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A QUALITATIVE INQUIRY INTO THE EXPERIENCES OF PEOPLE LIVING WITH

HIV/AIDS FOR AN EXTENDED PERIOD OF TIME

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by

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ABSTRACT

The experience of living with a chronic illness such as HIV/AIDS is complex. The longevity of people living with HIV/AIDS is increasing and changing the medical and mental health care provision for these individuals. A qualitative approach was used to explore the lived experiences of long-term survivors of HIV/AIDS along three factors: (a) uncertainties, (b) stigma, and (c) coping. The research was guided by the constructivist paradigm and biopsychosocial approach. The methodology utilized was the constructivist grounded theory approach, which emphasizes simultaneous data collection and analysis. Semi-structured interviews were conducted with 10 participants who have been living with HIV/AIDS for a minimum of 10 years and who, at the time of the interview, were living in south Florida. The data were analyzed using open coding, focused coding, and theoretical coding. In addition, the constant comparative method was utilized throughout the data analysis process. The findings revealed that living as a long-term survivor of HIV/AIDS entails existing within an ongoing process of acceptance and living with this chronic illness. Such a process is often challenging and entails a constant reconstruction of goals, identity, and relationships. However, the process is facilitated by four interacting values of autonomy, belonging, resiliency, and hope that helped each person continue to accept and live with HIV/AIDS. Those who are able to continue to manage this process are able to live constructive, long lives with this chronic illness.

DEDICATION

To my mother,

my inspiration for life.

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To begin I would like to express my gratitude to each of my participants. Thank you for letting me into your lives and sharing with me your pain, hardship, strength, and love. I hope that your futures are bright and filled with joy and health. Without your help, I would have been lost.

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CHAPTER 1

INTRODUCTION

Human immunodeficiency virus (HIV) impairs the immune system and presents numerous problems for people living with HIV. HIV can be transmitted through unprotected sexual intercourse including oral sex with an infected person, through blood transfusions of infected blood by sharing HIV-contaminated needles or other sharp instruments, between a mother and her infant during pregnancy, in childbirth, and when the mother is breastfeeding (Centers for Disease Control and Prevention [CDC], 2011; World Health Organization [WHO], 2012). Anytime from 10 to 15 years after infection, HIV can develop into Acquired Immunodeficiency Syndrome (AIDS; AIDS Healthcare Foundation [AHF], 2008; WHO, 2012). AIDS is a disease that progressively reduces the effectiveness of the immune system, lowering its resistance to fight infection, in turn increasing the risk for opportunistic infections (WHO, 2010). Opportunistic infections are infections such as bacteria, certain viruses, and parasites that would usually not cause disease in a healthy immune system; however, in the weakened immune system of a person with HIV/AIDS such infections can cause devastating illness (CDC, 2011; WHO, 2012).

Opportunistic infections are the most common cause of death for people living with HIV/AIDS (CDC, 2011; WHO, 2012). Tuberculosis, the most common opportunistic infection, is the leading cause of death among people living with HIV worldwide (WHO, 2012).

Tuberculosis is responsible for killing nearly a quarter of a million people living with the virus each year. However, antiretroviral medications, which either stop or interfere with the reproduction of the virus in the body, can slow the progression of HIV (AHF, 2008; WHO, 2012). Some people living with HIV infection may not develop AIDS, or their HIV may take longer to progress into AIDS (WHO, 2012). Although HIV continues to be a chronic illness for which there is no cure, the longevity of those living with the virus continues to increase.

The HIV/AIDS epidemic was first recognized in the United States in 1981 when the increasing rates of Kaposi's sarcoma and pneumocystis pneumonia among gay men in New York and California (AHF, 2008; Cichocki, 2010) began to be noticed by medical personnel. Since the beginning of the epidemic, more than 576,000 people with AIDS have died in the United States (CDC, 2011). Over the past 30 years, HIV/AIDS has entered the public eye through the media, government-funded research, and law making. One area of focus for research has been stigma. Popular media, scientific research, and advocacy groups have been speaking out against the stigmatization of those living with HIV/AIDS. Stigma not only negatively affects the stigmatized individual, it also plays a role in the individual's access to necessary health care and impacts the effectiveness of service provision by public health programs (Sambisa, Curtis, & Mishra, 2010; Van Brakel, 2006). The consequences of stigma include delayed diagnosis and treatment, decrease in mental health, faster progression of the illness, continued participation in risky behavior, and delayed disclosure of HIV-positive status (Brashers et al., 2003; Emlet, 2006; Van Brakel, 2006). Since the beginning of the epidemic, public health programs have been working to combat stigma. However, the need for interventions and prevention programs to continue to address stigma systematically remains. At the beginning of the epidemic, a diagnosis of HIV meant that the disease would eventually, and rather quickly, progress into AIDS,

providing a certain death sentence. However, with increased treatment options, the longevity of people living with HIV has improved (WHO, 2012). Nonetheless, increasing the lifespan of those infected has introduced new obstacles and challenges, and HIV/AIDS continues to be a highly transmittable, stressful, and chronic illness. Thus, the need to understand better the uncertainties, the experiences of stigma, and the effective coping strategies continues to be crucial. Accordingly, the purpose of this study was to understand better the experiences of people who have lived with HIV/AIDS and develop a theory about how their identities and self-concepts shift through the progression of the illness.

Global HIV/AIDS

The HIV/AIDS epidemic is global and affects millions of people. Currently, 34 million people worldwide are estimated to be living with HIV, of whom 30.7 million are adults, 16.7 million are women, and 3.3 million are children under 15 years of age (WHO, 2012). In 2011, an estimated 2.5 million people worldwide were newly infected with HIV, of which 370,000 were children under 15 years of age. A total of 1.7 million people died because of AIDS, of whom 1.5 million were adults, and 230,000 were children under 15 years of age.

The highest prevalence rates of the epidemic are found on the African continent, with the highest rates in sub-Saharan Africa where an estimated 23.5 million adults and children are living with HIV (WHO, 2012). In 2011 in sub-Saharan Africa, 1.8 million adults and children were newly infected with HIV, and 1.2 million adults and children died because of AIDS. In addition, fewer than 40% of people living with HIV were aware that they were infected (WHO, 2010). However, in 2011, the region had the greatest increase of people, a total of 6,200,000, receiving HIV/AIDS treatment, up from 2,950,000 in 2008. Of the 1.4 million pregnant women living with HIV, about 58% were receiving antiretroviral medications in 2011, an increase from

45% in 2008. Lastly, infants and children born to HIV-positive mothers are being inadequately

diagnosed and treated.

The second highest rates of the epidemic are in South and Southeast Asia, with 4.0

million adults and children living with HIV and an estimated 280,000 new infections and

250,000 deaths due to AIDS reported in 2011 (WHO, 2012). Subsequently, Eastern Europe and

Central Asia have an estimated 1.4 million adults and children living with HIV, and there are an

estimated 900,000 in Western and Central Europe, 1.4 million in Eastern Europe and Central

Asia, 1.4 million in Central and South America, and 1.4 million in North America. Lastly, in

2011 in low- to middle-income countries, an estimated 7,000 people were infected each day

(WHO, 2012). Of those, 1,000 were children under 15 years of age. Of the estimated 6,000

newly infected adults, almost 51% of the infections were among women, and approximately 41%

were among young people between 15 to 24 years of age (WHO, 2012).

Globally, the number of HIV tests being administered has increased, with a total of 95

million people tested in 2010, which represents an increase of 23 million people tested since

2009 (WHO, 2012). However, prevention interventions continue to be insufficient, as most

people remain unaware of their diagnosis. In addition, the number of facilities providing HIV

testing and counseling continues to increase, along with an increase in the number of countries

adopting policies on HIV testing and counseling. However, the need for public health programs

to improve and better tailor testing, counseling, and preventative services to local contexts

continues to be a theme surrounding universal access to care. Overall, public policy and health

programs have positive outcomes in combating the epidemic. Nonetheless, as part of the

continued commitment to end the epidemic, programs need to address stigma and social

marginalization better and to work to reach those at highest risk for HIV infections including sex

workers, men who have sex with men, people with transgender identity, migrants, and intravenous drug users.

HIV/AIDS in the United States

As of 2009, 1,148,200 people in the United States live with HIV/AIDS, of whom 77% are male and 23% are female (CDC, 2011). Of the infections among adolescents and adults, 55% are due to male-to-male sexual contact, followed by 25% due to heterosexual contact and 16% due to intravenous drug use. The remaining reported risk factors of infection include hemophilia, blood transfusion, prenatal exposure, and other factors not reported or not identified at time of testing. The virus is most widespread in the African American community, followed by the Caucasian community and the Hispanic/Latino community. The rate of new HIV infection for African American men is six times as high as that of Caucasian men, and the rate for African American women is nearly 15 times as high as that of Caucasian women (CDC, 2011). African Americans account for 44% of those living with HIV/AIDS; Caucasians at 32%; Hispanics or Latinos at 20%; and Asians, Native Hawaiians, and other Pacific Islanders, American Indians, and Alaskan Natives at less than 3% (CDC, 2011). Approximately 20% of those living with HIV/AIDS are between 40 and 49 years old. Additionally, 27% are between 30 and 39 years old, 39% are between 13 and 29 years old, and 11% are over 50 years old. The remaining 3% are newborns to 13-year-old children.

In addition, each year an estimated 47,500 people are newly infected with HIV (CDC, 2011). The most severely affected groups are gay, bisexual, and other men who have sex with men (MSM) of all races, with MSM accounting for 61% of all new HIV infections in the United States each year. MSM account for the largest number of new infections each year and are the only risk group in the United States whose number of new HIV infections has been increasing

annually since the early 1990s. Individuals infected through heterosexual contact account for

27% of new infections each year, and intravenous drug use accounts for 9% of new infections

(CDC, 2011). Overall, the annual number of newly infected people with HIV has remained

stable; however, it is estimated that one in five people living with HIV continues to be unaware

of their infection (CDC, 2011).

Conceptual Paradigm

This study used the constructivist paradigm as the conceptual framework. Ontologically,

constructivism emphasizes the relativist position, which assumes that multiple socially

constructed realities exist versus a single objective reality (Appleton & King, 2002; Denzin &

Lincoln, 2005; Ghezeljeh & Emami, 2009; Ponterotto, 2005). Accordingly, the goal of

constructivism is to understand how reality is constructed and interpreted by an individual based

on his or her lived experience within a social context (Ponterotto, 2005). Also, the lived

experience of individuals can sometimes be outside immediate awareness but can be brought to

consciousness through participant and researcher relationship and interactions (Appleton &

King, 2002; Denzin & Lincoln, 2005; Ghezeljeh & Emami, 2009; Ponterotto, 2005).

Epistemologically, constructivism emphasizes the subjective interrelationship between the

researcher and participant in the construction of meaning (Denzin & Lincoln, 2005; Ponterotto,

2005). Thus, constructivism accentuates a non-hierarchical relationship between the participant

and researcher as well as the necessity for the researcher to acknowledge his or her own values

and to be transparent throughout the research process, as these influence construction and

interpretations of the lived experience. In addition, constructivist epistemology requires

interpersonal contact between the participant and researcher that is essential to capturing the

lived experience (Denzin & Lincoln, 2005). Thus, the interview is often where the co-

construction of knowledge takes place.

This study used the biopsychosocial approach in order to aid participants in bringing their experiences of living with HIV/AIDS to consciousness and to assist me as the researcher in broadening the analytical lens. Engel (1977) proposed the biopsychosocial model, which states that in order to develop a better and more inclusive understanding of health, biological, psychological, and social factors need to be taken into account, as they all play a significant role in human functioning. The biopsychosocial model provides a valuable framework for understanding the complexities of living with HIV/AIDS. The model attends not only to the individual stressors within the biological, psychological, and social dimensions of experience but also to how all three factors interrelate to explain the complexities of living with a chronic illness, including what people think and believe and how they react and behave. Through thinking about the complex self, the environment, and their daily experiences, people construct their own knowledge and reality (Bandura 1989; Ponterotto, 2005). Similarly, according to social-cognitive theory, how people think and feel, how they perceive and what they believe about themselves, as well as the goals and intentions they hold influence behavior (Bandura, 1989). Biology also influences cognition and behavior, and all three are modified by social or environmental influences. In addition, the roles people hold in society and the way they are perceived influence people's self-perceptions and other's perceptions and reactions. Overall, however, people have control over their own behaviors, motivation, goals, and development.

As cognition, biology, and daily experiences within a social context seem to be critical pieces of reality and its construction, the current study aimed to understand the complex realities of living with HIV/AIDS through the multidimensional lens of the biopsychosocial approach. By incorporating the biopsychosocial model through interview protocols, the current study aimed

to develop a theory about how identity and self-concept of people living with HIV/AIDS (PLWHA) shift through the progression of the illness, specifically exploring the three major themes of uncertainty, stigma, and coping.

Methodological Approach

A qualitative methodology was utilized for the current study. Qualitative researchers use a naturalistic approach to seek to understand phenomena in settings that are not manipulated but rather are context-specific and reflect real world phenomena (Denzin & Lincoln, 2005). In addition, qualitative inquiry allows the researcher additional freedom and flexibility to learn about the experiences of the participants.

Thus, the current study used constructivist grounded theory. Glaser and Strauss (1967) described grounded theory as theory about the world that is derived from gathered data. Constructivist grounded theory further emphasizes the role of the researcher, stating that "people construct grounded theories through past and present involvement and interactions with people, perspectives, and research practices" (Charmaz, 2006a, p. 10). Accordingly, it is important to understand that the derived theory is a researcher's interpretation of participants' reported perspectives of the world (Charmaz, 2006a).

Researchers using grounded theory can utilize several data collection methodologies to collect detailed information and to set a strong basis for data analysis (Charmaz, 2006b; Denzin & Lincoln, 2005). Grounded theory emphasizes simultaneously collecting and analyzing data, writing memos throughout the research process, and cycling through the data in order to reach data saturation (Charmaz, 2006b). Most importantly, the researcher questions not only the experiences of participants but also how and why participants construct the meaning of their experiences. Lastly, through the process of data gathering and analysis, the researcher comes to

learn that he or she is part of the theory's development, not solely providing an explanation of the participants' experience. I conducted this study to begin developing a theory about how identity and self-concept of PLWHA shift through the progression of the illness.

Need for the Study

HIV/AIDS research is conducted in laboratories, in people's homes, and in care provision centers by researchers within the medical, biomedical, sociology, anthropology, and psychology fields. Although worldwide both quantitative and qualitative methodologies are being used, within the United States qualitative studies on HIV/AIDS, specifically on long-term survivors of HIV/AIDS, are less frequently conducted. One objective of the current study, therefore, was to use qualitative methodology to add to the knowledge base, specifically in terms of living with HIV/AIDS for an extended period of time.

In addition, this study has the potential to (a) influence the design of interventions that can enhance the life satisfaction of PLWHA, (b) improve the professionals' knowledge of problems associated with living with a chronic illness, (c) increase the mental health provider's clinical understanding of the uncertainties of everyday experience faced by PLWHA, (d) contribute to more effective continuation of care outcomes by sensitizing care providers to a better grasp of the impacts of stigma, and (e) integrate the information to aid in the development of prevention programs that focus on eliminating stigma and on coping with uncertainties.

Purpose

The purpose of this study was to understand better the experiences of long-term survivors of HIV/AIDS and begin developing a theory about how identity and self-concept shift through the progression of the illness. This includes learning about the participants' experiences of

stigma as well as their approaches to uncertainties, decision-making, reconstructing life goals and plans, identity construction, meaning making, and coping strategies.

Research Questions

1. What is the lived experience of long-term survivors of HIV/AIDS?

2. Over time, how does a person incorporate his or her HIV/AIDS status when constructing identity?

3. Over time, how do long-term survivors of HIV/AIDS construct and reconstruct their relationships, life plans, and self-concepts?

Definitions

HIV: "The human immunodeficiency virus (HIV) is a retrovirus that infects cells of the immune system, destroying or impairing their function" (WHO, 2012, p. 1).

AIDS: "The most advanced stage of HIV infection is acquired immunodeficiency syndrome (AIDS). It can take 10-15 years for an HIV-infected person to develop AIDS; antiretroviral drugs can slow down the process even further" (WHO, 2012, p.1).

Extended period of time: In the current study, this is operationally defined as living with HIV/AIDS for at least 10 years.

Biopsychosocial approach: In the current study, it is an approach used to gain a more inclusive understanding of the experiences of long-term survivors of HIV/AIDS, through analysis of biological, psychological, and social factors that play a significant role in human functioning (Engel, 1977).

Uncertainty: Uncertainty is recognized as a state of feeling doubt, stress, and anxiety that often can cause people to experience psychological discomfort or pain (Brashers et al., 2003).

Stigma: Stigma is defined as an undesired difference that can alienate the individual and which often carries a burden of additional discriminating representations placed on the individual by others (Goffman, 1963).

Coping: Coping is operationally defined as a strategy aimed at reducing stress or developing behaviors that help manage a problem.

CHAPTER 2

LITERATURE REVIEW

Worldwide studies on HIV/AIDS with widely varied points of focus have been conducted

since the beginning of the epidemic. Thus the body of literature on HIV/AIDS is extensive, and

the knowledge expands the lens through which the epidemic is viewed. The following review

looks at research mostly conducted within the United States and some research from outside the

United States to provide a glimpse of the multitude of concerns people living with HIV/AIDS

experience. In general, the most commonly reported concerns are the experiences of stigma,

feelings of uncertainty, decision-making, re-evaluation of life goals and plans, and development

of good coping strategies. Although increasing numbers of people are living longer, they are still

coping with a complex terminal illness and are faced with a variety of challenges. The

challenges that arise are a combination of medical, psychological, and social factors that

influence the progression of the disease, quality of life, and ability to cope. The biological,

psychological, and social factors associated with HIV/AIDS are embedded throughout research

conducted in the field.

Biopsychosocial Approach

Engel (1977), who theorized about the biopsychosocial model for medical issues,

proposed that, in order to develop a better and more inclusive understanding of health, the

psychological and social factors that play a significant role in human functioning need to be

taken into account. Engel did not minimize the role of the biological factor but rather incorporated it into the model.

The biopsychosocial model includes biological, psychological, and social components as a framework for understanding the ill patient (Engel, 1977). Specifically, the biological component seeks to understand how the cause of the illness stems from the functioning of the individual's body or changes that occur during the progression of the illness. Although the biological component of HIV/AIDS is evident throughout the progression of the disease, including numerous opportunistic infections and chronic pain conditions, psychological and social concerns often aggravate the physical state (Brashers et al., 2003; Feist-Price, 1997; Marcus, Kerns, Rosenfeld, & Breitbart, 2000; Remien, Rabkin, Williams, & Katoff, 1992).

The psychological component looks for potential psychological causes for health problems (Engel, 1977; Feist-Price, 1997). Examples of psychosomatic causes include insurmountable losses, stressors, and uncertainties such as a future with lack of independence, loss of relationships, loss of an acknowledged lifestyle, and fear of opportunistic infections; impacts of pain of depression and anxiety; and financial struggles (Engel, 1977; Feist-Price, 1997; Marcus et al., 2000; Remien et al., 1992).

Finally, the social component of the biopsychosocial model investigates the influence that social factors such as culture, religion, poverty, stigma, and social isolation have on physical and mental health (Engel, 1977; Feist-Price, 1997). For example, because of stigma, HIV-positive individuals often see themselves as outcasts of society, which increases their feelings of rejection and hopelessness, and increases their level of stress, which in turn results in a faster progression of HIV into AIDS (Plattner & Meiring, 2006).

The dimensions of the biopsychosocial model are also important in clinical practice. For

people living with HIV/AIDS who seek psychotherapy, conducting a thorough biopsychosocial assessment is crucial for successful service provision (Rubenstein & Sorrentino, 2008). An accurate biopsychosocial assessment that addresses the impact HIV/AIDS has had, and continues to have, on an individual allows the clinician to address specific problems, create appropriate goals, and use appropriate interventions and treatment (Marcus et al., 2000; Rubenstein & Sorrentino, 2008). Specifically, a good biopsychosocial assessment will also incorporate how people feel and what they believe about themselves, the multitude of uncertainties these people face, experiences of stigma, and coping skills.

Uncertainty

Uncertainty is recognized as a state of feeling doubt, stress, and anxiety (Brashers et al., 2003) that often causes people to experience psychological discomfort or pain. Although uncertainties are experienced by everyone, people with chronic illness tend to find them more common.

A qualitative study conducted in Namibia, one of the five countries in the world most affected by HIV/AIDS, explored meaning making, or the process of how HIV-infected individuals make meaning of life after learning their diagnosis (Plattner & Meiring, 2006). The study supports that when dealing with the stressors and uncertainties associated with living with HIV, people go through a process of re-evaluating their lives. Accordingly, the process of meaning making is complex, including the evaluation of numerous uncertainties and the impacts of life satisfaction, and the results of the evaluation can be different for each person.

The often complicated and unpredictable course of HIV can result in numerous uncertainties for those infected (Brashers et al., 2003). Although uncertainty diminishes over time, the level or number of uncertainties increases once the illness returns or worsens, as well as

when someone is awaiting a diagnosis. Brashers et al. (2003) also argued that when someone's HIV treatment is working or prognosis is improving, he or she has to renegotiate several areas of live such as looking toward the future, renegotiation of relationships and roles within them, and personal identity. Thus, with the progression of the disease, the amount of uncertainty diminishes, but the potential for new uncertainties is still present.

Because PLWHA often are awaiting a new diagnosis or to hear the course their illness is taking, they have many potential sources of uncertainty with which they must cope. Some of the most common uncertainties these people face are due to (a) the ambiguity of their diagnosis, (b) treatment acquisitions and medication safety, (c) patterns of prognosis, (d) issues of identity and decision making, and (e) social implications (Brashers et al., 2003).

Regarding ambiguities of diagnosis, people living with HIV/AIDS report concerns about fluctuating CD4 cell counts and viral load counts that indicate the stage of the disease a person is in at a given time (CDC, 2011). CD4 cells are white blood cells that fight infection and help identify the strength of the immune system, and the viral load is the number of copies of HIV in the blood. Knowing both counts helps a person monitor and guide HIV treatment and predict how the illness may progress. Being unsure of the stage of the disease causes a lot of uncertainty about the current state of health and about the prognosis (Brashers et al., 2003). In addition, as opportunistic infections are always a great concern for PLWHA, they often impact prognosis and increase uncertainty. Uncertainty can also be caused by confusion about which symptoms are caused by the progression of HIV and which are related to a change in medication. In addition, PLWHA express significant concerns regarding access to health care, paying for medications, qualifying for disability, and the effects that new, often unproven, medications may have on the body. Finally, with the existence of antiretroviral therapies that extend lives, there is an

increased concern regarding the long-term side effects of the medications (Giles, Hellard, Lewin, & O'Brien, 2009; Volberding, 1999).

The social and personal implications of living with HIV/AIDS involve uncertainties surrounding identity dilemmas, relationships, and disclosure. Disclosure of HIV status is a very significant event in the life of an HIV-positive person (Brashers et al., 2003; Emlet, 2006; Varas-Diaz, Toro-Alfonso, & Serrano-Garcia, 2005) and is often associated with numerous uncertainties such as whom to disclose to, and how and when to disclose. This is a stressor because a person does not know if he or she will be rejected and ostracized or accepted by those to whom he or she is disclosing (Brashers, Neidig, & Goldsmith, 2004; Derlega, Lovejoy, & Winstead, 1998). In addition, as the individual often can feel ashamed for being HIV positive, the unpredictability of people's reactions to the disclosure is an additional stressor (Brashers et al., 2004; Emlet, 2006; Shippy & Karpiak, 2005; Wilson & Moore, 2009).

Concealing one's status, however, is often associated with low levels of perceived social support and loneliness, and revealing one's status can prevent a partner from becoming infected and serve as a means of accessing resources and support (Emlet, 2006; Holt et al., 1998). In a qualitative study conducted by Holt et al. (1998) participants reported that although disclosure to significant others and family members was a significant stressor, those who delayed revealing their status experienced more social isolation, additional uncertainties, stress, and guilt. Those who informed others of their status reported experiencing fewer uncertainties and less stress related to non-disclosure and a sense of increased control over own life. Accordingly, making the decision to reveal one's status is also associated with acceptance and adjustment to living with HIV/AIDS (Holt et al., 1998).

Decision-making often proves to be very complex; sometimes the well-being of children or spouses takes precedence over the infected person's health (Brashers et al., 2003). This is especially true for women living with HIV/AIDS. Women who are pregnant and HIV-positive often find that decision-making affects not only their well-being but also the health of their children. These women make decisions about treatment, the future, finances, and relationships as well as with the possibility of the death of an HIV-infected child (Giles et al., 2009). For example, a study conducted in Australia (Giles et a., 2009) found that the primary concern for women living with HIV was the care of their children, specifically preventing HIV transmission and hoping for their children's health, followed by the minimization of the children's experience of stigma. These women also were concerned about being mothers, which was heavily influenced by the women's preexisting societal views that brought about uncertainties in their decision-making. The women also reported the importance of gathering information about HIV from reliable sources including other women living with HIV who had children, support groups, HIV literature, and doctors. Throughout the decision-making process, women applied the costs and benefits approach, looking at the risks and benefits of making decisions.

Feeling blamed for becoming infected with HIV/AIDS, being blamed for transmitting HIV to their own children or partners, and blaming themselves for becoming infected are common experiences of many women living with HIV/AIDS (Lather & Smithies, 1997). Subsequently, reconciling of identity, coming to terms with being diagnosed with HIV, and having to reconstruct the future are all factors that for women bring much uncertainty, suffering, and difficult decision-making.

Women also experience gender inequality that in certain sociocultural contexts places women in situations where they are unable to negotiate safe sex (Longfield, Glick, Waithaka, &

Berman, 2004; McCreary et al., 2008). In turn, this increases the risk of HIV transmission

(Lather & Smithies, 1997; McCreary et al., 2008). For example, in Malawi, a country in sub-

Saharan Africa where poverty is widespread, condom use is discouraged, and it is socially

accepted that older men have sexual intercourse with significantly younger girls and have

multiple partners, women in Malawi are placed at higher risk of HIV infection (McCreary et al.,

2008). Finally, because of poverty, men often relocate and commonly have sexual relations with

other women, which places them at greater risk for infection. Thus, economic factors impact

HIV transmission, prevention, treatment, and decision-making (Bandali, 2011; Lather &

Smithies, 1997; McCreary et al., 2008).

The consequences of economic factors that impact HIV often place people in positions

that require them to make difficult decisions regarding retaining or gaining resources simply to

survive. A qualitative study conducted in Mozambique found women and men exchanging sex

for money, food, transportation, shelter, and various gifts (Bandali, 2011).

Stigma

One of the most significant and constant challenges PLWHA must face is stigma. The

effects of stigma are inescapable and similar even across cultures (WHO, 2010).   Brashers et al.

(2003) posited that stigma may be a larger concern for PLWHA compared to people living with

other chronic illness. As such, studying stigma can have important implications for medical and

mental health care provision, effective interventions, and in understanding the psychosocial

problems related to living with HIV/AIDS.

Goffman (1963) identified three different types of stigma. The first he termed

abominations of the body, the second *blemishes of individual character*, and the third *tribal*

stigma. When describing abominations of the body, Goffman referred to abnormalities of the

body or physical characteristics that are not commonly seen every day. For PLWHA, few physical abnormalities are visible in the stages of HIV but are often quite visible in AIDS patients, including lesions of Kaposi's sarcoma and tremendous weight loss. Blemishes of individual character (Goffman, 1963, p. 4) include negatively viewed or radical behaviors such as unprotected sexual intercourse, mental illness, and an alternative sexual orientation. Finally, tribal stigma (Goffman, 1963, p. 4) refers to discriminations that are passed on through generations. Such discriminations may be against an individual's ethnicity, nationality, and religion. Goffman described such characteristics as differences that others view as undesirable and that can alienate the individual.

As relevant as Goffman's description of stigma was in 1963, the description continues to be applicable in today's research (Emlet, 2006, 2007; Varas-Diaz et al., 2005). Goffman stated that stigma encompasses a variety of social situations and experiences and continues to be perpetrated by individuals as well as society. Because an individual can be stigmatized due to a variety of factors, such as the physical features they possess, individual characteristics, or social factors, stigma often has a significant influence on a person's identity.

Stigma not only attributes negative stereotypes to PLWHA but also results in negative evaluations of their lifestyles, contributes to them being rejected from their communities, and leads to them experiencing active discrimination or physical hurt (Varas-Diaz et al., 2005; Zaccagnini, 2009). The devastating consequences of social stigma include depression, isolation, social exclusion, problematic access to health services, anxiety, reevaluation of sexual activities, and deterioration of relationships, both personal and professional (Kalichman, Nachimson, Cherry, & Williams, 1998; Varas-Diaz et al., 2005). This continuation of stigma can lead to the reduction of HIV testing, late diagnosis, late disclosure of HIV-positive status to partners, and

additional environmental stressors (Wilson & Moore, 2009). Also, the lack of access to service and outreach were commonly noted concerns of the community, as were problems with social networks such as family, friendships, and sexual partners.

AIDS service organizations, community-based organizations, and departments of health are just some sites established to disseminate HIV/AIDS information and provide care for PLWHA (Shippy & Karpiak, 2005). While they fight a constant battle to eliminate stigma, they continue to face many challenges. It is a sustained challenge to eliminate stigma in society, and PLWHA often continue to internalize the stigma and therefore perceive their disease to be highly stigmatizing (Buseh, Kelber, Hewitt, Stevens, & Park, 2006; Lee, Kochman, & Sikkema, 2002). The stigma of living with HIV/AIDS increases if the virus has been transmitted through male-to-male sexual contact, intravenous drug use, or unprotected sexual intercourse, as compared to those whose transmission route was through a blood transfusion or mother-to-child transmission (Berger, Ferrans, & Lashley, 2001; Reidpath & Chan, 2005). In addition, Goffman (1963) pointed out that stigma specific to cultural values or ethnicity as well as the public's perception of HIV/AIDS can alter the impact stigma has on people living with this disease (Buseh et al., 2006). A qualitative study conducted in China (Sabin et al., 2008) found that people living with HIV reported that stigma was the most common barrier in their adherence to antiretroviral medication regimens. Because of the fear of being stigmatized at work, fear of disclosure of HIV status, and fear of stigma being directed toward the family members of the HIV-infected individual, participants reported hiding or disguising their medications and delaying their regimen. In addition to stigma being a barrier to adhering to a medication regimen, other common barriers include mental health issues such as depression and loss, financial hardships such as depending on others for financial help, and lack of employment.

Again, the decision to disclose one's HIV-positive status is often viewed as being accompanied by uncertainty (Brashers et al., 2004; Emlet, 2006; Shippy & Karpiak, 2005; Wilson & Moore, 2009). Disclosure is associated with the belief that once status is disclosed, the HIV-positive individual will experience increased stigmatization (Buseh et al., 2006). In turn, the fear of being stigmatized affects people's willingness to disclose, increases protection or secrecy over their status, and diminishes their sense of self-worth or self-image. Due to such concerns of stigmatization, many people refrain from disclosure, and some of those who do disclose their status regret doing so because they feel judged and their relationships often grow more distant. In addition, disclosure has been linked with having an impact on identity, including an individual's self-concept, and the construction of a new identity that incorporates being HIV positive (Frye et al., 2009). Although some individuals have reported that disclosure does not impact their identity, others have reported that being HIV positive is part of their identity, and in concealing their status, they felt untrue to themselves. Finally, some individuals have chosen to disclose publically, while others have chosen to disclose only to specific individuals, such as potential sex partners.

Social perceptions of and behaviors toward HIV/AIDS impact the mental and physical well-being of those living with HIV/AIDS. For instance, Buseh et al. (2006) showed that blaming people living with HIV/AIDS for contracting the virus or treating them like outsiders contributes to the branding impacts of stigma. Also, perceived stigma, a gamut of negative public attitudes towards HIV/AIDS, and uncertainties surrounding disclosure increase a negative self-image of those living with HIV/AIDS. Finally, as the person internalizes stigma, his or her self-image and satisfaction with life decrease.

Coping

Living with HIV/AIDS and the subsequent possible diminished life satisfaction, numerous uncertainties, and experiences of stigma are often very stressful. Over time, stress can weaken the immune system and is often associated with a more rapid progression of the virus (Moskowitz, Hult, Bussolari, & Acree, 2009). Also, the duration and type of stress influence how a person will respond to stress (Carver et al., 1993; Penninx et al., 1998). For these reasons and because inadequate coping can lead to risky sexual behaviors (Tate, Van Den Berg, Hansen, Kochman, & Sikkema, 2006), it is crucial for PLWHA to develop appropriate and useful coping mechanisms. In general, people respond better to stress if they use humor, hope, and spiritual coping and if they accept the diagnosis instead of denying illness or avoiding help (Carver et al., 1993; Folkman, 1997).

Cultural factors such as ethnicity, socioeconomic status, and unemployment are also important when examining coping techniques, effectiveness of social support, and stigma (Brown & Sankar, 1998; Tate et al., 2006). In a study conducted by Tate et al. (2006), African American men expressed more need for social support than Caucasian men. However, African American men expressed higher levels of stress than Caucasian men, which could be explained by higher levels of stigma attributed to homosexuality and racial discrimination not experienced by Caucasian men (Tate et al., 2006; Wilson & Moore, 2009). Increased stress also has been identified in people with HIV/AIDS of low socioeconomic status and those who tend to have insecure attachments with others (Koopman et al., 2000; Stein & Rotheram-Borus, 2004). Also, individuals who have limited or ineffective social support tend to experience higher levels of stress and anxiety (Kelly et al., 1993).

Along with stress, the anxiety that is experienced by PLWHA can often be a barrier to coping. Reducing anxiety and providing more information about the illness have been identified as areas that care providers can use to help manage some of the uncertainties and the anxiety associated with chronic illness (Mishel, 1990). Another important factor that relates to levels of anxiety and affects coping, social support, and depression is the disclosure of a person's sexual orientation (Foley, Skurnick, Kennedy, Valentin, & Louria, 1994; Mosack, Abbott, Singer, & Weeks, 2005). Gender is also an important factor that influences coping. Specifically, when disclosing sexual orientation, compared to heterosexual or gay men, heterosexual or bisexual women experience more symptoms of stress and anxiety (Mosack et al., 2009).

Lazarus and Folkman (1984) identified two coping strategies: problem-focused and emotion-focused (Carver, Scheier, & Weintraub, 1989; Stein & Rotheram-Borus, 2004). The problem-focused coping changes the source of stress or develops behaviors that help manage the problem (Pakenham, Dadds, & Terry, 1994; Stein & Rotheram-Borus, 2004). The emotion-focused coping reduces the stress through avoidant behaviors. Pakenham et al. (1994) showed that problem-focused coping lowers levels of stress, as do emotion-focused coping strategies such as optimism or emotional regulation. Problem-focused coping strategies also increase better health behaviors and physical well-being over time (Moskowitz et al., 2009). Additionally, HIV-positive individuals on a regimen of highly active antiretroviral therapy and positive reappraisal techniques report better mental health outcomes. Emotion-focused coping strategies are associated with lowering the emotional or mental wellbeing of PLWHA (Lobel, Yali, Zhu, DeVincent, & Meyer, 2002) and also impacting physical health and increasing participation in risky behaviors (Moskowitz et al., 2009; Pakenham et al., 1994; Terry, 1994). Alcohol or drug use and personal and social isolation are identified as ineffective coping

strategies that do not result in better physical or mental health outcomes (Moskowitz et al., 2009).

Turner-Cobb et al. (2002) found that people who are better adjusted to their chronic illnesses such as HIV/AIDS are those who, instead of denying their illness, deal directly with the stressors that it brings. Some effective coping mechanisms include positive social support, peer support groups, seeking information to manage the virus, following medication regimens, implementing the help of a caseworker, seeking mental health services, implementing the help of a caretaker to help with daily activities, and seeking organizational support (Moskowitz et al., 2009; Turner-Cobb et al., 2002). Positive thinking, or a positive state of mind, also often is associated with better adjustment and coping (Folkman, 1997). In addition, adherence to medication regimens, although very complex, plus a healthy attachment style increase adjustment to living with HIV/AIDS (Turner-Cobb et al., 2002).

Spirituality is an important factor regarding HIV/AIDS and coping. In an all-female study conducted by Kaplan, Marks, and Mertens (1997), participants reported spiritual coping to be effective in helping them come to terms with their HIV-positive status as well as emotions regarding the future of their children. Women are often stigmatized because they are blamed for infecting their children with HIV (Chung & Magraw, 1992), but women who embrace spiritual and religious faith reported to adjust more easily to their HIV status and their continued personal growth (Kaplan et al., 1997). It is important, however, to note that spiritual or religious coping is not effective for everyone. The type of problem, level of depression or anxiety, amount and type of religious participation, and the personality of the individual are most often the factors that influence spiritual or religious coping (Lilliston & Klein, 1991).

Finally, to eliminate stress and uncertainties as well as to gain information, increasing numbers of people are turning to the Internet as a source of information. Kalichman et al. (2006) found that many individuals use the Internet as a source of HIV/AIDS and other health-related information. Seeking information on the Internet is part of problem-focused coping, but selecting and avoiding particular pieces of information are emotion-focused coping strategies (Carver et al., 1989; Stein & Rotheram-Borus, 2004). Such avoidance may put the person at risk for misleading or harmful information regarding treatment and progression of the illness (Kalichman et al., 2006). Kalichman et al. (2006) also found that the African American participants in their sample reported decreased use of the Internet as compared to the Caucasian participants. However, the African American participants who used the Internet believed the information to be more credible than the Caucasian participants believed it to be.

Although the limitations of the Internet for searching health information are evident, several benefits exist in using the Internet for this purpose. A significant benefit is that the information is widely spread and easily accessible, providing people with coping resources such as peer support websites (Kalichman et al., 2006). Also, the range of information available can help people access health benefits and even encourages people to participate more actively in caring for themselves and in coping with their illness.

A qualitative study (Reeves, 2000) exploring the impact of Internet use on coping with HIV, revealed that the Internet promotes empowerment, augments social support, and facilitates helping by others. Participants reported that being able to access HIV/AIDS-related information on the Internet gave them a sense of empowerment or hope that they can have control over their lives. Participants also felt more knowledgeable about their condition, which allowed them to make more informed decisions about their health care, and increased their confidence in having

the resources to accomplish their own goals. The Internet was also described as a good source of social support, especially for those who were home-bound.   Lastly, being able to use the Internet to communicate with others by seeking or providing support was reported as a good coping strategy.

CHAPTER 3

RESEARCH METHODOLOGY

This research was conducted using qualitative methodology, specifically the constructivist grounded theory approach. Because living with HIV/AIDS is a complex and sensitive topic, I worked to develop rapport with the participants prior to and during the interview process, providing a comfortable environment free of threat in order to gain insight into the inner world of these 10 individuals. Because grounded theory emphasizes simultaneous data collection and analysis, an audit trail or a transparent description of the research steps taken from the start of a research project to the development and reporting of the findings was recorded throughout the process.

Philosophical Paradigm

Using the constructivist grounded theory approach, I attempted to explore how the participants construct their own realities on a daily basis while living with HIV/AIDS for an extended period of time. One of my assumptions was that, over time, people attribute meaning to events in their lives. Specifically, those who are living with a chronic illness such as HIV/AIDS constantly reevaluate their life goals and daily living. Through the participants' stories, I gained insight into the process of how the participants construct their own realities.

Through the use of grounded theory, my objective was to understand better the experiences of long-term survivors of HIV/AIDS and begin to construct a theory grounded not in

preexisting theories but rather in the data gathered (Glaser & Strauss, 1967). Several

components set grounded theory apart from other qualitative methodologies including the

constant comparative method, the construction of analytic codes, theory development during

each phase of data collection and analysis, memo-writing, and theoretical sampling. The

methodology of the current study aimed to meet these components of grounded theory. In

addition, constructivist grounded theory "assumes that any theoretical rendering offers an

interpretative portrayal of the studied world, not an explicit picture of it" (Charmaz, 2006a, p.

10). This approach does not just emphasize how participants viewed a particular situation but

stresses that the final theory is an interpretation influenced by the researcher's views. "The

constructivist approach means learning how, when, and to what extent the studied experience is

embedded in larger and often hidden positions, networks, situations, and relationships." Thus,

during the analysis of the data, the researcher must remember the context of the analysis,

including time, culture, place, and situation.

Finally, the constructivist approach emphasizes the need for the researcher to be aware of

his or her own preconceived notions and how these affect the research process (Charmaz,

2006b). Thus, the researcher needs to be reflexive and transparent about his or her own

assumptions and interpretations and to understand that the researcher's views influence how he

or she sees the data and the research process.

Researcher-as-Instrument

I am a 31-year-old Caucasian woman who is currently pursuing a doctoral degree in

counseling psychology. I am a first-generation college student and an immigrant to the United

States from Eastern Europe. Before coming to Indiana to pursue my current degree and then to

Florida to complete my internship requirement, I lived in New York City for 15 years.

Beginning in my sophomore year of high school, I participated in AIDS Walk NYC for seven consecutive years by collecting donations. Walking for this cause sparked my interest in HIV/AIDS prevention.

During my sophomore year of college, I wanted to gain experience in research and was offered the opportunity to work on a National Institute of Mental Health funded HIV/AIDS prevention research project at Hunter College. The topic immediately sparked my passion for helping underserved populations and humanitarian affairs, and I continued to work on this project for five years. As the senior research associate on the project, I utilized quantitative methods and conducted extensive qualitative interviews. This disease had affected all participants in the study directly, either through knowing someone who was infected or through having HIV/AIDS themselves. Although I have never personally known anyone with HIV/AIDS and am HIV-negative myself, I connected and empathized with every individual I encountered in the study. When talking to these individuals, I was touched by their lived experiences in relation to the stigma they endured. I was also intrigued by the reevaluation of life goals, the changes in relationships, the tremendous amounts of loss, and the variety of coping strategies that emerged as a result of HIV/AIDS. In addition, their resilience and ability to create meaning despite life's long lasting challenges seemed to echo through their life stories.

My interactions with the participants increased my interest in pursuing work in the field. Due to the complex life stories of people affected by this disease, I wanted to explore the daily lived experiences of these people. Also, because the epidemic has been impacting the world for over 30 years, I believe it is important to explore the changes in the lives of people who have lived with HIV/AIDS for an extended period of time.

Finally, for the past five years I have been working as a therapist in community mental health settings, a behavioral health setting, and a university counseling center. My primary theoretical framework for working with clients is cognitive theory, coupled with the influence of systems theory. In my interactions with colleagues, I find myself occasionally concerned about how little training some clinicians have regarding people living with a chronic illness, especially HIV/AIDS. Thus, I hope that the results of this study can be used to inform the work of clinicians working with PLWHA.

Instruments

Participant Information Form

Participants were asked to complete an information form (Appendix A) that contains demographic information. The demographic information includes age, gender, ethnicity, sexual orientation, years of education, number of years since diagnosis, and relationship status. Participants were also asked to decide if they wished to be referred to by their first names or pseudonyms.

Interview Protocol

The design of the semi-structured interview protocols that I developed was influenced by the biopsychosocial view of people with chronic illness and the common themes found in the literature review. The questions addressing the three broad themes of uncertainties, stigma, and coping were divided into two sections.

The purpose of the first interview (Appendix B) was to build a warm and accepting atmosphere and establish rapport. In the first protocol, the participants were asked about their reactions to learning of their HIV-positive status, the process of disclosing their status and the choices that guided their decisions at the time, and how their reactions to living with HIV/AIDS

have changed over time. The interview also inquired about participants' experiences with

stigma. The questions focused on experiences of discrimination because of being HIV-positive,

the stigmatizing effects on the person's professional and social relationships, and any changes

that have occurred in constructing short- and long-term plans since being diagnosed with

HIV/AIDS.

The purpose of the second interview (Appendix C) was to close the interview process by

asking participants about coping, including utilizing systems of support and managing their

illness. The participants were also invited to provide their reflections on the interview process

and asked about their future plans.

Procedures

Participants

Criterion-based sampling was utilized in participant selection. Participants were required

to meet the following criteria: participants had to (a) have been diagnosed with HIV as adults, (b)

have been living with HIV/AIDS for a minimum of 10 years, (c) be fluent in English, (d) be his

or her own guardian, (e) be able and willing to participate in two interviews, and (f) agree

potentially to be contacted between interviews for additional clarification of information or

questions.

In planning for participant recruitment, I had originally defined long-term survivors of

HIV/AIDS as persons who had been living with HIV/AIDS for the past 15 years. However, in

the current study, I defined a long-term survivor as someone who has lived with HIV/AIDS for

the past 10 years. Because the literature does not provide a universal definition for the term

long-term survivor, I decided to change my original definition in order to improve participant

recruitment. This period of time was also selected based on my assumption that over a span of

several years, an individual living with a chronic illness would be able to provide a detailed and extensive account of a variety of experiences. In addition, living with a chronic illness may allow the individual to formulate a life story that encompasses a variety of factors including readjustments to life goals and development of coping techniques and resiliency, all factors that I hoped to address through the interview process.

Lastly, participation in the study was voluntary. All participants were informed that their decision to participate or refusal to participate would not interfere with the services they received from the care coordination site and that they could withdraw from the study at any time without penalty. I interviewed a total of 10 participants.

Site Selection and Recruitment

To meet the criterion-based sampling requirements, the research site selected for the current study was a comprehensive care coordination site for PLWHA located in south Florida. The care coordination site addresses the medical, financial, mental health, residential, and nutritional and wellness needs of PLWHA and those closest to them. The site also provides HIV/AIDS education programs, outreach, HIV testing, and prevention within the community. This site was purposefully selected for several reasons. First, the site was selected because it is conveniently located in an adjacent county to where I reside, which increased my ease of access to the site. Second, the site is the oldest and largest community service organization serving PLWHA in the county, which I believed would improve the chances of recruiting long-term survivors of HIV/AIDS. Third, because I am interested in learning from a wide range of individuals, I purposely selected this site as it serves a number of culturally diverse PLWHA.

As part of the recruitment process, I contacted the director of a care coordination agency and asked for permission to post recruitment flyers. Once I received her permission and IRB

approval, I posted the flyers in the common waiting area at the care coordination site. Once a

potential participant was interested in becoming part of the study, he or she contacted me directly

at the telephone number posted on the flyer to schedule the first interview.

Data Collection

When an interested potential participant called me, I introduced myself, informed him or

her about the purpose of the study, and verified if he or she met the requirements to be able to

participate. At this stage each participant provided me with his or her name and phone number.

I kept this information locked electronically on a password-protected computer and a password-

protected Excel file. Once the potential participant agreed to participate, we scheduled a day and

time we both could meet to start the interview process. At this time we also discussed and

finalized the location the interview would take place, making sure the participant had the

autonomy to identify a location that was both safe and confidential for the participant and safe

for me.

When the participant and I met to begin the interview process, I began each interview by

sharing some personal and professional information, explaining the process of the study, and

answering any questions the participant had. In addition, each participant and I discussed the

informed consent, and I obtained a signature that indicated the participant's consent to participate

in the study. At this stage, I assigned each participant a three-digit identification number, which

I used to identify the participant's responses throughout the interview process. Confidentiality

was maintained by the use of non-identifying numbers when labeling consent forms, participant

identification forms, and the transcribed interview protocols.

In order to show appreciation for their time, each participant received a $20 VISA gift

card upon signing the consent form. Each participant was able to keep the gift card even if he or

she was unable or unwilling to continue participating in the study. Each participant was asked to partake in a minimum of one interview session and the maximum of two interview sessions during which two interview protocols would be conducted. At the end of the first interview each participant was given the option to continue and complete the second interview protocol that same day or to schedule a different day and time to complete the second interview protocol. All participants chose to continue the second interview immediately following the first. In addition, all participants completed the entire interview process. The average duration for completing two protocols was between 90 minutes and 120 minutes. All participants were offered a break between the protocols and throughout the interview process as deemed necessary by the participant or me.

I conducted all interviews in person, recorded them with a digital voice recorder, and transcribed them. At the conclusion of the interview process, I asked each participant for the permission to make a follow-up phone call if I needed to clarify any information I received during the interview. All participants gave me permission to make a follow-up phone call. Throughout the data collection and analysis process, the participant identifiers, including names, phone numbers, and ID numbers, were noted in a password-protected Microsoft Excel file on an electronically password-protected desktop computer accessible only by me. All audio recordings, paper informed consents, and interview data were kept in a locked safe.

Data Analysis

Coding in grounded theory is a major aspect of the analysis in which the researcher summarizes and sorts information, thus viewing the data through a theoretical lens from the beginning of data collection (Glaser, 1994). As grounded theory emphasizes simultaneous data collection and analysis (Charmaz, 2006b; Glaser & Strauss, 1967), I worked on multiple pieces

of data at the same time. Thus, after I completed each transcription, I began coding each transcript, wrote a memo reflecting my experience during each interview, and maintained an audit trail.

During the first phase of coding, I categorized the data by utilizing open coding, specifically the sentence-by-sentence coding technique (Glaser, 1978, 1994). Through the sentence-by-sentence coding, I assigned initial codes to every sentence of the interview. At the completion of the sentence-by-sentence coding, I began the second phase of coding, axial or focused coding (Glaser, 1978). During focused coding, I began sifting through the sentence-by-sentence coded data and identifying the most significant codes to use in categorization (Charmaz, 2006b; Glaser, 1978). Using focused coding required me to reexamine the data, clarify or build upon the categories, or divide a category into subcategories (Glaser, 1994).

In addition to sentence-by-sentence and focused coding, I also attended to any phrases, metaphors, or terminology used specifically by the participants, and I used in-vivo codes to delineate the meanings of the phrases and terminology and their construction (Charmaz, 2006b). By coding and further exploring the meaning of the in-vivo codes, I gained additional perspectives and understanding of the participants. I also coded for information that was emphasized or ignored by the participants.

I utilized theoretical coding as the third level of coding, which is intended to assist in the further exploration and development of an emerging theory (Glaser & Strauss, 1967). Also, because data saturation is an important aspect of grounded theory, I utilized theoretical sampling to exhaust the identified categories, to explore hunches I had, or to ask additional questions and provide direction (Charmaz, 2006b; Glaser & Strauss, 1967). Theoretical sampling allows the researcher to go through his or her categories and identify places in the data that lack information

or that do not tell the entire story. In addition, theoretical sampling allows the researcher to explore the same group or a new group of participants in more detail. Theoretical sampling is often achieved by gathering data from comparative groups (Glaser & Strauss, 1967). The researcher selects the most appropriate type of comparative group to attain data saturation; however, the decision should be guided by the theoretical relevance of the group, which will further the development of emerging categories. Given my interest in gathering rich information about living with HIV/AIDS for an extended period of time and the expertise of my participants on this topic, data saturation was achieved by the time I interviewed the seventh person.

In addition, I utilized the constant comparative method throughout the data analysis process. Through the use of the constant comparative method, I compared data to data, data with categories, categories with categories, and categories with concepts (Charmaz, 2006b; Glaser & Strauss, 1967). The purpose of constant comparison is to make "probable the achievement of a complex theory that corresponds closely to the data" (Glaser, 1994, p. 192).

Throughout the process of data collection and analysis, I completed successive memo writing. Memo writing is intended for the researcher to note his or her own ideas about the data, new analytic ideas, and emerging codes (Charmaz, 2006b). This technique enhances and guides the data collection process. Memos were intended for my personal use to aid me in advancing and organizing my thinking throughout the study. I do not intend to publish my memos; however, I shared them with my dissertation committee members during debriefing sessions. I used memo writing to conceptualize and gain an understanding of the data by noting my ideas or hypotheses about codes and categories I developed and about how categories related to each other. I also maintained field notes in which I described my reactions to the overall data collection experience and to each encounter I had with a participant. Overall, the memos and

field notes not only enhanced my conceptualization of the data but also added to the credibility and trustworthiness of this research.

Trustworthiness and Consistency

In quantitative research, reliability refers to whether a study can be replicated and produces consistent results over time; validity refers to whether the research truly measures what it is intended to measure. In qualitative research, however, replicability is not a concern, and validity is viewed in terms of trustworthiness; therefore, these quantitative definitions do not necessarily apply in the same way to the qualitative research paradigm. Replicability is not a concern because not every individual constructs meaning in the same way or shares the same reality. Therefore, it would be highly unlikely that even the same researcher, given the unique nature of the same research effort, could replicate an identical study (Denzin & Lincoln, 2005). Also, because the purpose of a qualitative study is to understand a phenomenon rather than explain it, the definition for reliability carries a different meaning in qualitative research (Golafshani, 2003). Instead, qualitative research is interested in the dependability of the study, meaning whether one can depend on the research process including the methodology for collecting and analyzing data and the qualifications of the researcher. To address dependability, I was transparent about the methodology used in the study and provided a clear explanation of the process of gathering and analyzing the data (Shenton, 2004). This should enhance the reader's understanding of the methodologies used and enable another researcher to reproduce the study without being concerned about replicating the results.

In addition, in qualitative research, the dependability of the study is connected to validity or trustworthiness, precision, credibility, and transferability, all of which provide the lenses for

evaluating findings (Denzin & Lincoln, 2005; Olesen, 2005). The following provisions were utilized to meet credibility in the current study:

- I used constructivist grounded theory, a well-established research methodology, through the data collection and analysis processes.

- I included a section entitled Researcher-as-Instrument to identify subjectivity.

- I utilized triangulation, or applied various methods during data collection and analysis including interviews, field notes, and memos.

- I engaged in debriefing sessions with members of my dissertation committee and peer debriefing with colleagues so that any biases, perspectives, and assumptions on my part could be uncovered and addressed.

- I asked my dissertation committee members to complete an external audit of the final work.

- I utilized memo writing throughout the data collection and analysis process.

Qualitative researchers are not concerned with transferability, or generalizing their findings to a wider population; instead, it is the researcher's responsibility to provide sufficient information about the process of the study so that a reader can transfer the findings in his or her own way and relate them to their personal experience (Denzin & Lincoln, 2005; Shenton, 2004).

Lastly, confirmability needs to be addressed in qualitative research (Guba, 1981). I addressed confirmability by being transparent about the lack of objectivity, as researcher's biases are inherent and inevitable (Denzin & Lincoln, 2005; Morrow, 2005). This is often described as reflexivity and is defined as the process of a researcher acknowledging that his or her perspectives affect the research process from its inception until its end (Olesen, 2005). I did so

by being transparent about the methodology used, by describing myself as a researcher, by writing memos, and by keeping a detailed audit trail throughout the research process.

An audit trail is a record of transparent descriptions of the research steps taken from the time the study begins, through its development, and until reporting of findings (Olesen, 2005; Wolcott, 1990). To provide a clear description of the path the study takes, I have included the rationale behind the research design and data collection decisions as well as the steps taken to manage, analyze, and report the findings (Rolfe, 2006; Wolcott, 1990). In addition, the audit trail includes information on the roles of different people involved in the research, such as the participants, the person at the care coordination site who gave me permission to recruit participants, and dissertation committee members who participated in the data analysis process (Rolfe, 2006). The procedures that were utilized to keep track of the research process include notes of day-to-day activities, methodological notes, and notes regarding decision-making procedures (Olesen, 2005).

Limitations

Although I believe that throughout this research process I was able to develop and conduct a strong qualitative research study, I also identified several limitations which could be addressed. First, to increase the credibility and trustworthiness of my study, I would have liked to have prolonged my engagement with the participants and their contexts and to have utilized member-checking at various stages of data collection and analysis. Second, with the intention of prolonging my engagement with the participants, I could have developed more detailed interview protocols, met with each participant several times to complete a series of interviews, and used persistent observation as part of my methodology to increase the credibility and confirmability of the study.

Third, during the development of the protocols, I could have used a focus group of long-term survivors of HIV/AIDS to ensure that the quality and type of questions I was utilizing were clear to understand and were adequately addressing the core of what I was intending to ask. Fourth, I could have enlisted the help of an additional coder who would have simultaneously coded each interview, following which we could have reviewed our analyses together. I believe this would have further helped me in uncovering additional biases I may have had toward the data. Finally, to improve the triangulation in my study, I could have recruited participants from various settings. I believe this approach could have enhanced my understanding of the studied phenomenon.

CHAPTER 4

RESULTS

I interviewed a total of 10 individuals during the course of this study. These individuals

invited me into their lives and offered me a glimpse of their worlds by sharing openly their

deeply personal stories. I worked closely with the data to portray accurately their experiences,

which reflect in the results presented in this chapter. These results are my interpretation of their

stories.

Introduction to the Context

I conducted all of the interviews in south Florida, where large numbers of people

vacation. With beautiful beaches, a diverse population, and plenty of entertainment, for many,

south Florida is a true vacation destination and for others it is home. Florida's reality, however,

also includes being the state with the third highest number of individuals living with HIV/AIDS

in the country, totaling an estimated 97,978 individuals, most of whom are located in south

Florida (AIDS United, 2011). Of these individuals 70% are male and 30% are female. In

addition, 34% are Black, non-Hispanic; 30% are Caucasian, non-Hispanic; and 20% are

Hispanic, all races. According to the South Florida Regional Planning Council (2010), Miami-

Dade and Broward Counties are the most populated counties in south Florida with a total

estimated population of over 3.5 million people. Currently, Miami-Dade ranks as the county in

Florida with the highest number of persons with HIV infections, with an estimated number of

25,372 PLWHA (AIDS United, 2011). Moreover, Broward County ranks as the second county in Florida with the second highest number of persons with HIV infections, with an estimated number of 16,456 PLWHA.

Prevention services in the two counties are well funded by the Centers for Disease Control and Prevention as well as the Ryan White CARE Act (AIDS United, 2011). Syringe exchange programs are available in Miami, and there are numerous grant-funded and not-for-profit agencies serving PLWHA. Prevention, testing, and counseling services; housing assistance; homeless shelters; mental health services; and other HIV/AIDS-related care services are numerous and located throughout both counties. Billboards by highways and advertisements on buses promoting rapid HIV testing, regardless of one's ability to pay, are common in both counties. I interviewed all participants in their homes located in Broward County.

The Participants Within Context

Throughout this process I remember leaving each interview feeling sad and weighed down. I felt nervous about meeting each person, and I was cautious about making sure that my appearance was appropriate so that I could at least attempt to blend into the surrounding community. Nonetheless, the drive to meet each participant was thrilling. Every time I met a new participant I was greeted with a handshake or a hug and I was led into an area of his or her home that was set up for the interview. This was not my first time interacting with HIV-positive individuals, so I felt very comfortable. However, I can recall feeling uncomfortable with physical contact the first time I ever interacted with an HIV-positive individual. Regrettably, I knew very little about HIV at the time and did not know what to expect. However, I learned very quickly and after this interaction I never had a similar uncomfortable experience. This time, I had no hesitation and I welcomed our interactions. I believe that my comfort level also helped

each participant and me to establish rapport and increased the participants' trust in me, something that I came to learn they greatly valued.

The Beginning

We began the interviews by chatting about the weather or the drive up. I was also asked questions about my accent, my background, and my work in HIV/AIDS. I was glad to see that they were interested in me, and I graciously answered their questions as best as I could. I was also relieved that the interviews were not going to be simple business transactions but rather really interactive discussions.

I conducted the interviews in the home of each participant. One male and one female participant were living in residential housing and the other participants were living in independent-living apartments all arranged by the care provision site. All of the homes were either located in a neighborhood known in the community for housing HIV-positive individuals and providing HIV services to the county or in a low income neighborhood. In the residential housing, each participant had a room he or she shared with one roommate. I interviewed the male participant in his room. The one room had two beds and bookshelves, one television, and one bathroom. I interviewed the female participant in the common living area of the residential housing unit. This common area had a large television, a few couches, and two tables with chairs. During the interview two people passed by our table. However, no one else was present during the interview.

I interviewed the couple in their home. Both partners, at their request, were present during each other's interview. I interviewed the other participants in their homes and no one else was present during those interviews. The insides of the homes were well maintained and had the main essential utilities. However, some had peeling paint and others had very old appliances. In

some homes, the furniture was also old and the participants used lawn furniture as a living room set. Overall, however, the ambiance of the homes was quiet, aside from the home of the couple in which meditation music was playing throughout the duration of the interview.

My Reactions

During the interviews, I felt a variety of emotions. I experienced grief, disappointment, anger, hopelessness, disgust about how others treated the participants, and admiration for their strength. Mostly, however, as I left each interview a sense of a heavy sadness weighed on me. I was sad to leave each participant knowing that this was the extent of my involvement in his or her life. As I drove away from each impoverished home, I felt disappointed with how unfair the world can be and the sorrow that is ever present. Often, on my way home, I would drive through Miami Beach and notice the high-rise buildings and all of the wealth behind those walls. Observing such drastic socioeconomic and social differences increased my sorrow.

During each interview, I empathized with each participant, but I felt an even greater sense of compassion after leaving their homes. I hope that I was genuinely able to portray my emotions during the interview process. Even now, when I see HIV-related billboards in Miami, the first thing that comes to my mind are my participants. Honestly, I never expected that it would be so difficult for me to disengage from this process. However, I am happy that I was able, even if briefly, to meet such wonderful individuals. I spoke with women and men from diverse ethnic and cultural backgrounds, of different ages and belief systems, and with different stories to tell. Unexpectedly, I was even able to speak with an HIV-positive couple who had been living together for the past eight years, Louis and Mary. I also met with individuals who had been HIV positive anywhere from 11 years to 24 years. I found these numbers surprising because I expected that it would be very difficult to find people living with HIV for more than 10

years who would be interested in participating in a research study. Because all of the

participants were receiving services at the site where I displayed my recruitment flyers, most of

them knew each other and spoke to each other about the study. To further describe each

participant, I organized the participants' demographic information in Table 1, which is intended

to be read line-by-line from left to right. Reading it in this order will allow the demographic

information to be more descriptive and continuous.

Table 1

Participant Demographic Information

Participant pseudonym	Age	Ethnicity	Marital Status	Gender	Completed education	Years since diagnosis	Current HIV/AIDS status	Using antiretroviral medication
Louis	52	African American	Married	Male	11th grade	24	Detectible	Not using
Mary	38	Jamaican	Married	Female	12thgrade	11	Undetected	Using
Amy	32	African American	Single	Female	12th grade	11	Undetected	Using
Lila	34	Caucasian	Single	Female	12th grade	12	Undetected	Using
Lilly	42	Hispanic	Single	Female	12th grade	13	Undetected	Using
Adam	51	African American	Divorced	Male	12th grade	14	Undetected	Using
Joy	35	Hispanic	Divorced	Female	12th grade	16	Undetected	Using
Amanda	45	African American	Single	Female	12th grade	16	Undetected	Using
Bob	49	African American	Single	Male	9th grade	21	Undetected	Using
Jack	42	African American	Divorced	Male	12th grade	23	Undetected	Using

Note. *n* = 10.

Their Identities

In addition to the information listed in the table, all participants identified as heterosexual and identified their route of HIV transmission as unprotected sexual intercourse with an individual of the opposite sex. When speaking about learning of their infections, overall the participants were brief and initially did not elaborate on their experiences. However, as the interview continued and our rapport increased, each participant became more candid about his or her experience. None of the participants knew for certain which sexual partner they contracted HIV from, but each speculated a potential sexual partner or a point in time during which they became infected. Participants struggled with identifying the potentially infected sexual partner mostly because at the point each participant was tested, he or she had already engaged in sexual intercourse with another partner being unaware of his or her own status. This made it difficult to undoubtedly identify the source of the transmission. This also meant that the likelihood of each participant having infected another person with HIV existed.

Each participant also had a different experience in regard to how they came to learn about being HIV-positive. One male participant learned he was HIV-positive through mandatory testing in a prison. He reported that he was shocked by the news and for several years, while in prison, he successfully worked at keeping his status a secret. He feared the effects of being stigmatized by the other prisoners or by the guards. Another man learned he was HIV-positive by being tested in a health center bus in the late 1980s. This man was originally from New Jersey and moved to south Florida a few years after he became HIV-positive. He reported that because of the high incidence rates of infections in New York City and surrounding areas, HIV testing was common in his neighborhood. He explained that one day he was passing by the health bus and one female outreach member convinced him to get tested. He reported she had

called him a day or a few days after the test with his results, also encouraging him to seek services. The other two men learned that they were HIV-positive by responding to similar HIV outreach prevention staff in their communities, who were encouraging people to get tested.

One of the female participants reported that she learned her HIV-positive status after coming out of a coma at a hospital. She reported feeling like her entire world came crushing down when the doctors shared this information. She also reported initially blaming the hospital for infecting her, even in light of the hospital staff informing her that her CD4 count was so low and her viral load was so high that she was bordering on a diagnosis of AIDS. The hospital staff also informed her that HIV could have been the reason for her coma. This participant reported that it took her some time to accept responsibility for becoming infected. Overall, participants either directly stated or implied that they took responsibility for becoming HIV positive.

Of the other five women, one learned her HIV status after donating blood and the other four after being tested at the recommendation of a primary care physician, family member, or both. The primary care physicians or family members made the recommendations based on medical knowledge or knowledge that each woman was sexually promiscuous and was at risk of contracting HIV. I found it interesting that none of the participants sought HIV treatment immediately. However, most sought treatment within the first year of being diagnosed. Two main factors that seemed to have contributed to a delay in seeking treatment were substance use by the participants and lack of emotional support from either family or friends.

The Obstacles

The site at which all participants received services also provided substance abuse treatment. During the course of the study, only one male participant was enrolled in a substance abuse treatment program. However, all of the male participants and one of the female

participants had long histories of polysubstance use prior to becoming infected with HIV. These individuals also continued to use drugs for several years after being diagnosed. In addition, they reported that the substances they used more commonly were alcohol, cannabis, heroin, and cocaine, listed in order from most to least frequently used. One of the male participants stated that his substance use problem had led to someone putting a gun to his head and threatening to kill him. The female participant was guarded about the extent of her substance use history but stated that she had been a chronic alcohol and cannabis user since even before contracting HIV.

For these five individuals, substance use was a risk factor that contributed to them becoming HIV-positive. In addition, all four men had histories of multiple incarcerations for drug-related charges, and one of the men also had a history of being incarcerated on an assault charge. All men reported receiving HIV treatment while incarcerated and some reported that once they were released, they stopped treatment and began to abuse drugs. Often, this marked a continuation of instability in their lives including a fluctuation of their HIV status. One man reported that he looked like he had AIDS while out of the prison system because he became so impoverished due to his drug use. He recalled walking into jail with a handful of cannabis so that he could go back into the system. He reported that this was the last time he was incarcerated because he became clean and continued HIV treatment once released. Overall, however, all of these men contracted HIV outside of the prison system and were already infected upon their first incarceration.

The instability in their lives already created by substance use and multiple incarcerations was further exacerbated by living in low socioeconomic households with few resources. Although all participants worked at the time they became aware of their diagnoses, keeping their status a secret at work was important to the participants. Those participants who were not born

in south Florida relocated to Florida for a variety of reasons including employment opportunities and escaping their families or other communities in which they felt unwanted. With the exception of Mary, who was born in Jamaica and relocated to Miami as an adolescent with her family, all other participants were either born on the east coast, south of New York, or were born in south Florida. Also, each participant reported that he or she had disclosed his or her status to at least one family member or friend before relocating. They also reported having disclosed their status to at least one family member within a few months or the first three years of being diagnosed with HIV. There was only one participant whose time of disclosure was different from the others.

Their Relationships

Lila, the 34-year-old Caucasian woman was the exception. Although she had been HIV-positive for the past 12 years, she disclosed her status to her family only eight months before the interview for the current study took place. Lila reported that it took her a long time to disclose to her family because she felt ashamed of having contracted HIV. Also, since learning she was HIV-positive, she went through a long period of depression and alcohol use. Not until a few months before her interview did she begin to feel better and take care of herself emotionally and physically. Taking better care of herself helped her gather up the courage to disclose her status to her mother. Lila was also the first person to respond to my recruitment flyer, and although still guarded at times, she was eager to share her story. She shared that she felt excited yet scared because she was about to begin dating. Several of the single or divorced participants were either dating or interested in dating someone. Since becoming HIV-positive, all participants reported being sexually active and only a few wanted to speak about their past romantic relationships. Those who hesitated or did not want to speak about past romantic relationships

seemed pensive, sad, or disappointed or simply stated that they did not care to talk about relationships specifically. I wanted to respect their limits and did not press further. However, when they brought the topic up on their own I listened attentively. Instead, most wanted to focus on their future relationships.

At times, it was difficult for me to see their sorrow. I found myself frequently validating their emotions, habitually returning to my role as therapist. I think having good active listening skills, being genuinely interested in what they had to say, and not rushing them helped put each participant at ease with my questions, which evoked sensitive topics.

Among breaching such topics as stigma, disclosure, stress, fear, and more, relationships with family or friends seemed to be a topic frequently discussed by each participant. The couple, Mary and Louis, was most candid about their relationship and their relationships before they were married. Mary discussed an extensive history of abuse she experienced after contracting HIV and before she met Louis. Mary also has a 19 year-old HIV-negative son from a past relationship. Toward the end of the interview, both Mary and Louis spoke about Mary's son. Louis does not have any other children and considers Mary's son to be his own. Adam also spoke about his two adult-age daughters from his marriage, both of whom were HIV-negative. Although he has very little contact with them, he speaks with his eldest daughter on the phone once a month. Bob, on the other hand, had a sad story to tell about his HIV-negative child who died in infancy. Joy and Lilly each had HIV-negative adolescent children. Joy had a daughter, and Lilly had a son and a daughter. Their children lived with them in the same house. Amanda also had an HIV-negative adult-age daughter who had her own family and frequently visited Amanda. Jack, Amy, and Lila did not have children. Some participants asked me about my family history and if I had any children, but none asked me whether I was HIV-positive. I found

this interesting because I expected them to inquire about my status, because I was asking about theirs. On the other hand, however, disclosure is private and something each participant respected.

In regard to health care, each participant had access to medical and mental health care services. Each participant had a primary care physician and a caseworker and attended individual or group counseling. With the exception of Louis, each participant was on a regimen of highly active antiretroviral therapy. Louis had stopped taking HIV medications approximately two years prior to the interview to avoid the side effects of the medications. He also believed that herbal remedies and an improved diet would be enough to live a healthy life with his infection. His wife did not share this belief and often encouraged him to go back on a regimen of medication. At the time of the interview his viral loads were very high and his CD-4 count was below 200.

Overall, all of the participants looked well, had good energy levels, and seemed happy with their lives. Each participant had good relationships, plans, and goals; made decisions about his or her life; and was gracious enough to tell his or her story. But all participants went through a process of survival that helped them arrive to where they are today. The remainder of this chapter is devoted to a description of this process.

Organization of Data Findings

I analyzed the data generated throughout the interview process for similarities and differences among participants in their experiences of living with HIV/AIDS. From these data I generated four axial categories that support the core category. In addition, each axial category contains several subcategories that further clarify the connections among the data. I described the core category as the process of accepting and living. The four axial categories are autonomy,

belonging, resiliency, and hope. First, I introduce the core category and then I discuss the four axial categories and their subcategories. Finally, I describe the relationship between the axial categories and the core category.

Core Category: The Process of Accepting and Living

The core category, the process of accepting and living, represents the totality of the experiences I learned about through each participant's story. These stories consisted of pain, endurance, fear, joy, hope, and hard work, as well as values that helped these 10 long-term survivors of HIV/AIDS accept their diagnosis and continue living. Each story began in a context of instability that led to an increase in risky behaviors for all participants and resulted in them contracting HIV. The instability in each participant's life was created by multiple social factors such as poverty or economic hardship, poor access to health care, discrimination, substance use, and poor quality education. In addition, personal characteristics such as ethnicity, gender, and sexual orientation had an impact on the above-mentioned social factors, contributing to stigma, poor access to resources, and psychological stress (Pellowski, Kalichman, Matthews, & Adler, 2013). These social factors and stressors are greatest among individuals who are at or below the poverty line and are ethnic minorities in an area with high rates of HIV infection (CDC, 2011). Such social factors also tend to influence the prevalence of HIV within communities and the risk behaviors of individuals (Pellowski et al., 2013). In addition, these factors are stressors individuals experience daily, which in turn influence their personal lives, often creating unstable relationships with poor communication, infidelity, and mistreatment. Further, relational instability often results in an individual having multiple partners, which increases their chance of becoming infected with HIV or other sexually transmitted infections, as was the experience of each participant.

Often, becoming HIV-positive exacerbates poverty, unemployment, and other social stressors that existed pre-diagnosis (Pellowski et al., 2013). In the midst of such instability, all participants learned about their HIV status, adding to their experience of trauma and mental health concerns which created more instability. This exacerbated instability also impacted the psychological and physical health of these individuals. Accordingly, the most common mental health concern of PLWHA is depression (Bing et al., 2001). Co-morbid psychological or physical problems such as depression, anxiety, stress disorders, substance use, overeating, or hypertension are common for PLWHA (Crum-Cianflone et al., 2010; Soller et al., 2011) and create uncertainties in the lives of these individuals that impact their functioning. This was also true for the participants in the current study because each participant reported co-morbid mental health or physical health problems, such as depression, substance use, diabetes, obesity, and cardiovascular problems they experienced either prior to or since learning of their diagnosis.

After learning of their diagnosis, participants expressed concern regarding treatment and disclosure. All of the participants described disclosing their HIV-positive status as a difficult process. However, disclosure is crucial because without it the treatment and emotional support for PLWHA is negatively impacted. Importantly, HIV disclosure has been linked with acceptance of one's HIV-positive status (Holt at al., 1998; Kako, Stevens, & Karani, 2011). This acceptance, in turn, helped individuals increase their disclosure, live more positive lives, adhere to treatment regimens, and improved utilization of social support.

Once each participant disclosed his or her HIV-positive status and accepted the diagnosis, the process of living well with HIV began. For each participant this meant having to incorporate his or her HIV status into his or her daily reality by restructuring goals, relationships, and self-concepts. This process involved managing his or her illness including the symptoms of HIV and

other co-morbid conditions, side-effects of the medication, stress, and the challenges of maintaining a healthy lifestyle. This also involved making decisions about employment, increasing relationship stability, and identifying and executing goals.

Beginning this research, I assumed that such changes would happen over time and be dynamic. At that time, however, I was unable to identify the pieces of the puzzle, the necessary characteristics or steps that a person would experience during this process. I learned that the necessary values for these 10 participants to be able to reconstruct their lives since becoming HIV-positive were autonomy, belonging, resiliency, and hope. These values did not occur in a linear fashion; instead they were fluid, interwoven, and came together to help these long-term survivors of HIV restructure their lives so that they could continue living with this chronic illness.

The necessary values include several subcategories or characteristics that clarify each value (Figure 1). The first necessary value is autonomy, which began when each participant became aware of his or her HIV diagnosis and sought to increase his or her knowledge about HIV/AIDS. This resulted in a sense of gaining control over life and feeling empowered to make conscientious decisions, while maintaining privacy about one's HIV status and navigating the disclosure process. Accordingly, being able to make autonomous decisions regarding disclosure helped the participants accept their HIV status and function within their community. This was the first step toward being able to live long-term with HIV. The second value is belonging, which is defined by a deep human desire to relate to others, followed by feeling respected and accepted, especially in emotionally or physically intimate relationships. Through this process each participant attempted to create relational stability by improving the quality of his or her relationships and support systems.
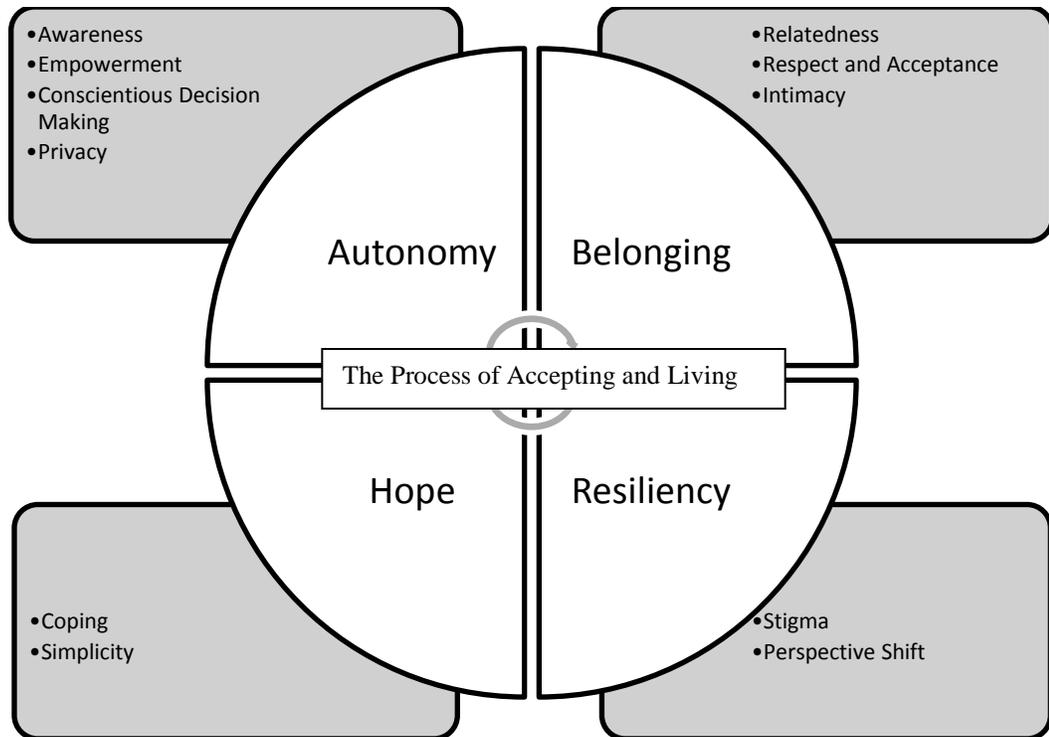
Figure 1. An illustration of values within the process.

Third is the value of resiliency. This value helped the participants cope with their

experiences of stigma and resulted in their ability to persevere through numerous uncertainties

and develop a shift in perspective about their lives. This value was also influenced by each

participant's personal characteristics. Last is the value of hope. Hope seemed to motivate

participants to develop coping strategies, be active change agents in their own lives, become

more optimistic about their futures, and simplify their lives to make them more manageable,

which decreased their stress levels and improved their overall health. This process buffered the

influence of social factors on living with HIV/AIDS for an extended period of time.

These values helped each participant to reconstruct his or her relationships, goals, and

perspectives and resulted in each participant making his or her life more stable, manageable, and

hopeful. I also see this as an ongoing process that becomes a way of continuing to live positively

with HIV/AIDS. Those who are able to continue managing this process are able to live constructive, long lives with this chronic illness.

Autonomy

The first axial category I identified from the data was the value of autonomy. Autonomy relates to the degree of control a person has over his or her life. This includes the freedom and skills to make decisions along with being motivated to create positive change. Exerting control over one's own HIV care or treatment, utilizing support systems, and making decisions has been associated with living well with HIV/AIDS (Chacham, Maia, Greco, Silva, & Greco, 2007; Gordijn & Boven, 2009; Phaladze et al., 2005; Tsarenko & Polonsky, 2011). For these participants the first step toward gaining control over their lives was learning of their HIV status and increasing their awareness about HIV/AIDS. Prior to this, participants struggled with decision-making, had a tendency to make impulsive decisions or ones that put them at risk, and further perpetuated the instability they had experienced in their lives until that point. After being diagnosed with HIV, the changes and uncertainties that kept coming up for them were many. However, once they increased their awareness and felt empowered to make conscious decisions about the future, the sense of control over their lives increased. This helped each participant disclose and accept his or her HIV status. Accordingly, this began the process of creating positive change and increased their ability to function well. The value of autonomy echoes throughout the interviews and is described in detail below throughout the subcategories of awareness, empowerment, conscientious decisions making, and privacy.

Awareness

In order to live well with this chronic illness, it is imperative to learn one's HIV status and acquire knowledge about HIV/AIDS. However, it is important to note that becoming aware

of one's HIV status can elicit a gamut of strong emotional reactions, which may lead to negative health outcomes (Herek et al., 1998). When asked to describe his reaction to learning about his HIV status, Adam stated,

> At first it didn't really hit me and then it did. I said no. No. It was a, was a hell of a blow. I was like upset and thinking I'm gonna die. It felt strange. Then there was a lot of anger. I didn't want to be around nobody. I was like you know it's like, your mindset goes into a state that you ain't got but just a little bit of time to live and you feel like you don't even really want to live.

Similar negative reactions or shock and hopelessness were common for the participants. Such emotions lasted anywhere from several months up to two years for most participants and decreased in intensity over time. The decrease of these emotions resulted in participants beginning to disclose their HIV-positive status, with the exception of Amy whose disclosure took place several years after she learned of her status. It is important to point out however, that Amy had a long history of alcohol abuse and depression, factors that increased instability in her life and made it more difficult for her to cope with her HIV status. In addition, those participants who struggled with substance use had more difficulties coping with their emotional reactions to learning their diagnosis. Substance use also extended the length of time before they were ready to approach treatment, disclose their status, and move toward accepting their diagnosis.

Furthermore, after learning of their HIV status they were more likely to seek information autonomously about HIV/AIDS. While learning about HIV/AIDS, participants also began to learn about available treatment options. Although strong emotional reactions to learning of one's HIV-positive status, such as denial about having HIV, are one barrier to learning about this chronic illness or receiving treatment, there are additional barriers identified by researchers that

often prevent HIV/AIDS awareness (Pollini, Blanco, Crump, & Zuniga, 2011). Some of these barriers are fears of perceived and real stigma; age at diagnosis, with younger persons waiting longer to seek treatment; lack of information about treatment cost; lower education level; reluctance to take medication; concerns about the side effects of medications; and mistrust of health care providers (Beer et al., 2012; Pollini et al., 2011). After overcoming reactions to their diagnosis, breaking through barriers, experiencing symptoms of HIV, and moving toward accepting the reality of being HIV-positive, participants slowly became more motivated to begin exploring how to live with this illness. Lila described her reactions to developing awareness about HIV/AIDS, stating, "okay, so I realized that I was exposed to an incurable disease . . . and there are a lot of resources and services you can reach and get, so I tried to use them the best I can." She reported that from this point on things in her life began to improve.

Once participants learned about HIV/AIDS, reading results of blood work and understanding their status, and available treatment options, they seemed to find more control over their lives. This control began to motivate and empower each participant to continue gaining control over his or her future. Joy described her reaction to acquiring control of her life stating, "so I was to the point when in my mind I want to live, you know."

Empowerment

Becoming aware and feeling more in control of their lives inspired the desire for change within each participant. Lila described feeling empowered after learning about HIV and treatment options and challenging her belief that HIV was a death sentence, stating,

> I can do things on my own that I don't really have to have a person by my side 24 hours a
>
> day, you know, like a nurse with me all the time. You know, like that I can build my
>
> strength back up.

By learning that she can autonomously take care of herself, Lila felt in control and empowered. Whether participants gained awareness on their own or with the help of a supportive individual, they reported that this increased awareness also increased their sense of feeling empowered to exert control over their decisions. Those participants who sought the help of a health care professional, whether a social worker, a mental health counselor, or a physician, expressed an even greater sense of empowerment. This finding is supported by research on HIV and that empowerment is an essential part of the role for health care professionals working with PLWHA (Cote et al., 2012). Feeling empowered also strengthens the skills an infected person can use to manage his or her illness by increasing his or her use of social support systems and available resources. In addition, when relationships between care providers and patients are fostered, patients often feel empowered to become better consumers of their own health care (Mutchler et al., 2011).

Empowered participants made better decisions about their health care, sexual practices, and relationships and were more involved in their own treatment, which resulted in a decrease of risky behaviors and increased control over their life choices and goals (Beyeza-Kashesya et al., 2011; Mutchler et al., 2011). This was the experience of the 10 individuals in the current study simply described by Lilly, who stated that "just knowin' made a difference. See, it gave me reason to go on. I just had to figure out how." Mary elaborated on this idea stating, "But that's where the social workers and those people [outreach personnel] came in handy 'cause there, they had all the resources."

Through awareness, participants became more autonomous consumers of available health services and felt motivated and empowered to exert control over their lives. This process helped each participant accept the reality that he or she was HIV-positive and was going to spend life

living with HIV. Jack discussed his reactions to gaining awareness about how his substance use

was affecting his HIV status, feeling empowered through the help of a physician, and finally

coming to accept this reality:

But since I came to the point and started cleaning my life up, I'm not in the mental state

of being tormented with it [having HIV]. The anxiety is gone, the stress died down about

being HIV-positive and so right now it is what it is, and I just want to keep living.

The acceptance of his status was a decision that not only Jack made, but other participants made

as well. The sense of stability that came as a result of acceptance empowered each participant to

continue making adaptive decisions and gave him or her hope that living well with HIV/AIDS

was possible. Louis, who had a long history of substance use and incarcerations, struggled with

awareness and empowerment for years before coming to terms with being HIV-positive. He

sounded relieved when he described finally accepting that he could live a better life even with

this diagnosis, stating,

At first, even with my HIV, I appeared to not really care about going into prison and

contributed to me not caring, but every time I got arrested and knew I was going back,

every time the fear of dying of HIV was there. So at one point I wanted to start living, so

that's what I did and so far I am fine.

Making the autonomous decision to live gave Louis and other participants the courage to

understand that they could live well with HIV for an extended period of time.

Conscientious Decision-Making

Another subcategory of autonomy was conscientious decision making. The chronic

nature of HIV/AIDS forced each participant to be his or her own primary care taker. Participants

faced a multitude of stressors since being diagnosed with HIV. As part of living well with HIV

they had to learn how to approach and manage each stressor, approaching decision making in a cautious and diligent way. In addition, when participants made decisions about goals they would like to accomplish, such as moving into independent living, they carefully weighed their options before selecting the best route. When participants spoke about feeling empowered, being in control of their lives, and making conscientious decisions, often I could sense how proud they were of themselves for feeling this way. For example, Adam was proud that he was able to radically change his life, stating,

> I always believed I was put here because I would be an example of a crack addict. So I
>
> was just a person with HIV, in prison, smokin' crack. Now I do have my goals and make
>
> my own decisions.

For Adam and other participants the decisions they had to make constantly included whether to begin or to continue taking antiretroviral medications, how to approach romantic relationships or disclose their status, when to begin substance use treatment, how to select the resources that would best meet their needs, and to make employment decisions.

In regard to making decisions about taking antiretroviral medications, participants often reported being concerned about the side effects of the medications. They also reported difficulty choosing the best treatment options and being concerned about being able to adhere to medication regimens. Many studies identified other PLWHA having similar concerns about taking antiretroviral medications (Ironson et al., 2005; Kremer, Ironson, Schneiderman, & Hautzinger, 2006). Also, Kremer et al. (2006) found that a factor influencing decision-making regarding taking antiretroviral medication was a belief about a mind-body connection. This is the belief that thoughts, emotions, and perspectives affect the psychological and physical wellbeing of an individual.

In the current study only three participants mentioned the importance of a mind-body connection as a factor that had a positive impact on their ability to cope with living with HIV/AIDS. Mary illustrated this belief, stating, "It's the mindset, you've got to stay positive not negative. And then good things happen. You start to feel better, emotionally and otherwise. That's why we meditate, 'cause it helps us stay positive and physically stronger." Although this related to coping, the decision-making process that was involved in aiding participants in selecting the most appropriate coping mechanisms, such as meditation for Mary and Louis, was just as important. Interestingly, other studies have found that those who believe in a mind-body connection, or that a strong mind can help the body heal, often decide not to take antiretroviral medications and, if they do, have poor adherence to the medication regimen, which results in poor treatment outcomes (Kremer, Ironson, & Porr, 2009; Parsons, Cruise, Davenport, & Jones, 2006). Of the 10 participants in the current study, only Louis, who was not taking antiretroviral medications, alluded to a similar notion:

> You know a lot of people say you look good for 53 years old but little do they know my CD is below 200 and my viral load is very high, but you see, you can't see, it's hiding. I've been fooling around for three years and I haven't taken meds because of the fear that I'll get one of the side effects and really feel bad so you know, I said I'll just go ahead and not take any medication but take these herbs and keep relaxing my mind. And I was fine. I was going to the doctors and my CD4 and viral load was always okay but after about two years or two and a half years I started gaining problems so now I've still got issues with taking the meds. So if what I do now don't work, at least if I die today I'll know I lived.

Although Mary, Louis's wife, does not approve of him not taking medication, she tries her best not to interfere with his decision despite its impact on both of their lives.

Further, the decision-making process was often complicated for the participants because the decisions they made impacted several areas of their lives. This made it more crucial for participants to make careful decisions. Decisions impacted their functioning in interpersonal and social areas of life, employment settings, and the state of their mental and physical health. In addition, these autonomous decisions were guided by their desire to care for themselves and gain stability in their lives. Jack illustrated the decision-making process he underwent to gain more stability in his life. He described the process in the following way:

> Until I came to a conscious decision that this [abusing substances] was no longer part of my life and that people do things to get better, so I got stable and stopped what I was doing. Until three to four years ago I was still struggling with the drugs and alcohol. After this I started another conscious decision. I started with the AA and it helped me a great deal and I started getting more people in my corner for support.

Since, Jack has not used any substances and has experienced a lot of growth in several areas of his life such as improved interpersonal relationships, adherence to his medication regimen, and increased financial stability.

Lastly, the female participants mentioned an additional area of their lives that required active decision-making in addition to the decisions men made: women also reported making decisions regarding sexual behaviors and pregnancy. Regarding sexual behaviors, more frequently than men, women were concerned about disclosing their HIV-positive status to potential sexual partners and whether to have unprotected sex with potential partners who were already HIV positive. I would like to note that the women in the current study had no intention

of having unprotected sexual intercourse with HIV-negative men and were aware that by law they were required to disclose their status to potential sexual partners.

Women struggled making decisions regarding disclosure for a variety of reasons including fear of being rejected, stigmatized, or mistreated by a potential sexual partner. Such fears also increased their hesitation to disclose, which is further discussed in the subcategory of privacy. Although not endorsed by the men in the current study, it is common for both men and women to struggle with disclosing their status to potential sexual partners due to a fear of the other person's reactions (Derlega, Winstead, Greene, Serovich, & Elwood, 2004).

In deciding whether or not to have unprotected sex with HIV-positive men, women believed they could take such a risk. In addition, since they could not infect the other individuals, their level of concern for their partners' wellbeing decreased. However, they continued to be concerned for their own health, especially concerned with contracting other sexually transmitted infections. This concern often resulted in solidifying a female participant's decision to decrease risky behaviors. This was evident in Joy's description of this struggle as she stated,

> So okay, like with my ex, he's positive right, I wouldn't want to use condoms, but then
>
> again I don't know who he's been around. But okay, like with someone new, right, that I
>
> knew was positive. I don't know, I could ask him to put it on, right. 'Cause I don't know
>
> where he's been and there are all those STDs and shit, and I don't want none of 'em.

Of course because Mary was in a monogamous relationship with Louis, she did not express this concern. However, she did briefly speak about potentially wanting to have a child with Louis.

Last, the women of childbearing age in the current study expressed difficulties making decisions about having children in the future. Although most expressed a desire to have a child,

no participant expressed any intent to do so. However, they identified several concerns that impacted their decision to act on their desire to have a child. The concerns included bearing an HIV-positive child, being able to take care of the child, and having an unpredictable longevity within the child's life. In addition to identifying these concerns, a study conducted by Kirshenbaum et al. (2004) also found that fear of experiencing stigma and having strong religious values further complicated the decision making process.

A study conducted by Sowell, Murdaugh, Addy, Moneyham, and Tavokoli (2002) explored factors that influence the intent of HIV-positive women to have children. Their findings indicated that younger women seem to have stronger intent of having a child due to faulty perceptions of the threat of HIV, greater avoidance of the threat of HIV, and an overall avoidance approach to coping. In addition, more intense beliefs about upholding gender and sex role expectations increased the intent to have children in younger women. Accordingly, because the women in the current study were older, were more aware and informed of their illness, and did not seem necessarily as concerned with upholding gender or sex roles to the same extent as younger women, they did not express the intent to have children. Instead, they had difficulties deciding if they intended to have children among the multitude of concerns expressed above.

In conclusion, although participants generally felt empowered to make autonomous decisions, they sometimes struggled with this process, as many people do. Their awareness about HIV/AIDS and the highly transmittable nature of HIV greatly weighed on how they made decisions. Another way for the participants to express their autonomy was by constantly reevaluating their decision-making regarding maintaining privacy.

Privacy

Since learning about their HIV status, participants were cautious about to whom, when, and how they disclosed their status. Participants reported being cautious in order to maintain a level of privacy and autonomy in their lives, prevent being stigmatized, prevent losses of or changes in relationships, and protect their children or family members from being mistreated or placed in uncomfortable situations because of the participants' HIV status. The overwhelming amount of literature on disclosure of PLWHA agrees that disclosure is a difficult and complicated process that affects the individual and his or her social environment. In addition to being a difficult process, disclosure can negatively or positively impact the well-being of PLWHA (Chaudoir, Fisher, & Simoni, 2011). Thus, disclosing is a risk that every PLWHA fears and approaches with caution, as did the participants in the current study.

Often, participants did not disclose to their employers or co-workers. Although Jack was the only participant employed at the time of the study, all participants were employed at the time of learning their diagnosis. At the time of their diagnosis and since being diagnosed, participants expressed that they protected their privacy at work by not disclosing their status in employment settings. They feared that disclosing their status at work would eventually cause them to lose their jobs or be discriminated against at work, which would prevent them from doing their jobs, a common concern for many PLWHA (Hoffman, 1997; Hunt, Jaques, Niles, & Wierzalis, 2003). Other concerns frequently reported by PLWHA about disclosing their status in the workplace included privacy when taking their medications, the loss of insurance coverage, changes in career goals or the inability to continue their job due to their physical health, and the loss of social support at work (Hunt et al., 2003). In the current study, participants reported being concerned about having privacy while taking their medications and worrying about the inability

to maintain their jobs due to physical problems. None of the participants directly reported being

concerned about having social support, but all reported that they believed no one at work would

understand what it meant to be HIV-positive or keep such information private. When I asked

Bob about his disclosure experiences he reported that aside from his immediate family and one

best friend, no one knew he was HIV-positive. He also mentioned that he worked hard to

maintain his privacy at work and while in jail. When I asked him to discuss his decision not to

disclose at work, he spoke about the first two jobs he had after learning he was HIV-positive,

stating,

> At that time I was working at a fast food restaurant, but I was doing janitor type of work.
>
> At the beginning it was hard because I was around everybody and then they moved me to
>
> closing the store and it was great because they gave me a key and I was around nobody
>
> and it was easier because I didn't have to worry about nobody knowing. It was one of the
>
> best jobs I had but it was tough because of taking the medicine. But this time I was
>
> working until 6 o'clock in the morning. At the next job I started getting real sick, that's
>
> when I was working at a seafood plant and you can't tell nobody 'cause the whole plant
>
> would know. It was all guys and if they found out it would be over with. The whole
>
> plant would know about that and it would be hard for me to stay there and work.

Fear that others would misunderstand what living with HIV meant and that they would not

maintain the privacy of such information were the main barriers toward disclosure in work

settings for each participant.

Similarly, those participants who were incarcerated reported never having to disclose

their status to other inmates in the facilities. Participants reported that they maintained a private

HIV status because they feared that others would discriminate against them and the information

would not be kept private, thus affecting their daily functioning. Participants also expressed that such information was not intended to be shared with people who had little knowledge about HIV/AIDS. An interesting finding in a study conducted by Derlega, Winstead, Gamble, Kelkar, and Khuanghlawn (2010) found that inmates commonly keep their HIV status private due to the fear of being stigmatized. The effects of stigma resulted in being rejected or treated unfairly by other inmates and being a victim of bullying and gossip within the facility. The participants in the Derlega et al. study also reported that other inmates lacked knowledge about HIV/AIDS, which contributed to their fear of HIV-positive inmates. Lack of knowledge also resulted in inmates making negative assumptions about the HIV-positive individual, including that the infected person was homosexual or that HIV was an airborne disease. However, those who were open about their HIV status reported that they disclosed in order to address the lack of knowledge and educate other inmates about HIV/AIDS and to feel relief from carrying the burden of keeping their HIV status secret. In the current study, participants were guarded about discussing their experiences during the times they were incarcerated, specifically not wanting to speak about those experiences in order to avoid having to revisit those unstable times in their lives.

Subsequently, participants in the current study first disclosed their status to an immediate family member, most commonly their mothers, followed by a sibling or a spouse. In addition, the length of time each participant kept his or her status confidential varied from several weeks to several years. Finding, as research shows, that HIV-positive individuals who wait longer to disclose their status have more time to accept their status and become more comfortable with disclosure (Serovich 2001; Winstead et al., 2002). Each time a participant disclosed his or her

status, he or she made a careful autonomous decision to do so. Following is an excerpt from a

conversation Bob had with his mother after being diagnosed with HIV for over two years:

> I talked to my mama on the phone and I say mama there's something I need to let you
>
> know. She said, what? And I said I'm HIV positive. And my mama said, my God how
>
> did that happen?! She said, how the hell? And I say, what do you mean how the hell?
>
> Well, I said that I had sex and that's how I got it. And she said, well who gave it to you
>
> so I can get her. [*Bob laughs*] And I said, no, after all these years I don't remember who
>
> I slept with, if I would have known who it was I wouldn't be bothering with her. And she
>
> was like, oh my god. And I said, mama look, don't worry about it, don't worry about it
>
> 'cause I'm gonna be all right. So I said, don't say nothing to nobody or tell nobody
>
> nothing.

Even after disclosing to his mother, he asked her to keep his status a secret from others until he

made the autonomous decision to disclose himself.

The decision to disclose seemed to always be influenced by how much the participant

trusted the other person to keep the information confidential. Also, participants reported that

they disclosed their status in hopes that the persons they confided in would become sources of

support. Also, the decision to disclose was made on an as-need-to-know basis. For example,

Jack described an experience in a narcotics anonymous group, stating, "Even in NA or whatever

anonymous, they discuss their life openly, but I never shared that [HIV] part of my life. Just

didn't see the point to tell them." For those participants who had children, disclosure was even

more difficult.

Participants reported that the main reason they decided to disclose their status to their

children was the fear that someone else would tell them first and that this would negatively

impact their trust and relationship with the children. Mothers in a study by Schrimshaw and Siegel (2002) cited additional reasons for disclosing their status to their children, including wanting to teach their children about HIV/AIDS and wanting their children to know the parent's status before the parent became very ill. Further, HIV-positive parents are often concerned about the effects their HIV-positive status may have on their children. However, disclosure is associated with an improvement in the parent-child relationship. Nonetheless, children of HIV-positive parents experience higher levels of emotional distress because their parents are living with a highly stigmatized chronic illness. Participants in the current study reported that although this was an emotional disclosure, it was helpful to have correct information about HIV/AIDS in speaking with their children about being HIV-positive. Also, during the disclosure process with their children, parents were very concerned that their children might experience mistreatment because of their parents HIV status or feel burdened by keeping the status a secret from others. Overall, however, participants reported that this disclosure did not negatively impact their rapport. In fact, each parent continues to have a positive relationship with his or her children, and the children adjusted well to the news.

Importantly, although some participants disclosed their status with the support and encouragement of another HIV-infected individual or HIV professional, all participants were given the autonomy to decide how they wanted to approach this process and how much privacy they wanted to maintain. For some participants, being able to keep their HIV status private provided them with a sense of stability and validation so that they could function in their communities. To increase their privacy in the community they lived in, some participants sought support outside of their neighborhoods. Seeking such support also further empowered the person to function independently, while decreasing their daily stressors and sources of worry. Lastly,

although each participant placed great importance on keeping his or her status private, as a result

of the neighborhoods most of them lived in at the time of the interviews, their neighbors either

knew or suspected each participant to be HIV-positive. Accordingly, participants maintained

other information about their lives private, such as the results of their blood work, their

relationship status, and concerns for the future.

In conclusion, autonomy was highly valued by each participant and helped him or her

gain and maintain control over living long-term with HIV/AIDS. In spite of the fact that all

participants had an individual story to tell, their experiences varied, and the paths the participants

took through this stage were diverse, they also had commonalities. Participants described

autonomy as a process of becoming more aware of and about HIV/AIDS, becoming motivated

and empowered to make changes, and making conscientious decisions to facilitate change while

maintaining privacy. This process helped them to accept their HIV status and learn to live well

with HIV/AIDS. Although autonomy was emphasized, each participant also emphasized the

importance of social interactions, without which living well with HIV would have been more

difficult.

Belonging

Illustrating the importance of the basic human desire to feel wanted and not alone, Mary

stated, **"**I was crying out for somebody to take care of me and he saw that I needed somebody."

Accordingly, the second axial category I identified from the data was the value of belonging.

Although all of the participants had different stories regarding disclosing their status, they all

expressed an underlying fear of being abandoned, ostracized, and alone. They all also expressed

that the emotional support they received from other people who made them feel respected,

validated, and like they belonged in the world helped them to cope and accept their new reality.

Research in the area of coping, relationships, and support indicates that emotional support is strongly associated with emotional and physical well-being, and better adjustment to living with HIV/AIDS (Siegel & Schrimshaw, 2000; Turner-Cobb et al., 2002). Participants in the current study sought emotional support and a sense of belonging by attempting to relate to other HIV-positive and HIV-negative individuals, as well as continuously seeking respect and acceptance in their intimate relationships.

Relatedness

One of the most helpful aspects of human connection described by the participants was having the ability to relate to another HIV-positive individual. This sense of relatedness seemed to normalize their experiences, provided them with hope of a long future and validation, and helped them to develop an understanding of what living with HIV was like. According to Amy, "things changed [for the better] because it's made me a stronger person to, you know, sit back and look back that I'm not alone and that there's a lot more people that have it [HIV] and they're fine." In addition, by being able to relate to other PLWHA, the participants found a profound amount of emotional support, without which their work toward accepting their status would have been harder. Consequently, being satisfied with one's social support network has been associated with increased psychological well-being and an improved quality of life for PLWHA (Safren, Radomsky, Otto, & Salomon, 2002; Turner-Cobb et al., 2002).

Specifically, these long-term survivors of HIV/AIDS had to restructure their relationships with friends, family, and partners multiple times since they learned of their diagnosis. Often, this meant that they lost relationships and support and had to build and define a new relationship. This was a challenging task because participants noted that the loss of a relationship, mostly due to effects of stigma, resulted in negative health outcomes including increased emotional distress

and withdrawal from social interactions. However, such experiences directed the participants to seek support among other HIV-positive individuals. In a study examining long-term survivors of AIDS, Barroso, Buchanan, Tomlinson, and van Servellen (1997) also found that, due to the effects of stigma, people living with AIDS lost relationships and had to renegotiate new relationships throughout the progression of their illness, often seeking support in other PLWHA. They often found help in support groups or by helping others living with HIV/AIDS to live well.

Although all of the participants in the current study attended either a support group, individual counseling, or both, none of the participants worked or volunteered to help directly newly infected individuals. However, it is important to point out that a few participants like Louis, Adam, and Amy recommended that newly infected individuals would greatly benefit from speaking with an HIV-positive individual as a means of coping with their new diagnosis. Louis made the following recommendation to a newly diagnosed person and a long-term survivor:

> Sit down and talk with them and let them tell you about their experience. You tell them how you dealt with it whether highly emotional or not, explain how you coped with those emotions and what you used to cope with them. That can help them.

These participants also reported that they would be interested and willing to sit down and share their experiences with a newly infected person and believed other HIV-positive individuals would feel the same. A study by Baumgartner (2002) with long-term survivors of HIV also found that making positive changes by speaking about HIV/AIDS and making meaningful contributions for other HIV-positive and HIV-negative individuals with a community was highly valued. Lastly, while restructuring relationships to increase a sense of belonging and emotional support, participants sought relationships where they would feel respected and accepted.

Respect and Acceptance

Participants identified finding respect and acceptance in their relationships with other infected individuals, with their health care providers, and among certain family members and friends. The health care providers included physicians, case workers, mental health therapists, and HIV-prevention outreach personnel. These professionals seemed to offer significant guidance from the beginning of each participant's infection throughout the progression of his or her illness. Participants reported receiving quality guidance and support, while feeling close to their care providers. They also reported, consistent with other research findings (Cote et al., 2012; Mutchler et al., 2011), that the health care professionals instilled hope and encouragement for living a long life with HIV. For example, Lila described that she felt supported and respected by her case worker and other infected individuals while she was going through the process of disclosing her status to her mother:

> Uhm, well I talked about it with her [case worker] and a few friends of mine that had their HIV and they all sat down and talked to me and you know I said I'm not ready. And they said if you're not ready then don't tell her but she needs to know if something happened and not be the last one to know. And then they told me I still had time to say something, you know like time really wasn't running as fast.

Also, family and friends seemed to have the most impact on the participants' sense of belonging. However, most of the fear related to disclosure and restructuring relationships was negatively affected by stigma, including fear of the reactions to disclosure, loss of a relationship, and being ostracized by a close friend or a family member. For example, Mary described how her biggest fear came true after she disclosed to her mother that she had HIV:

My mother is awful, she doesn't care that I'm her daughter but only that I have HIV. Do

you know how hurtful it is for your own mother to drop you off at a facility and not let

you be at home because you don't want her to eat from the same utensils or sleep in the

same bed?

This experience for Mary resulted in her feeling victimized, mistreated, hurt, and unwanted.

This changed her relationship with her mother, which until the point of Mary being diagnosed

with HIV was close. Mary lost her mother's support and respect. Her mother no longer

accepted Mary as her daughter, and even after 11 years since this incident occurred, Mary's

mother continues not to accept Mary as her own. Finally, similar incidents or fears of such

incidents negatively impacted other participants' abilities to cope and restructure their

relationships, which made movement toward stability increasingly difficult.

Accordingly, it is important to mention that a common finding in the literature is that

PLWHA are often blamed for becoming infected, which is identified as a reason for increased

discrimination (Herek, Capitanio, & Widaman, 2002; Herek & Glunt, 1988; Mak et al., 2007).

However, of all the participants only Mary alluded to the fact that the way she contracted HIV

was part of the reason she was mistreated by her mother and other family members. When I

asked other participants about whether they believed their route of transmission influenced their

experiences of stigma, they denied believing it did.

Also, the experience of victimization or mistreatment implies that the stigmatized person

is a lesser person and in turn is not respected. Feeling unsupported decreased the sense of

belonging for participants. On the other hand, increased emotional support from family

members and friends, a well-documented phenomenon in the literature (Ndlovu, Ion, &

Carvalhal, 2010; Pequegnat & Bray, 1997; Siegel & Schrimshaw, 2000), resulted in the

participants feeling accepted and increased their sense of belonging. Bob described a strong sense of being accepted and respected by his mother who during Bob's most difficult moments never abandoned him. Bob described this, stating,

> [She would] literally drive to the corner to bring me some food if I didn't go home and she would beg me to come home. But sometimes I said I would come home but I didn't but she was always there. My mama loved her children.

Respect and acceptance by health care professionals, family, and friends had an impact on belonging and the restructuring of relationships. Another factor that impacted belonging and was often very complex for participants was intimacy.

Intimacy

The ability to have an intimate relationship with partners who were presumed to be emotionally supportive was a recurring concern for the participants. Having a physically and emotionally intimate relationship was something each participant desired but hesitated to initiate. Most of the participants reported that with time, beginning and maintaining intimate relationships became easier, but starting a relationship continues to be stressful.

Mary and Louis, who were married to each other, reported feeling fulfilled in their relationship. Although they have a physically intimate relationship, they placed great value on emotional intimacy. Mary described the intimacy in their relationship by comparing her past relationships immediately before and after she was diagnosed to her relationship with her husband stating:

> I've been treated like I'm a worthless piece here in the world. I was living with some other couple of guys on the street and they were physically beating on me and taking

> things from me and it's rough for me, but that's why I'm with my husband. He keeps me
>
> under his wing and I know that I'm going to be all right.

Being loved and accepted gave Mary courage, hope, and reassurance to continue living. For

Louis, Mary also had a significant impact on his life, which he described: "She has given me

more reason and purpose to live with my HIV, to accept it even more." Intimacy impacted their

relationship and resulted in them feeling like they belonged in the world and that they could be

loved while living with HIV.

For the single or divorced participants, they were either romantically interested in

someone at the time of the interviews or hoped to be in a romantic relationship in the future. The

most common concern that came up for these participants included how an HIV-negative or

HIV-positive potential romantic partner would react to them being HIV-positive. Joy, who had

been divorced, reported that she often finds men being attracted to her and yet she is cautious

about how she approaches a relationship with them. Joy reported that often "when I tell 'em I've

got HIV that's when I want to have a sexual relationship with 'em and then I see how they

react." Each participant knew that by law they would need to disclose their HIV status to a

potential partner and did not have any hesitations doing so. Although past studies indicated that

some HIV-positive individuals would misrepresent their status to potential sexual partners, more

recently PLWHA accurately disclose their HIV status and take precautions to prevent infecting

sexual partners (Benotsch et al., 2012). Benotsch et al. (2012) identified that one factor that

influences HIV-positive persons to misrepresent their status to a sexual partner includes being

less aware about HIV/AIDS. In other words, being more aware about their status and

knowledgeable about HIV/AIDS increases how candid HIV-positive individuals are with their

sexual partners about their HIV status. Being less candid during disclosure was the second factor

that increased the chances of misrepresenting their status. If HIV-infected individuals are open about disclosing and do not suspect that their partners are also being deceitful in some way, the infected individuals are more likely to be candid when disclosing their status, thus preventing transmission.

In addition, participants felt seeking relationships with others who are living with HIV will make it easier for them to be accepted and understood. Having an intimate relationship with another HIV-positive person also seemed to increase relatedness between the partners. Also, having sexual intercourse with another HIV-positive person decreased the amount of worry regarding transmitting HIV to the other individual. Although intuitively this makes sense, participants were also aware of other risks of being sexually involved with HIV-positive persons. Studies also support this notion and stress the importance of disclosing HIV status accurately but assert that the risk for contracting other sexually transmitted infections still exists and should be taken seriously (Niccolai, D'Entremont, Pritchett, & Wagner, 2006). Lastly, it is important to point out that the participants did not exclusively have sexual relations with only HIV-positive individuals, nor did they exclude the option of having sexual relations with HIV-negative individuals.

Although their partners' HIV status was of concern, the main benefit of pursuing physical and emotional relations was to gain emotional support. When participants had poor or unhealthy relationships, the degree of intimacy decreased as did their emotional support. When participants were able to find positive relationships with physical and emotional intimacy, the level of emotional support increased. This resulted in an increased sense of relational stability, which in turn positively influenced their sense of belonging.

Resiliency

The third axial category I identified from the data was the value of resiliency. Throughout the interview process, I was struck by the tremendous resiliency these individuals exhibited when faced with a multitude of hardships prior to being diagnosed with HIV and even more hardships since being diagnosed. They showed strength in the face of adversity. They persevered through being stigmatized, mistreated, and labeled. Unfortunately, these experiences were part of the process of change in learning how to live with HIV for an extended period of time. An overwhelming amount of research on HIV/AIDS speaks to how difficult and complicated living with this illness can be. One area of hardship that a large body of research focuses on is stigma. Unfortunately, no HIV-infected individual can escape its effects and this was true for each participant in the current study. Even though each participant experienced stigma, participants' experiences were diverse in regard to how different areas of their lives and how severely their functioning was impacted by discrimination they experienced due to being HIV positive. Most importantly, however, they persevered.

Stigma

Participants possessed skills that protected them from being discriminated against for living with HIV/AIDS. Their conscientious decision-making, ability to maintain privacy, access to social support, and self control served as protective factors against the effects of stigma. A commonly reported experience of stigma was overhearing others speaking about HIV around the participant without knowing he or she was HIV-positive. Bob described a similar experience:

I know that people have to socialize. I don't mind barbecuing, but when it gets

overwhelming and uncomfortable conversations come up they have a tendency to say

certain things. And the talk about someone having the s-h-i-t [HIV] and how they're

going to die--they really don't know what they are talking about.

Amanda had a comparable experience while on a bus:

It's sad that at our time people are still like this. I've been on the bus and I could hear

them talking about he's just got it or she's just got it, AIDS. They will literally make

jokes about it. They even got a name for it, "ninja," it means HIV. You'll hear them say,

don't mess with him he got that ninja. That's the word like as if it's a cold they got. It's

sad. I've heard this numerous times.

Both Bob and Amanda, as well as other participants with similar experiences, believed that

others made such comments because they lacked knowledge about HIV/AIDS, including routes

of transmission, and thus feared interacting with PLWHA. Sadly, even though over the years

knowledge about this epidemic has been widely disseminated, people continue to be uninformed

(Varni, Miller, McCuin, & Solomon, 2012). Also, listening to such comments and not reacting

took great self-control in the midst of hurt and disappointment. Although the intensity and

frequency of the stigma experienced by the participants varied, it always resulted in negative

emotions and increased stress for the participants. In addition, being actively discriminated

against or mistreated and experiencing stigma frequently result in higher levels of depression

(Emlet, 2007), an illness some participants struggled with during the course of their disease

progression.

One way that Bob and Amanda, like many other participants in similar situations, chose

to cope with this stigma was by avoiding participating in such conversations. Often, avoidance

was a protective factor. Avoidance in the form of walking away or not participating in such

conversations resulted in not having to broach the subject and preventing others from suspecting

their HIV status. Although it was an effective coping strategy in the moment, avoidance had a

negative impact on participants' psychological well-being, including increased levels of stress,

emotional discomfort, and in some instances feelings of worthlessness. Similarly, people who

tend to cope with stigma through avoidance experience higher levels of anxiety and lowered self-

esteem compared to those who actively cope with stigma (Varni et al., 2012).

One factor that increased the participants' resiliency toward stigma was being able to

speak about its effects with others. Thus, their willingness and ability to seek help from others

were important factors that improved resiliency. Consequently, by speaking with others about

their experiences of stigma, participants gained confidence, another factor that seemed to

increase their resiliency to the stress associated with stigmatization.

Another area where seeking help and increased confidence became important factors of

resiliency was being stigmatized by family or friends. This seemed to have the greatest

emotional impact on participants and often resulted in loss. The effects of stigmatization were

particularly clear in Jack's story. He reported that his immediate family members allowed him to

continue living in their home, but provided him one particular plate and set of utensils that he

was to use:

> It was just mine and it wasn't put away, it was just always left on the table and just sat
>
> there. I could use the bathroom, but when I was finished, the bathroom would get
>
> sprayed down and everything. If I'd just walk in, the bathroom would be sprayed with
>
> stuff. After that I was there for about a year or so and then I left.

After that year, Jack moved out and lived with an HIV-negative friend before moving to south

Florida. For Jack, leaving his situation and using his support system was what gave him the

freedom and strength to change his situation. Thus, gaining control over one's life was a factor that influenced resiliency.

In addition to using social support, talking about emotions, and taking control over one's life, clarifying information about HIV for others seemed to improve resiliency. Lila struggled with disclosing her HIV status for several years due to fear of experiencing stigma. Although she had been diagnosed with HIV for the past 12 years, she began disclosing her status just a few months before the interview occurred. This is how she described her experience with using social support and briefly educating her friends about HIV:

> Well they [friends] told me you don't look like you got it and I said that well ok but some people can live with it long time and you can't tell, and they didn't know. One of my friends didn't take it too well and she worried about me and I said that as long as I'm doing what I have to do I'm here and I'll call you every day. But she's like a big support for me. . . . Before, I was just keeping it bottled inside and I didn't know how I was going to tell it, how they were going to react to it, and I finally felt not too bad when I was telling. It made me feel really good when I told them, especially when I told my mom.

Being able to speak about having HIV resulted in a sense of relief for Lila and other participants. Educating others about their illness further increased their resiliency.

Overall, asking for and utilizing systems of support, speaking about their experiences of stigma, increasing confidence, and educating others about HIV/AIDS were factors that positively affected participants' resiliency toward stigma and toward living with HIV/AIDS for an extended period of time. Living without these factors would have likely resulted in increased levels of stress and mental health concerns. An additional factor that helped improve resiliency was a

shift of perspective toward becoming more optimistic about their abilities to live long term with HIV/AIDS.

Perspective Shift

At some point in the process of learning to live with HIV, participants experienced a shift in their perspective about living. Initially, the reactions participants reported to learning their status were shock, fear, disappointment, pain, helplessness, and hopelessness. Following is an example of how negative and helpless Lilly felt about her life upon learning of her infection:

> I had gotten with my mom and she said, Lilly, baby, don't commit no suicide. God says it's a sin to take your own life. Well, I said, so if they say heaven is as great as it is, then why can't I take myself out and go on ahead?

She saw no hope in her life and felt powerless. However, with her mother's support she persevered. As Lilly's and other participants' illness progressed, their coping became more advanced, their perspectives started to become more positive, and their resilience increased. Their attitudes toward their illness began to change and many used a sense of humor as a lens through which they viewed their lives, which improved their overall affect and well-being. In turn, they began to feel hope for the future, to have control over their lives, and began to see possibilities for a better future. Accordingly, they became more oriented toward thinking about their future, a perspective shift also identified in a study by Courtenay, Merriam, Reeves, and Baumgartner (2000). In addition, optimism is highly associated with an increase in PLWHA perceiving positive change since learning of their diagnosis (Brydon, Walker, Wawrzyniak, Chart, & Steptoe, 2009; Ironson et al., 2005; Milam, 2006) and believing in their abilities to be change agents in their own lives (Mukolo & Wallston, 2012).

For the participants in the current study, being optimistic about the course of their lives decreased levels of stress and improved their overall emotional well-being. Such was the case for Adam, who stated, "You know I've come from places that are dark and then sunlight, and so I try to look at the light instead of the dark." Such a viewpoint improved Adam's functioning and gave him the strength to continue living and the courage to make positive changes in his life.

Hope

The fourth axial category I identified from the data was the value of hope, which seemed to motivate participants to continue living. When participants felt hopeless or lost, they also lacked direction for the future. They were less motivated to act, live, seek support, or work toward change, which resulted in depressed mood, increased anxiety, risky behaviors, substance use, and sometimes suicidal ideation, as illustrated by Louis:

> Before I was diagnosed I had little plans for the future but over the years I developed more goals. Before I didn't have goals 'cause I always believed I was put here because I would be an example of a crack addict, so I had no plans. So I was just a person at work, in prison, with HIV, smokin' crack. Now I do have goals.

Hopelessness perpetuates instability and makes it more difficult to begin reevaluating or identifying future goals; hope, as has been identified by other researchers, is a necessary characteristic of living with HIV/AIDS (Cutcliffe & Zinck, 2011; Folkman, 2010). However, hopelessness is often a necessary step in a process of developing hope and meaning for PLWHA (Zinck & Cutcliffe, 2013).

For the participants in the current study, as their illness progressed, hope developed from a variety of sources including religion, love, support, availability of improved medications, hitting rock bottom, asking for help, and psychoeducation about HIV. Once a participant began

to feel hopeful, he or she became energized to make changes in his or her life, and the depressed

mood, anxiety, and risky behaviors decreased. Hope seemed to influence positively the

participants' ability to cope with living with HIV, a concept supported by the literature (Harris &

Larsen, 2007; Plattner & Meiring, 2006). Also, having the knowledge that people now live with

HIV for several years and that the diagnosis is no longer a death sentence provided the

participants with a context within which they could make change in their lives.

Coping

One of the first steps for all participants after they learned they were HIV-positive was

increasing their awareness about the illness. Although the reluctance about receiving such

information and the timeline for doing so varied among the participants, learning about

HIV/AIDS seemed to provide each of them with relief that their life was not over. As

participants realized what it meant to be HIV-positive, they were faced with numerous

uncertainties about their present and future. The second step toward hope came from an array of

HIV-care professionals. As Amanda reported, "Yeah, you know, the first few weeks you are

shocked and get your bearings, but the next few weeks you gotta get the information and start

thinking what you gonna get done and get the help." Or as evident by Joy's comment, "Going to

support groups that they had and having a case worker that I can sit and talk to about it [a]

majority of the time and getting phone numbers for support places, that helped a lot." In addition

to interacting with physicians, counselors, and case workers, participants also reported that

attending peer and other support groups helped them to cope, a commonly reported experience of

most PLWHA (Hedge & Glover, 1990; Slomka, Lim, Gripshover, & Daly, 2012).

Those participants who sought support and were proactive about getting help, as opposed

to participants who were more avoidant of learning about HIV, seemed more hopeful about their

futures. Avoidance coping is frequently identified as a poor coping style that results in negative

health outcomes for PLWHA (Ironson et al., 2005; Lobel et al., 2002; Slomka et al., 2012).

Participants also seemed more hopeful when identifying future goals.

It is also important to note that a large body of literature identifies religion and

spirituality as factors associated with good coping that improves the quality of life for PLWHA

(Kaplan et al., 1997; Plattner & Meiring, 2006; Simoni, Martone, & Kerwin, 2002; Vance,

Brennan, Enah, Smith, & Kaur, 2011). However, in the current study, only two of the 10

participants identified faith as an important factor that helped them to cope or feel hopeful about

their life. Not only did faith give them hope, but it also gave their life meaning and purpose,

which helped them come to terms with their illness and cope with living with HIV/AIDS.

Following is a statement Adam made when I asked him about coming to terms with living with

HIV:

> My spiritual foundation, my mom and dad had instilled this faith that there is a reason for
>
> everything and I believe strongly in a higher power. Otherwise I'd blame him [God] for
>
> what he did to me, but I don't. I believe that it's going to be all right. I believe my faith
>
> carries me every day. It's an unseen fact that I'm going to be all right.

Faith gave Adam and Bob the will to continue living and hope for a positive future. Being

hopeful helped them to develop goals for an independent, simple, and satisfying life.

Simplicity

As participants continued to live with HIV they became more hopeful about their futures

and made positive changes in their lives. Factors that made life more manageable were

simplicity and a sense of security. "Staying away from drama and living within my means is

something new to me, but it's worth it" (Lila); thus, keeping things less complicated and being

surrounded by supportive people helped the participants to continue working toward their goals. Often, reflecting on what one values and needs to survive, being thankful for living, and appreciating nature and simple things in life contribute to living well with HIV/AIDS (Baumgartner, 2002). Although all of the participants continued to struggle financially, they lived within their means, which seemed to make their lives more manageable. Such simplicity decreased their reactions to stress, helped them to avoid increased problems, improved their ability to manage their illness and relationships, and made their decision making less complicated.

Overall, simplicity seemed to impact positively the number of uncertainties in the lives of the participants by reducing their levels of stress. The literature illustrates that reduced stress is linked to positive health outcomes for PLWHA (Antoni et al., 2008; Leserman, 2003). Adam agreed:

> You can weave yourself into a web of problems and getting out of it is tough. I just want to live in my means. It is what it is, it's not easy to do but I try not to complicate my life, because it's easy to do. . . . I'm living close to the beach. It's peaceful and quiet.

As a result of keeping their lives simple, the participants remained motivated and hopeful that they could control their futures as HIV-negative individuals do.

Overall, feeling hopeful about their futures helped participants to cope, accept, and live with HIV/AIDS. Simultaneously, hopefulness decreased their stress levels and improved their functioning. Their improved functioning also made them feel more hopeful about their future and gave them the confidence to believe that they could continue living well with HIV/AIDS.

The Process of Accepting and Living

Living with HIV is a complicated process. With pharmaceutical and medical advances, the life expectancy for PLWHA continues to expand. Due to increased longevity, PLWHA face numerous challenges that have to be balanced in order to live well with this illness. All 10 participants in the current study are long-term survivors of HIV/AIDS who function well within the world. Through their lived experiences they tell a story of how they survived trauma and came to embrace life.

Substance use, risky behaviors, and volatile romantic and family relationships created instability, resulting in each participant contracting HIV. Although their stories began in a time of instability, they continued creating stories within their realities of an ongoing process of accepting and living with HIV/AIDS. The process of accepting their diagnosis and living with this chronic illness cannot be identified by a succession of steps and does not have a clearly defined end point. Instead, this ongoing process entails a constant reconstruction of goals, relationships, and identity, an extremely complex and fluid process. Amy best described this process through the use of a metaphor that captures the realities of life for these 10 participants:

Everything just went pitch black and I would just be sitting there feeling like a mouse, just there, like in a dark hole, just waiting for some light. But you know, it was tough and like real tough sometimes, but I crawled out of that hole and keep crawling into the light.

In addition, their lives were marked by turmoil, shock, trauma, and loss immediately after being diagnosed. For these 10 participants, this process was challenging and ongoing. With time, each participant began to adjust and accept his or her illness and the new reality that came with it. Throughout this process, participants learned how to adapt to the world, but they also had to readjust constantly. Thus, the process of acceptance is not as easy as accepting one's status and

moving on. Once the trauma of learning one's status takes an emotional toll on the infected individual, the shock of learning one's diagnosis lessens, and the challenges of living with this illness set in. The HIV-positive individual continues to be reminded throughout life that he or she is living with a highly stigmatized chronic illness. Because this reality is always present, accepting one's status is a process that is constantly reevaluated and fluid. Also, living does not end as one comes to accept one's illness. Instead, acceptance and living are one process and occur continually. In addition, the necessary values for accepting and living with HIV/AIDS for an extended period of time are autonomy, belonging, resiliency, and hope.

These values are also fluid processes that interact and are interwoven as they facilitate this continuous development. Specifically, although the process begins once an individual becomes aware of his or her HIV status, it continues as he or she learns about HIV/AIDS and available treatment options and comes to terms with the fact that life is going to change forever. It continues because no person is ever finished increasing his or her awareness or learning new things about him or herself or the world. In turn, this often empowers individuals to make autonomous and conscientious decisions about their lives. Feeling empowered and making decisions was part of each participant's life even prior to being diagnosed with HIV. However, since being diagnosed, each participant developed a will to endure increasing amounts of uncertainty, which he or she managed effectively by making autonomous decisions about his or her life. Through the decision making process each participant addressed numerous uncertainties, including how to manage his or her health, relationships, finances, living arrangements, substance use problems, and disclosure, all while maintaining privacy. In addition, this process continued within a social context fueled by a strong desire to belong.

All of the aforementioned values interplay within a dynamic social context to which each participant had a desire to belong. Participants seemed to experience a greater sense of belonging when they were able to relate to other HIV-positive individuals. Part of relating was speaking to someone like themselves who underwent a similar process. Having this type of relationship seemed to normalize each participant's experience of living with HIV and decreased his or her feelings of loneliness and loss. Other ways participants sought to belong was by seeking the respect and acceptance of family, friends, and health care personnel. Being respected and accepted was specifically important at times of disclosure. Participants' biggest fear regarding making decisions around disclosure was the fear of being stigmatized, victimized, or mistreated because of their HIV-positive status. At one time or another, their fear came true. However, there were also other instances in which they experienced respect and acceptance from family and friends who loved them and empathized with them. In addition, the positive relationships they developed with HIV-care providers provided them with encouragement and hope for a bright future.

Lastly, each participant sought physical and emotional intimacy in their relationships with current or potential romantic partners to intensify their sense of belonging. All of those meaningful relationships provided the participants with the support systems they needed in order to adapt continually and readjust to living with HIV/AIDS. Belonging made the participants feel that they continued to have a place in this world, which motivated them to continue living, which was impacted by their resiliency and perseverance.

Because belonging provided participants with emotional support, it also strengthened their resiliency to persevere through experiences of stigma. Being part of a group and having a strong system of support acted as a shield against uncertainty, changes, and stigma. Resiliency

was marked by being able to utilize systems of support that further strengthened the individual and improved his or her functioning and coping.

Accordingly, resiliency was highly valued by, and a necessary characteristic of, the participants, especially when each participant reported experiencing direct or indirect stigmatization. Often, participants dealt with the stigma by avoiding confrontations or actively addressing them by educating others about HIV/AIDS. Taking an active approach toward addressing stigma also increased their confidence. Another factor that contributed to their resiliency and courage was a process of shifting perspective toward optimism. Participants went through a process of shifting their perspective from a negative and hopeless attitude about their future to a positive and hopeful attitude. Such a perspective shift was a strong resiliency factor for the participants that resulted in an increased sense of hope for the future. This gave participants hope that they were able to be autonomous individuals within a social context, where they could build up resiliency and cope with stress, even if they were going to remain HIV-positive throughout their lives.

Hence, hope seemed to motivate each participant through the process of accepting and living well with HIV/AIDS for an extended period of time. Hope perpetuated the participants' desire to continue living and making positive changes in their lives. Changes began when participants felt hopeful and relieved that being diagnosed with HIV did not mean that their lives would become drastically shorter. Instead, by utilizing numerous coping resources and strategies, participants were able to make autonomous decisions about their futures. This autonomy also empowered participants to pursue actively a sense of belonging. Whether through faith or other sources of support, participants felt hopeful that they could live meaningful, long lives with this diagnosis. They also decided to live within their means to

simplify their lives and reduce life stressors in order to improve the quality and longevity of their lives.

The process of accepting and living with HIV/AIDS is multidirectional, continuous, and achievable. It is a process in which autonomy, awareness, empowerment, conscientious decision making, privacy, belonging, relatedness, respect and acceptance, intimacy, resiliency, stigma, perspective, hope, coping, and simplicity create a dynamic that make it possible for long-term survivors of HIV/AIDS to readjust continuously in order to accept and live meaningful lives with this complex illness. The life experiences of the participants made them experts on the topic of living with HIV/AIDS for an extended period of time. As experts they shared their stories with the hope that newly diagnosed persons gain some understanding and hope that, although accepting and living with HIV/AIDS is difficult, living a long and happy life is possible. To conclude are words of advice from Lilly:

> You can't let the fear of dying hinder you, you have to let it go to starting living your own life with HIV. So I'm at the point, Sylwia, that I'm, I'm comfortable with it now. I'm content with it because it is what it is and I'm not letting it put the fear in me but just live and enjoy life.

CHAPTER 5

DISCUSSION

The rich data from the interviews with ten long-term survivors of HIV/AIDS provide an understanding of what the process of accepting and living with this complex illness is like. This chapter concludes as I outline (a) a summary, (b) a conclusion of the current study, (c) implications of the study, and (d) recommendations for future research.

Summary of the Study

Because HIV/AIDS has been around for three decades and millions of people continue to be affected by this epidemic, it is crucial to learn about those who have been living with this chronic illness for an extended period of time. The purpose of this study was to gain an understanding of the experiences of long-term survivors of HIV/AIDS and begin to develop a theory about how identity and self-concept of PLWHA shift through the progression of the illness.

To do so, I chose the constructivist paradigm, which emphasizes that reality is constructed, interpreted, and based on a person's lived experience within a social context (Ponterotto, 2005), as the conceptual framework for the study. In addition, I used the biopsychosocial approach as a framework for understanding the complexities of living with a chronic illness around which reality is constructed (Engel, 1977). To gain accurate understanding of the phenomenon of long-term survival with HIV/AIDS, within a naturalistic

context (Denzin & Lincoln, 2005) as opposed to a controlled environment, I chose the qualitative approach as the theoretical framework for the current study. Specifically, I utilized constructivist grounded theory to aid me in developing a depiction of the experience of living with this chronic illness for an extended period of time.

During the course of my interactions with 10 long-term survivors of HIV/AIDS, I was able to enter their world briefly and inquire about their experiences with some of the most common concerns reported by PLWHA, as identified in the literature. By conducting semi-structured interviews, transcribing, coding, and analyzing the information I gathered, I was able to learn about their daily uncertainties and stressors, experiences of stigma, decision making, reevaluations of their goals and relationships, disclosure, and coping. Throughout this study, I learned a great deal about the process each participant experienced to be able to live a meaningful life with HIV/AIDS.

Conclusion

I found that coming to accept and live with HIV/AIDS for an extended period of time is a complex and fluid process that involves the constant reevaluation or shifting of one's sense of self, goals, and relationships. Throughout this process, each infected individual is affected by a multitude of stressors, traumatic experiences, challenges, and obstacles. However, each person continually accepts the illness and the fact that living with it is possible and overcomes the trauma, stress, and challenges that often impede growth and stability.

Experience of Living with HIV/AIDS

The primary research question in the current study sought to identify what the experience of living with HIV/AIDS is like for long-term survivors. I found that the overall experience is complex, ridden with uncertainties and stress, as well as resilience and hope, and is constantly

reevaluated, reconstructed, and fluid. Specifically, I identified four values that were a part of this process, including autonomy, belonging, resiliency, and hope.

Participants' lives revolved around these dynamic concepts that helped them to accept and live with this illness. Within this ongoing process, through autonomy they were able to gain and maintain control over their lives and learn how to manage their illness, a crucial element for people living with a chronic illness, especially HIV/AIDS (Swendeman, Ingram, & Rotheram-Borus, 2009). Simultaneously, they longed for belonging and a sense of relational stability in their lives and a much needed and important source of support (Safren et al., 2002). Meanwhile, they struggled with their experiences of stigma and yet persevered and gained resiliency, which helped them to develop an optimistic and a future-oriented perspective about a hopeful future. Also, throughout this process they coped with uncertainties brought on by their illness. Similarly to other long-term survivors of this epidemic (Barroso et al., 1997; Shernoff, 1996; Slomka et al., 2012), participants in the current study lived day to day constantly reevaluating their relationships and goals, reconstructing their lives throughout this dynamic process.

I learned that a major milestone of living with HIV/AIDS is accepting the illness. Although it may be challenging, living with HIV/AIDS is no longer a death sentence. Also, acceptance is not a solitary step that one can complete. Instead, it is part of the fluid process of living. Although people might accept their HIV-positive status and cope with the initial trauma, disclosing their status at different points throughout life stirs up stressors that result in individuals having to accept their status and conceptualize their lives once again. For example, some of the women in the current study disclosed their status to their children, a difficult process for many, especially HIV-positive women (Ndlovu et al., 2010). In addition, at some point they also disclosed to their children's partners or friends. Such disclosure required them to

reconstruct their senses of self and identities, as they needed to continue redefining their roles as

mothers, mothers-in-law, grandmothers, and friends in the context of their HIV-positive status.

Because they played numerous roles throughout the years, this was an ongoing experience for

the participants, a commonly identified experience for chronically ill persons (Sparud-Lundin,

Ohrn, & Danielson, 2009; Swendeman et al., 2009). Thus, accepting one's status was a major

part within the process of living with HIV/AIDS. Also, I speculate that one can never truly

completely accept such a complex illness and move on without continuing to think about it or

acknowledging it as a change. I believe that the constant reminders of being HIV positive

continue to impact the daily functioning of these 10 long-term survivors.

Further, the advancement of antiretroviral medications, the diagnosis and treatment of

opportunistic infections, and the availability of organizational support have given PLWHA hope

that they can live their lives well for an extended period of time (Shernoff, 1996; Watkins-Hayes,

Pittman-Gay, & Beaman, 2012). Hope also energized participants to reevaluate frequently their

daily experiences of living with the uncertainties of their diagnosis. I also believe that the

sources of hope for the participants were many, especially relationships in which participants felt

respected and accepted as human beings and not as diseased individuals with mounds of

problems.

Since being diagnosed with HIV, participants had experienced a multitude of biological

and medical uncertainties that were caused by their illness and other opportunistic infections.

The uncertain progression of their illness, fluctuation in adherence to medications, and side

effects from the medications also affected participants' levels of psychological stress. This

uncertainty often resulted in mental health issues, substance use problems, and increased risk

behaviors that negatively impacted their overall psychological well-being and abilities to manage

their own care. In addition to the aforementioned stressors, stigma and disclosure also complicated the self-management of care for the participants, a challenge often identified by PLWHA (Swendeman et al., 2009).

Consequently, the highly stigmatized nature of their diagnosis also impacted their social functioning. Unfortunately, worldwide, most people hold negative views of HIV/AIDS and thus have negative attitudes toward PLWHA (Herek, 1999). In addition, because the prevalence of the epidemic is highest among already stigmatized groups, including gay men and ethnic minority groups, a person living with HIV/AIDS is often a target of layers of stigma resulting from lack of education, preexisting attitudes of prejudice, discrimination, and fear of contagion and death (Herek, 1999; Herek & Glunt, 1988; Lee et al., 2002; Shernoff, 1996). The participants in the current study had to address the psychological and social effects of disclosing their status and redefining their relationships throughout the years they lived with this illness. The process of disclosure was difficult for each participant. The consequences of their disclosure either enhanced or destroyed the participants' support systems. Either outcome further impacted their emotional well-being, which also impacted their physical health.

Lastly, because their experiences were filled with uncertainties, it was crucial for each participant to maintain autonomy through a sense of control over his or her life. Participants maintained control over their lives in numerous ways, simultaneously increasing their awareness, empowerment, and decision making while maintaining privacy and increasing their sense of belonging within a social context. All of these elements interacted, along with the participants' levels of resiliency, helping them to cope with uncertainty, establish goals, and accept and live with HIV throughout the progression of their illness.

HIV-Positive Identity

To further elaborate on the experience of living with HIV/AIDS for an extended period of time, the current study sought to explore how an HIV-positive person incorporates his or her HIV/AIDS status when constructing identity. Similarly, incorporating one's status into identity is a dynamic aspect of accepting and living with this chronic illness. Often, this results in an ongoing reevaluation and reorganization of how HIV-positive persons interpret the world, their expectations of themselves and others, and emotionally intimate relationships with family and friends (Baumgartner, 2002). I believe that the four values involved in the process of accepting and living with HIV/AIDS also influenced the identity development of each participant. Each time a participant would attempt to restructure a relationship, develop and accomplish a goal, make a decision, or feel empowered or hopeful in the face of uncertainties, his or her self-concept and identity changed. Overall, identity development seems to be shaped by a variety of experiences occurring throughout the life span. For HIV-positive individuals, this identity development process is further complicated by the unique stressors they experience.

For the participants in the current study, incorporating their status meant learning to accept and live as HIV-positive individual, which began with learning their status, a step that initially shattered their world. This also meant that learning how to manage their illness and normalize their experiences would become important components of the reconstruction of their identities (Swendeman et al., 2009). Research on HIV and identity describes identity construction as an ongoing and complex process (Baumgartner, 2002; Courtenay et al., 2000) within a stigmatized social context. Often, HIV-positive individuals report feeling a shift in identity upon learning of their diagnosis. They work towards reconstructing this identity by

making decisions about either incorporating or rejecting their status, identifying with other HIV-positive individuals, and managing their illness (Stanley, 1999; Tsarenko & Polonsky, 2011).

Although each participant identified him or herself as an HIV-positive individual, some made the conscientious decision to hide this identity from most HIV-negative individuals, a common experience for other PLWHA (Frye et al., 2009; Stanley, 1999). When participants in the current study decided to maintain their status privately, they did so because they feared being stigmatized, they believed others did not need to know their status, or they wanted to be accepted in their relationships or in their communities. Research also indicates that HIV-positive individuals who do not exhibit any symptoms of HIV have a tendency to disclose their status less frequently, as compared to individuals who are symptomatic (Frye et al., 2009). However, in the current study, participants did not report this to be a reason that had influenced their decisions regarding disclosure. Lastly, although studies have indicated that commonly PLWHA are ashamed of the stigma attributed to them for contracting HIV (Herek et al., 2002) and desire to shed such an identity (Rasera, Vieira, & Japur, 2004), the participants in the current study reported that they did not feel that the route of their transmission influenced their self-perceptions.

Most importantly, each participant constructed his or her identity within a social context. Similarly, other studies have shown that each individual's context defines that individual and he or she defines his or her context, and this is why identity development for a person living with HIV/AIDS is a dynamic and ongoing process (Frye et al., 2009; Laws et al., 2012; Tsarenko & Polonsky, 2011). Also, positive social interactions, especially within the community or support groups, result in decreased fear of stigma and increased sense of confidence among long-term survivors of HIV/AIDS (Baumgartner, 2002). In addition, for the participants in the current

study the sense of belonging impacted their perceptions of themselves, the amount of relatedness they experienced, and the quality of their relationships, all of which impacted their psychological well-being, sense of confidence, and sense of self. Accordingly, belonging, group membership, and relatedness influence identity development (Tewksbury & McGaughey, 1998). This was evident in the current study, as participants noted that their overall well-being, confidence, and self-concept changed according to the negative or positive nature of their social relationships. Accordingly, the utilization of systems of support has also been shown to impact positively the development of self-perceptions and the process of identity development of PLWHA (Tsarenko & Polonsky, 2011). Lastly, the process of becoming more aware of themselves and their illness empowered the participants to live life as an HIV-positive individual and gain control over their future.

With increased control and empowerment, participants became active change agents in their own lives. They learned which changes benefited or hurt them, decided what kind of resources best suited their needs and ability to maintain privacy, and explored what they expected from relationships. Such transitions impacted their way of interacting with the world since their diagnosis, as well as their ongoing identity reconstruction and development. Identity reconstruction and development are ongoing because growth and learning opportunities continue to be present in people's lives. Specifically, social interactions are integral to facilitating growth and identity development (Baumgartner, 2002). Accordingly, I speculate further that participants experienced increased autonomy when they chose to act on opportunities of growth, which impacted their overall identity development.

Overall, for these 10 participants being HIV-positive is a daily reality. However, the degree to which they allowed their status to define them was in their control. They were not

solely defined by their HIV status, as they are also mothers, fathers, partners, caregivers, providers, and friends. They are able to choose which roles define them most at any particular time in their lives.

Reconstruction and Survival

Another research question the current study aimed to examine centered around how long-term survivors of HIV/AIDS reconstruct their relationships, life plans, and self-concepts. Participants restructured their lives among the four special values that comprise the process of accepting and living. As autonomous survivors of HIV/AIDS within a social context of living with HIV, they became resilient to uncertainties, learned how to cope with stressors, and continued to accept and live within the fluid reality of this chronic illness. Simultaneously, their approach to relationships, life goals, and themselves continued to morph within this process.

Since learning of their diagnosis, participants had to renegotiate their relationships due to the effects of stigma associated with HIV/AIDS, a common experience reported by other long-term survivors of this epidemic (Barroso et al., 1997; Slomka et al., 2012). Participants had to reevaluate the quality of their relationships, as many of their friends and family members, neighbors, and co-workers rejected or mistreated them. They had to make careful decisions about disclosing their HIV status, upholding their privacy with family and friends, and managing intimate relationships. Throughout the progression of their illness, participants had to reevaluate their disclosure decisions and monitor membership within their support systems, an observed factor in older adults living with HIV/AIDS (Foster & Gaskins, 2009).

Also, participants felt a desire to restructure their relationships to involve other HIV-positive people in their lives, a concept other studies on long-term survivors of HIV/AIDS have found (Barroso et al., 1997; Baumgartner, 2002; Kahana & Kahana, 2001; Slomka et al., 2012).

This was also part of an ongoing process of normalizing their experience of living as an HIV-positive individual. Additionally, for the participants in the current study, relatedness or relationships with other HIV-positive individuals increased their sense of belonging, which resulted in an increase of self-esteem. Participants needed to make particularly careful decisions, as these decisions could significantly affect their psychological and physical health.

Participants also had to reevaluate how they functioned within their environments, including how to access and manage their own health care. This was especially important because most HIV-positive individuals endure the challenge of being their own primary caretakers (Swendeman et al., 2009). They had to reevaluate their life plans and goals based on the uncertain progression of their illness. Although participants continued to make life plans, they often limited themselves to developing daily and short-term goals not exceeding a year. Another study on long-term survivors of HIV found that due to frequent uncertainties surrounding the diagnosis, HIV-positive individuals have a difficult time making decisions beyond six months (Davies, 1997). Although participants made short-term goals, they also had long-term hopes and dreams for themselves and important people in their lives. While reconstructing their goals, participants were always simultaneously conscious of how their decisions would impact other people in their lives, as well as their own survival. However, their long-term plans were less concrete than their short-term goals.

Those participants who accomplished their goals did so by making their goals small and concrete, often utilizing their system of support to help along this process. Both women and men who received little support from their partners, friends, or family members often experienced increased levels of depression and other psychological distress (Dew, Ragni, & Nimorwich, 1990; Slomka et al., 2012). This further illustrates the importance of high-quality social support

for PLWHA and addresses the need to reevaluate constantly one's social support network. Accomplishing goals decreased their stress, caused them to live a simpler life, and empowered them to create more change. This increased their resiliency to stress and helped them to develop and utilize a multitude of good coping skills. Over time each participant gained more control over his or her life and felt more confident and hopeful about setting additional goals. When participants failed to accomplish goals, they experienced lower confidence, less optimism, and hopelessness. Conversely, after accomplishing goals, they experienced higher confidence, more optimism, and hope.

Overall, I speculate that social support, control over their lives, and hope positively influenced participants' environments, providing them the safety to reconstruct their goals. Without a sense of safety, restructuring goals would have proven to be more difficult and resulted in increased relational, personal, and overall life instability.

Synthesis of Findings

The experience of accepting and living with HIV/AIDS is an intricate dynamic process of interrelated values. For the participants in the current study this process was facilitated by four values of autonomy, belonging, resiliency, and coping. These values worked together to help participants continually reconstruct their lives, including identities, relationships, and goals since becoming HIV positive. Reconstructing one's life is a necessary part of accepting and living with HIV/AIDS. Otherwise, if an individual is unable to reconstruct multiple areas of his or her life, the process becomes more difficult and agonizing.

Further, experiencing acceptance and life as long-term survivors of HIV/AIDS is complex and involves working through various uncertainties and a world ridden with stigma. It takes a strong individual to navigate through so many challenges and still find the will to live.

Also, through hardship and challenges, hope and moments of joy, the strong long-term survivors in the current study found a way to accept and live with this complex chronic illness and create their own realities.

Lastly, other long-term survivors of HIV identify family, friends, care providers, pets (Slomka et al., 2012), hope, and optimism (Crossley, 1997) as reasons that motivate them to continue living. However, for the participants in the current study, it was their faith in themselves and their own abilities to survive and hope for a better future that motivated them to continue creating their realities as HIV-positive individuals.

Implications

The results of the current study have several implications for working with long-term survivors of HIV/AIDS. First, as PLWHA are continuing to live longer and are a part of our aging population, it is important that programs are developed that can enhance their life satisfaction. Specifically, programs that are designed to enhance the resiliency, effective coping strategies, and promote interacting with other HIV-positive individuals, would provide support and empower long-term survivors to make autonomous decisions and maintain control over their lives. In addition, such programs could also help newly infected individuals cope with accepting and living with HIV, by helping them to relate to other PLWHA, simultaneously normalizing the experience for them and informing them about the progression of their illness. Also, because awareness about the epidemic continues to be an important factor in decreasing stigma, it is imperative that outreach programming continue to educate the public on HIV/AIDS.

Outreach programming focused on addressing stigma should begin in multiple settings throughout childhood, adolescence, adulthood, and old age. Programming should continue to include components of education about the epidemic, to include contagion prevention strategies,

and to dispel myths about HIV/AIDS, utilizing PLWHA as speakers with whom the audience can interact. Such exposure would potentially benefit audience members by decreasing their fear of HIV-positive individuals. In addition, the process of educating others about the epidemic for the HIV-positive speaker would result in a sense of empowerment. Finally, developing peer support groups specifically tailored toward women, men, and long-term survivors would also improve the life satisfaction of PLWHA, presenting them with a reliable and regular support system that could help them to cope and live well.

Second, the findings of this study expand our knowledge about the experiences of long-term survivors and the process of accepting and living.   These findings can help care providers to gain a better understanding of problems associated with living with this chronic illness and to enhance their ability to individualize treatment approaches with PLWHA, specifically long-term survivors. Care providers can enhance their perspectives about the gamut of uncertainties, constant reevaluation, and reconstruction of relationships, identity, and goals that long-term survivors experience. Specifically, because of the increase of PLWHA, mental health professionals could benefit from learning about the process of accepting and living with HIV/AIDS for an extended period of time. Even in college settings, students are living with HIV/AIDS and could benefit from free counseling services at university counseling centers. Such sites could tailor their outreach programing to this population of students. In addition, being aware of the complexities involved in living with this illness can help therapists with appropriate treatment planning goals and objectives. Lastly, knowing that optimism and hopefulness are important factors that enhance the well-being of HIV-positive individuals, therapists could tailor their approaches to treatment appropriately.

Third, this study validates the extensive body of literature on stigma and can contribute to

more effective continuation of care outcomes by sensitizing care providers to a better grasp of the impacts of stigma. Care providers need to inform themselves about the effects of stigma and potential microaggressions they can act out that may be inadvertently affecting their clients. Collaborative, sensitive, and supporting relationships between care providers and clients often result in improved adherence to treatment. Therefore, being sensitive to clients' needs and treating clients with acceptance and respect are crucial for maintaining good rapport and helping PLWHA live well with this illness.

Recommendations for Future Research

One recommendation for future research is to continue conducting studies with long-term survivors of HIV/AIDS. Specifically, studies should further inquire about identity construction, acceptance, and lifestyle choices and how these change as the illness progresses. Additionally, studies can explore the benefits of simplicity as a lifestyle choice, housing concerns of PLWHA, and end-of-life issues. Future research can also focus on the HIV-positive college student and the non-traditional or returning HIV-positive college student. Such studies would help administrators and institutions develop programs to decrease stigma among the college population.

Further, with new medical developments such as at-home HIV test kits and rapid medication prevention for individuals at high risk for HIV infection, studies need to explore how these advances will affect disclosure and privacy among PLWHA. Also, most studies exploring the lived experiences of PLWHA have focused on individuals. Future studies should expand to explore couples where one or both partners may be HIV positive. Results of such studies could potentially have additional implications to help PLWHA build stable romantic relationships within the context of HIV/AIDS.

In sum, future research could continue to explore the process identified in the current study with individuals from different sites or through in-depth case studies. The purpose of such a study would be to identify other values that impact the process of accepting and living with HIV/AIDS. Further, as the epidemic ages, it will be important to observe how medical advances and sociocultural changes affect the way long-term survivors experience this process. Such findings could also assist care providers in developing appropriate interventions to improve the well-being of PLWHA, as we wait for a cure.

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APPENDIX A: PARTICIPANT INFORMATION FORM

Information Form

Before we start today, do you have any questions for me? Or is there anything you'd like to comment on or share with me?

ID: _____

Please answer the following questions by either filling in the blank or placing a check mark next to the answer.

Age: _____   *Gender:* Male _____   Female _____

Sexual Orientation:

Heterosexual _____   Homosexual _____   Transgender _____ Bisexual _____

Ethnicity:

Caucasian _____   African American _____   Hispanic _____   Asian _____

Pacific Islander _____   Bi-Racial _____

Number of years of education: _____

Number of years since diagnosis: _____

Relationship status:

Single _____   Married _____   Divorced _____   Widowed _____   In a relationship _____

APPENDIX B: INTERVIEW PROTOCOL ONE

Before we start today, do you have any questions for me? Or is there anything you'd like to comment on or share with me?

ID: _____

(During the interview, if you feel like the questions are not clear or specific enough, or you would like to add more to your answer, please feel free to do so at any moment).

1. Could you tell me a little about yourself?

(optional-probe) Can you please share some about your background with me?

2. How long has it been since you've been diagnosed with HIV?

3. What is the current status of your HIV?

4. I'm going to ask you to think back quite a bit. Can you share with me what your life was like prior to being diagnosed with HIV? (Probe for life goals and plans prior to diagnosis)

5. How did you find out you were HIV-positive?

6. What were your initial reactions to finding out you were positive?

7. What were some of the primary barriers you encountered?

8. Where did you find support?

9. Feel free to not answer the following question, but I want to ask you how you acquired HIV?

10a. Part of the societal stigma towards HIV/AIDS stems from people thinking that HIV/AIDS is something that the person living with HIV/AIDS has brought upon themselves through sexual intercourse or intravenous drug use. As opposed to 'no fault of your own,' i.e., through a blood

transfusion or breast milk, in which instances people are viewed as victims. Have you ever experienced discrimination because of the route through which you acquired HIV or your sexual orientation?

10b. Overall, what is your position on this?

11. Are there other ways you have experienced being discriminated against because of being HIV-positive?

12. Did discrimination or fear of being discriminated against influence your decision to whom and how you were going to disclose your HIV-positive status? (ask for length of time prior to disclosure if not mentioned).

12a. (If not already addressed, ask) Who did you first disclose your HIV-positive status to and how?

13. How did the person(s) respond to your disclosure?

14. In what other ways has discrimination or stigma affected your personal relationships?

15. How has stigma affected your professional or community relationships?

16. Since you have been living with HIV for the past _____ years, does being discriminated against have the same effects, i.e., emotional or behavioral effects, on you now as it did when you were first diagnosed? (probe… How has this changed over time? If not, why?)

17. What are some of the most effective ways you cope with stigma?

18. What do you find most useful in helping you cope with your HIV status?

APPENDIX C: INTERVIEW PROTOCOL TWO

Before we start today, do you have any questions for me? Or is there anything you'd like to comment on or share with me?

OPTION: Also, here are some themes that I have been identifying through our time together that I want to share with you. Let me briefly review a few of them and see if you can confirm that I am understanding you correctly.

ID: _____

The last time we met we spoke about your life prior to bring diagnosed with HIV, how you found out you were HIV-positive, how you made the decision to disclose your status, and about your experiences of stigma.

Today, I would like us to talk about how your reactions to stressors or uncertainties, stigma, and coping have changed over time.

1. Last time we spoke, you shared with me the plans and goals you had before you were diagnosed with HIV. Over the past ____ years how did you have to alter your short and long-term future plans? (probe for specific areas of life)

2. If at all, how did your reactions to your diagnosis change over time? (probe for triggers of change)

3. How do you now make decisions about disclosure?

4a. What do you think would have been most beneficial for you in terms of support when you first became aware of your diagnosis?

4b. What about now, what helps you to reduce or cope with the multitude of stressors/uncertainties in life?

5. If you could eliminate one stressor/uncertainty from your experiences of living with HIV, what would it be and why?

6a. Being a (man, woman) _____, how different do you believe living with HIV is for a (woman, man) _____?

6b. Being a (man, woman) _____, how differently do you believe (women, men) cope with the uncertainties, inclusive of stigma, that living with HIV brings?

7. Have you come to terms with your chronic illness? If so, how did you get here? If not, what obstacles are in your way? OR If yes, what obstacles did you face along the way?

8. What advice would you like to give to newly diagnosed persons?

9. What advice would you like to give to either medical and/or mental health care professionals regarding working with persons living with HIV for an extended period of time?

10. Do you think stigma towards HIV/AIDS could be combated? If so, how? If not, why not?

11. Is there anything else you would like to share with me that we did not speak about regarding your experiences of living with HIV/AIDS for the past ____ years?