned his Bachelor's degree in Telecommunication from the University of Florida, his Masters in Advertising degree from Michigan State University, and is on track to earn his Ph.D. in August, 2014. Scott has accepted an offer to join the faculty at Western Carolina University in Cullowhee, North Carolina, beginning with the fall 2014 semester where he will be an Assistant Professor of Communication.