

“THIS ILLNESS AIN’T GONNA KILL ME” – A QUALITATIVE INSIGHT TO
VARIOUS BEHAVIORAL AND BIOPSYCHOSOCIAL FACTORS
OF STRESS FOR ADULTS LIVING WITH HIV

by

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ABSTRACT

Research on HIV and stress is not uncommon in academic literature. However, little research has been done through a qualitative psychological perspective that aims to identify specific realms of stress people living with HIV (PLH) experience. Furthermore, there is no developed psychosocial measurement of stress specific to living with HIV that can be used in either clinical settings or research settings. This study uses Grounded Theory qualitative methodology and semi-structured interviews to assess and conceptually develop stress in PLH. Participants (n=20) were 12 PLH and 8 individuals who work primarily with clients who are living with HIV. Participants participated in semi-structured interviews where interviews were audio-recorded and transcribed for data analysis. Identified themes included Housing Strains, Engagement in Substance Use, Limited Financial Abilities, Relationship Dynamics, Internal Pressures, and Psychosocial Resiliency. Results from this study suggest that unsatisfactory housing situations, such as location, lack of choice, and intrusive environment, can foster growth of stress. Engagement in substance use can be seen as both a previously utilized and familiar method of coping with stressors as well as a rational behavior that does not cognitively register as coping with stress. Limited financial means can create a constraint cycle where the individual is unable to fund basic necessities and is thus unable to be employed; this cycle can lead to a situation of strained financial resources. Because of this cycle, necessities are often placed on a hierarchy of demand and neglect. With regard to relationships, HIV can both build and sever bonds with others, depending on how

disclosure is received. Lastly, data showed an overall positive regard towards life and towards the future as HIV+ individuals progress in life. These accounts can be utilized in creating a greater understanding of stress for PLH and in developing a more comprehensive and cohesive care for PLH and experiencing stress.

CHAPTER I

INTRODUCTION

Overview of Human Immunodeficiency Virus

Human Immunodeficiency Virus (HIV) is a virus, transmitted through the exchange of certain body fluids, which destroys the immune system and can invade the central nervous system (CNS), leading to severe neurological problems (National Institute of Neurological Disorders and Stroke, 2015). HIV can also result in Acquired Immunodeficiency Virus (AIDS), the most severe phase of HIV infection with severe damage to the immune system (Centers for Disease Control and Prevention, 2014). It is believed that HIV was first transmitted to humans from infected blood of chimpanzees in Central Africa, where humans hunt chimpanzees as a source of food (Centers for Disease Control and Prevention, 2014). The chimpanzee version of the virus, the simian immunodeficiency virus, likely mutated into HIV and may have crossed species as far back as the late 1800s, through consumption of infected chimpanzee meat (Centers for Disease Control and Prevention, 2014). However, HIV has existed within the United States only since the 1970s.

Anyone can contract or transmit HIV, as it does not limit contraction or transmission of infection to specific peoples (Centers for Disease Control and Prevention, 2014), and each year about 50,000 people living in the United States are newly infected with HIV (Centers for Disease Control and Prevention, 2014). Worldwide, it is estimated that 36.9 million people are living with HIV/AIDS (PLH) (World Health Organization, 2014). Contraction of HIV/AIDS can also promote the onset of opportunistic infections, which are infections that are generally not seen in people who have a healthy and intact

immune system, such as certain types of cancers (Centers for Disease Control and Prevention, 2014). Within the United States in 2013, about 7,000 people died from HIV/AIDS complications, representing the 8th leading cause of death for those aged 25-35, the 9th leading cause of death for those aged 35-44, and the 10th leading cause of death for those aged 45-54 (Centers for Disease Control and Prevention, 2014). It is also estimated that 1.2 million individuals worldwide died due to HIV/AIDS-related medical complications in 2014 (World Health Organization, 2014).

HIV Transmission

HIV can be transmitted through exchange of body fluids from infected individuals, such as blood, breast milk, semen and vaginal secretion (World Health Organization, 2014). Certain behaviors put an individual at greater risk for HIV contraction, such as having unprotected anal or vaginal sex, sharing contaminated needles/syringes or other equipment for injecting drugs, receiving unsafe injections for medical procedures, and experiencing accidental needle stick injuries among healthcare workers (World Health Organization, 2014). Worldwide, injection drug use has been associated with some of the most severe HIV epidemics (Altice, Kamarulzaman, Soriano, Schechter, & Friedland, 2010). Transmission of HIV is most common in men who have sex with men (MSM) as they accounted for 63% of all new infections in the United States in 2010, though MSM comprise around 2% of the population (Centers for Disease Control and Prevention, 2014). Heterosexual contact accounted for 25% of all new HIV infections in 2010, and together African-Americans and Latinos/Hispanics account for 65% of new HIV infections (Centers for Disease Control and Prevention, 2014).

Within the United States, HIV is classified largely as an urban disease, as most infections occur in areas with 500,000 or more individuals (Centers for Disease Control and Prevention, 2014). The southern United States has the highest frequency of PLH, however the northeastern United States has the highest rate of PLH with respect to population size (Centers for Disease Control and Prevention, 2014). Young individuals, specifically those aged 12-24 are particularly affected by HIV, comprising 16% of the HIV positive (HIV+) population in the United States and 22% of all new HIV infections (Centers for Disease Control and Prevention, 2014). Even more so, young gay and bisexual men account for 92% of all new HIV infections and are most at risk for new HIV infections (Centers for Disease and Control, 2014).

Interestingly, people older than 50 represent one-quarter of all Americans living with HIV and experience the same HIV risk factors as younger people, but are more likely to be diagnosed as HIV+ late in the course of disease, resulting in significant immune-system damage, a poorer prognosis, and the added challenges of prevention of other diseases associated with aging (Centers for Disease Control and Prevention, 2014). Older individuals experience unique issues that may put them at risk for HIV acquisition, such as widowed and divorced people dating while not aware of their HIV risk (Centers for Disease Control and Prevention, 2014). Additionally, women who are no longer able to have children may be less likely to use a condom and practice safer sex (Centers for Disease Control and Prevention, 2014). With access to erectile dysfunction medications facilitating sex for older men, it is possible that older men may engage in sex without using protection as well, as pregnancy is typically no longer a major concern within their social cohort (Centers for Disease Control and Prevention, 2014). It is important to note that though

older individuals have more frequent visits with physicians, they are less likely than younger individuals to communicate sexual activity, drug use, and other personal information with their physician (Centers for Disease Control and Prevention, 2014). Doctors also may be less likely to ask older patients about these issues, as they are typically not issues for their peer groups (Centers for Disease Control and Prevention, 2014).

HIV Progression and Development

The progression of the HIV disease is well documented, and because it eventually and overwhelmingly deteriorates the immune system, it is almost universally fatal (Centers for Disease Control and Prevention, 2014). The HIV progression occurs in three stages. The first stage is acute infection, which occurs within 2 to 4 weeks after initial infection with HIV (Centers for Disease Control and Prevention, 2014). However, most people have a gray-area between 3 to 5 weeks of initial infection where HIV antibodies are still being produced and cannot be detected through blood tests (World Health Organization, 2014). This stage is often accompanied by feeling sick with flu-like symptoms and is often called the acute retroviral syndrome, or primary HIV infection. However, some people may not develop this first stage, and many do not experience symptoms (Centers for Disease Control and Prevention, 2014).

During the primary HIV infection, large amounts of HIV are being produced by the immune system's CD4 cells in the body, and, in turn, the HIV virus destroys those cells in the process of replication (Centers for Disease Control and Prevention, 2014). This phase of the infection also has the greatest potential for HIV transmission, because the amount of HIV in the blood is the highest, and the immune system has yet to increase CD4 count to

reduce overall levels of the virus to a stable point (Centers for Disease Control and Prevention, 2014).

The second stage of HIV is the clinical latency, or stage of inactivity and dormancy. This stage is often diagnosed as asymptomatic HIV infection or chronic HIV infection (Centers for Disease Control and Prevention, 2014). Here the body continues to have active HIV replication, however HIV reproduction is at low levels, and individuals undergoing antiretroviral therapy (ART) can live in this stage for several decades (Centers for Disease Control and Prevention, 2014). Without ART, individuals can live in this period for up to a decade (Centers for Disease Control and Prevention, 2014). However viral load, the total amount of HIV in an organism, begins to rise and CD4 counts begin to drop towards the middle and end of this period (Centers for Disease Control and Prevention, 2014).

The third stage of HIV is the development of AIDS and is characterized by the immune system being damaged to the point that the individual is now vulnerable to various illnesses, called opportunistic illnesses or opportunistic infections (Centers for Disease and Control, 2014). HIV is diagnosed usually through blood tests to detect the presence or absence of HIV antibodies (World Health Organization, 2014). Normal CD4 counts are between 500 and 1,600 cells/mm³, however for purpose of diagnosis, the transience of HIV to AIDS is noted when CD4 cell are reduced to 200 cells/mm³ of blood (Centers for Disease and Control, 2014). People diagnosed with AIDS need medical treatment to prevent death, and without treatment people typically survive on average of 3 years (Centers for Disease and Control, 2014).

Worldwide HIV Transmission and Symptomology

As previously stated, anyone can contract or transmit HIV, and at the end of 2013, 35 million people were living with HIV worldwide (World Health Organization, 2014). In 2013, HIV globally claimed more than 39 million lives due to HIV-related causes (World Health Organization, 2014). Most recent information from the Centers for Disease Control and Prevention indicate that in 2009, there were an estimated 48,100 new diagnoses of HIV in the United States.

Symptoms of HIV can take 10 years to develop to AIDS, and 1.1 million people in the U.S. have a Human Immunodeficiency Virus Positive Serostatus (HIV+), having tested positive for HIV (Centers for Disease Control and Prevention, 2014). That said, many are unaware and show no symptoms of the disease (Marks, Crepaz, Senterfitt, & Janssen, 2005). For example, in 2010, 1.1 million people in the United States were living with HIV, however about 16% were unaware that they were infected (Centers for Disease Control and Prevention, 2014). Currently, there is no cure for HIV, but there are medications that can inhibit production of HIV and lead to improved health in people living with this chronic illness (Mannheimer et al., 2005).

HIV Treatment and Psychosocial Treatment Issues

HIV is treated with antiretroviral therapy (ART), and in 2013, 12.9 million PLH were receiving antiretroviral therapy (World Health Organization, 2014). In addition to ART, PLH often need and utilize counseling and psychosocial support to maintain a high quality-of-life (World Health Organization, 2014). Antiretroviral therapy encompasses a combination of medications that target the HIV life cycle to end HIV replication and preserve or restore the immune system and its functioning (Günthard et. al., 2014).

Antiretroviral therapy is also the therapy that is recommended for all adults living with HIV (Günthard et. al., 2014). Adherence, defined as taking medications as prescribed (Brown & Bussell, 2011), to ART can help those living with HIV experience a longer and more productive life than without ART (Centers for Disease Control and Prevention, 2014). Adhering to ART is also critical to HIV suppression, reducing the resistance of medication, improving overall health, and quality-of-life, decreasing HIV transmission, and for survival (World Health Organization, 2014).

A variety of factors have the potential to influence medication adherence for PLH (Hinkin, Hardy, Mason, Castellon, Durvasula, Lam, & Stefaniak, 2004). Research on antiretroviral therapy indicates that factors including complex medication regimens, unpleasant side effects, competition of life priorities, and HIV stigma pose as barriers to adherence to antiretroviral therapy (Malta, Strathdee, Magnanini, & Bastos, 2008; Reisner et al., 2009; Simoni, Amico, Pearson, & Malow, 2008; Olem, Sharp, Taylor, & Johnson, 2014). Particularly, stigma is a major concern for older adults living with HIV, as they may face isolation due to prior illnesses, lose friends and family due to disclosing HIV status, and may resist seeking HIV care and disclosure due to negative views of HIV (Centers for Disease Control and Prevention, 2014). Older adults also need to be mindful of medication interactions with ART and medications treating age-related conditions, such as high blood pressure and diabetes (Centers for Disease Control and Prevention, 2014).

Adherence is also threatened by financial problems, housing problems, substance use, mental illness-related issues, lack of support, and individual negative perceptions of treatment efficacy (Olem, Sharp, Taylor, & Johnson, 2014). Specifically, research has found that current drug abuse is significantly predictive of poor medication adherence for

adults living with HIV (Hinkin, Hardy, Mason, Castellon, Durvasula, Lam, & Stefaniak, 2004). Thus, research recommends that new strategies need to be explored to eliminate HIV-associated stigma, discrimination, and other psychosocial factors that surround HIV to further promote an acceptance of early intervention and therapy to reduce occurrences of delayed care (Günthard et al., 2014) and the onset of adverse health behaviors (e.g., substance use).

If people living with HIV (PLH) are unable to adhere to their recommended treatment, they are more likely to develop resistance to medication, succumb to other illnesses and infections, and more easily transmit HIV to others (Olem, Sharp, Taylor, & Johnson, 2014). Because there is no known cure for HIV, adherence to a prompt, intensive, prevalent, and continuous treatment shows greatest potential to control the HIV pandemic (Günthard et al., 2014).

Theoretical Background of Stress, Coping, and HIV

As stated previously, PLH experience stress related to living with the chronic disease and are confronted with the stress of disclosing their health status to others (Hackl, Somlai, Kelly, & Kalichman, 1997) among other hassles and strains. Hassles can be defined as irritating and frustrating demands that occur during everyday transactions with the environment (Holm & Holroyd, 1992; DeLongis, Coyne, Dakof, Folkman, & Lazarus, 1982; Kanner, Coyne, Schaefer, & Lazarus, 1981; Lazarus & DeLongis, 1983). Strain can be viewed as an individual being treated in a manner that they do not like in a situation or encounter that is very difficult to escape (Agnew, 2001). Lazarus and Folkman's Transactional Model of Stress and Coping (1984) posits that stress is perceived in a primary evaluation of the event's significance (Glanz et al., 2008) and a secondary evaluation of

the situation's controllability through one's coping resources (Glanz, et al., 2008). Those who experience strain are more likely to cope with strain through deviance and crime (Agnew, 2001), such as substance and alcohol use. Particularly, drug use and addiction have been indivisibly linked with HIV/AIDS since the start of the HIV epidemic, bringing both heightened risk of both acquisition and transmission and greater HIV-related consequences from coping with substances (National Institute on Drug Abuse, 2012). Though there is no vaccine to cure or protect a person from acquiring HIV, addressing drug use as a coping mechanism can foster HIV prevention and limit transmission (National Institute on Drug Abuse, 2012).

Psychological Toll of HIV

Research cites HIV disease as a major source of both emotional and physiological stress for PLH (Faulstich, 1987). Disclosing health status to others, including disclosing to physicians and others, as well as living with a chronic illness are among the stressors PLH confront (Hackl, Somlai, Kelly, & Kalichman, 1997) among other hassles and strains of living with HIV. Stress can be seen as a state in which the environmental demands exceed the available resources (Lazarus & Folkman, 1984), and an individual's perception of stress as the degree to which situations in one's life are appraised as stressful (Cohen, Kamarck & Mermelstein, 1983). Research also suggests that the assessment of the event, or the perception of stress, is what primarily promotes the physiological and immunological responses to the stressful situation (Hand, Phillips & Dudgeon, 2006). Some research on PLH suggests that psychological factors may contribute to stress perception more than the physiological factors of HIV (Hand et al., 2006), such as dealing with the negative side effects of medication, and symptoms of HIV infection. These studies thus warrant further

research to assess how various psychological factors specifically relate to various types of stress and overall stress perception.

Maladaptive coping mechanisms are used in reaction to psychological stress, anxiety and negative affect (Armeli, Tennen, Affleck, & Kranzler 2000). Coping refers to the thoughts and behaviors a person uses to regulate distress or manage the problem causing distress (Hult, Wrubel, Bränström, Acree, & Moskowitz, 2012). Increased stress and maladaptive forms of coping (such as drinking to cope) are frequently cited as variables linking health related outcomes to alcohol misuse (Baumeister et al., 2003; Tomaka, Morales-Monks & Shamaley, 2012). Research also suggests that long term exposure to stressful events contributes to the progression of HIV to AIDS (van Eck et al., 1996). Research also suggests that levels of physical health, mental health, and quality of life improve among PLH engaging in stress management activities (Hand, Phillips, & Dedgeon, 2006; Gielen et al., 2001).

Researchers have recently developed the concept of poor health as a strain with possible outcomes leading to substance abuse (Agnew, 2001). Outcomes of poor health, or health strain, can promote psychological distress and increase risks of substance use (Agnew, 2001). To identify how daily hassles can affect health care, research suggests that those who continually face daily hassles may react more rapidly to situations and further reduce resources available for planning for the future or scheduling health activities (Jacob, Arnold, Hunleth, Greiner, & James, 2014; von Wagner Good, Whitaker, & Wardle, 2011). Research suggests that this heightened impulsivity is a characteristic and correlate of substance use (Verdejo-Garcia, Lawrence, & Clark, 2008).

Barriers to HIV Treatment Adherence

As previously stated, the two groups that comprise more than half of new HIV infections are Latinos and African Americans (Centers for Disease Control, 2014). Literature shows that both African Americans and Latinos tend to live in communities where HIV infection and non-straight sexual orientations are heavily stigmatized (Centers for Disease Control, 2014). Based on minority stress theory, chronic exposure to stigma from society can promote psychological vulnerability and are associated with both psychological distress and non-adherence behaviors (Skinta, Lezama, Wells, and Dilley, 2014).

Over half of PLH who receive antiretroviral therapy report experiencing stigma (Lowther, Selman, Harding, & Higginson, 2013). People who are stigmatized by their HIV status report negative experiences of prejudice, discrimination, job loss, violence, and threats to their personal well-being (Varni, Miller, Solomon, 2012; Zierler, Cunningham, Anderson, Nakazono, Morton, et. al., 2000; Gostin, Feldblum, & Webber 1999). The perception of being in a stigmatized group may create a psychological toll on many PLH, and experiencing stigma can also have negative psychological consequences (Herek, Saha, & Burack, 2013).

Depression, substance use and/or dependence, and anxiety and stress disorders are cited frequently as mental health issues affecting physical health and adherence to antiretroviral medication for PLH (Nel & Kagee, 2011). The DSM-5 describes depression as including aspects of low motivation, disturbances in sleep and concentration abilities, psychomotor delay, and feelings of fatigue, loss of energy, and worthlessness (American Psychiatric Association, 2013). Some patients experiencing depression while engaging in

antiretroviral therapy are up to three times less likely than non-depressed patients to adhere to medication treatment plans (Nel & Kagee, 2011; Ammassari et al., 2004). Thus, depression has very clear implications and relationship to adherence to medication (Nel & Kagee, 2011). Because depression is highly related to medication non-adherence, it also needs to be addressed in therapy for PLH.

In general population studies, depression and substance use disorders are not uncommon and often are comorbid or have co-occurrences with each other (Swendsen & Merikangas, 2000). The coexistence of HIV and substance use have been named the “twin epidemics” because of their interconnectedness (Pence, et al., 2008; Welch, 2000). PLH who use substances often surround themselves socially with other substances users and typically have poorer health and health behaviors than non-substance users (Ware, Wyatt, & Tugenberg, 2006) that reduce overall adherence support within these social circles (Nel & Kagee, 2011).

HIV and Substance Use

Accounting for age, the number of people infected with HIV who engage in substance use has increased levels of both mortality and morbidity when compared to PLH who do not engage in drug use (Altice et. al., 2010). Also, PLH who use drugs increase their own risk for severe medical comorbidities such as hepatitis, tuberculosis, and bacterial infections. PLH who use drugs are also at increased risk of psychiatric comorbidities (Altice et. al., 2010). Because of the likelihood of several comorbid disorders, diagnosis and treatment is further complicated and challenges for comprehensive care arise in HIV+ individuals who engage in substance use (Altice et. al., 2010).

For PLH, engaging in drug use is associated with decreased access to antiretroviral therapy and healthcare, a reduced likelihood of a medical professional prescribing antiretroviral therapy, and reduced overall adherence to antiretroviral therapy once prescribed (Altice et. al., 2010). Tuberculosis is one of the leading causes of death from complications of HIV/AIDS (World Health Organization, 2014), and a diagnosis of tuberculosis in PLH who use drugs increases the clinical challenges inherent in treating those individuals (Altice et. al., 2010). In PLH who use drugs, it is also thought that tuberculosis and non-AIDS comorbidities will begin to emerge as leading problems that further complicate a comprehensive care; This notion may continue to be true as antiretroviral therapy for PLH becomes successfully integrated and more readily available within the HIV community (Altice et. al., 2010).

Worldwide, the drugs associated with highest rates of use for PLH are heroin and cocaine (Altice et. al., 2010). It is important to note however that amphetamine substance use has been seen as a developing issue to address in the future (Altice et. al., 2010). Heroin, most widely used opioid, and cocaine, the most commonly used stimulant, each have consequences of both physical and psychological dependence and also lead to rapid psychological dependence (Altice et. al., 2010). Abuse of benzodiazepines, which are sedative-hypnotics, is also seen in association with decreased drug treatment retention, increased levels of HIV risky-related behaviors, increased mortality, and both fatal and non-fatal overdoses when combined with other drugs (Altice et. al., 2010). Transmission of HIV from shared and contaminated needles carries the greatest risk for HIV transmission as well as transmission of a variety of other infections through the blood (Altice et. al., 2010). Non-injection drugs, such as alcohol, further expedite HIV transmission through

alcohol use's association with risky sexual behaviors, such as exchanging sexual encounters for money or drugs (Altice et. al., 2010).

Individual Drugs' Effects on HIV

General Drugs/Substances

The literature has also mapped out how specific drugs affect HIV. Opioids, such as heroin, morphine, hydromorphone and codeine, often cause respiratory depression, comas, overdoses, and both physical and psychological dependence. These drugs are used by method of injection, inhalation, and oral ingestion and their effects on HIV include decreased access and use of care, decreased participation in antiretroviral therapy, and an overall decrease in adherence to antiretroviral therapy (Altice et. al., 2010). For opioids, evidence-based medication assisted therapies can promote abstinence, and they include methadone, buprenorphine, and naltrexone.

Cocaine, often called white power or crack, has common clinical consequences of agitation, hyperthermia, hypertension, convulsion, CNS disturbances, hallucinations, psychological dependence, and even death (Altice et. al., 2010). The method of use for cocaine is injection or inhalation, and this drug can lead to decreases in access and use of care, decreased likelihood of being prescribed antiretroviral therapy, decreased adherence to antiretroviral therapy once prescribed, and increased levels of risky sexual and drug-related behaviors (Altice et. al., 2010). However, unlike opioids, there exists no evidence-based medication assisted therapies for management and reduction of substance use for PLH and engaging in cocaine use (Altice et. al., 2010).

Alcohol use is noted to have consequences of CNS sedation, hepatic injury, dietary deficiencies and neurocognitive deficits (Altice et. al., 2010). The method of use for alcohol

is ingestion orally and is seen to have effects of increased hepatotoxicity, increased peripheral neuropathy causing feelings of numbness or weakness, decreased access and use of care, decreased participation of antiretroviral therapy, and decreased adherence to antiretroviral therapy in HIV+ individuals (Altice et. al., 2010). Naltrexone, acamprosate, and disulfiram are evidence-based medication-assisted therapies for management and reduction of use for PLH who engage in alcohol consumption (Altice et. al., 2010).

Club Drugs/Party Drugs

Nitrates, often called poppers, have clinical consequences of a presence of a higher than normal level of methemoglobin in the blood, hypotension, and cardiac arrhythmias (Altice et. al. 2010). The method of use is typically through inhalation of the drug in liquid form and use is associated with increased levels of HIV risk behaviors, specifically increase in risky sexual behaviors (Altice et. al., 2010). There also no evidence-based medication-assisted therapies for management and reduction of use for people using nitrates (Altice et. al., 2010).

Missing Literature, Needs for Future Research, and Purpose of Project

Research suggests that qualitative methodological research is essential in understanding phenomena of living with HIV (Power, 1998). While quantitative methodological research has the ability to identify gaps in knowledge and health behaviors, utilization of qualitative methodological approaches in health research could be used to fill these gaps and interpret why these gaps and discrepancies occur (Kitzinger, 1995).

As previously mentioned, stress is a factor in both the physiological manifestation and progression of HIV/AIDS as well as in the psychological toll experienced by individuals living with HIV. How individuals with HIV cope with stress also has the

potential to influence health-related behaviors. That is, stress has the potential to influence aspects of medication adherence, social interaction, and other health related behaviors, such as coping with stress through substance use. Though HIV and substance abuse have been labeled as the “twin epidemics”, (Pence, et al., 2008; Welch, 2000) very little research has been done on PLH who have a coexistent history of substance abuse (Klein, Elifson & Sterk, 2010). While some research on stress and substance use has been conducted in PLH, little to no research has been conducted to break down the specific types of stressors (familial, relationship, financial, health) that are most closely related with areas that have been commonly researched in PLH. Research highlights stress as something PLH experience, and something closely related to health behaviors, yet research is lacking on identifying the underpinnings of why PLH live with stress and how this stress is unique to living with HIV.

This gap of knowledge warrants future research that focuses on identifying the specific life stressors and strains that are significantly related to aspects of stress perception, quality of life, coping styles and strategies, likelihood of substance and/or alcohol use, and adherence to antiretroviral medication for PLH. Specifically, this study aims to focus on assessing the areas of one’s life that are perceived as stressful, and how living with HIV interacts with coping strategies, financial stability, and one’s relationships with family, friends, and intimate partners. The results from this study could potentially aid clinical implications through better assessment and identification of life strains that impact PLH and develop interventions and therapies for specific stressors to better improve the quality of life for PLH as a whole.

CHAPTER II

RESEARCH DESIGN AND METHODOLOGY

This section describes the hypotheses, methodological concepts and procedure, research instruments, selection of participants and population, as well as the proposed method used in this study. This study had several purposes involving both clinical implications and furthering connectivity and understanding of people living with HIV through psychological research. The purposes of this study were to explore, through qualitative research, the following issues: 1) what it means to be HIV+ from individual perspectives; 2) how HIV management affects and intrudes into life; 3) what aspects of living with HIV cause the most stress; 4) what coping strategies are used for living with HIV; 5) how substance use accompanies living with HIV; 6) how living with HIV affects self-perception; and 7) how living with HIV affects familial, interpersonal, and intimate relationships.

The qualitative component of this study was composed of semi-structured individual interviews of PLH and individuals who work primarily with clients living with HIV. Information obtained during this qualitative component will, in the future, be used to develop a measurement to assess stressors commonly associated with living with HIV. Currently, there is not a survey assessing stress related to living with HIV that can be efficiently used in a clinical setting. Thus, a future phase of this project will involve development of a clinically practical scale to assess stress related to living with HIV.

Research Design

This study used a qualitative design with semi-structured individual interviews with guided questions to engage participants in talking about stress and other stressful factors related to living with HIV. This method was chosen to gain a more representative and specific understanding of an otherwise taboo subject. Information from this part of the study will be used in the future to develop a clinically practical survey relating stress and HIV directly.

This study design also relied heavily on grounded theory qualitative research methodology. Grounded theory emphasizes a systematic and flexible method to provide tools of developing psychological theoretical analyses of data from interviews, personal narratives, in vivo observations, and individual case studies (Charmaz, 2011). Another major contribution of grounded theory is the ability to simultaneously engage in data collection and use exploratory theoretical concepts to guide successive data collection (Charmaz, 2011). With grounded theory, researchers construct theoretical analyses using significant processes for the data (Charmaz, 2011). With this technique of qualitative data interpretation, codes and themes arise from the interaction with the data rather than from predetermined thoughts applied to the data, which is what typically occurs in deductive qualitative research (Charmaz, 2011). Because of this, themes can be used to answer research questions, or questions of interest for qualitative study.

Grounded theory emphasizes two areas of conceptual development, grounded development and theoretical development (Chamberlain, 1999). The term “grounded” is intended to note that theory emerges and is developed from “from the ground up” via interactions with the data, rather than from a preconceived thoughts or notions

(Chamberlain, 1999). The theory that explains an observed phenomenon is developed from transitioning descriptive events to a more abstract phenomenological theory accounting for several relationships and processes that may be occurring (Chamberlain, 1999). “Theoretical” then means that the theory must be developed through more than simply describing a psychological phenomenon (Chamberlain, 1999). Theoretical sampling is also used in grounded theory, which means that researchers purposively recruit participants closest to the phenomenon in question, and that researchers have the flexibility to continue recruitment of new and additional perspectives and participants during data analysis (Breckenridge & Jones, 2009).

Within grounded theory, the researcher begins with data that relate to specific interests of the research, and then the analysis process involves progressively creating more abstract classifications that help in integrating and explaining the information provided by the data (Chamberlain, 1999). Categories are developed through interaction with the data (Chamberlain, 1999). This type of qualitative approach is often seen as an inductive approach, by means of allowing the data to bring theory, as well as deductive, through the further testing and collection of data and analyses (Chamberlain, 1999). Saturation, or the point at which no new categories are found that relate to a central issue being assessed, is a crucial element of grounded theory (Chamberlain, 1999). Saturation is also seen as a key to quality qualitative work, highlighting methodological integrity and significance (Morse, 1995), and is particularly emphasized in grounded theory qualitative approaches (Guest, Bunce, & Johnson, 2006).

Typically, saturation is met during analysis and can be confirmed with further data analysis (Chamberlain, 1999). Data collection ceases when saturation occurs and

phenomenology can be explained through the theoretical concept (Chamberlain, 1999). Though there are no discrete guidelines regarding sample size and saturation, signals of saturation are determined through consultation of researchers and evaluation of the adequacy and comprehensiveness of results (Morse, 1995; Guest, Bunce, & Johnson, 2006). Rather than being driven by quantitative frequency, saturation incorporates all forms of occurrences and places a higher emphasis in the value of variation over quantity (Morse, 1995). The lack of specific guidelines posits unique challenges in qualitative research (Bowen, 2008; O'Reilly & Parker, 2012), however methodological integrity is maintained through explanation of how saturation is achieved (Guest, Bunce, & Johnson, 2006; Bowen, 2008). It is also argued that setting pre-medicated approaches to qualitative work is not congruent with the principles of qualitative research (Mason, 2010) as many other factors may play role in the quality of data collected (Morse, 2008; Mason 2010). Specifically, rather than being driven by quantitative frequency, this project achieved saturation through constant and consistent meetings among the researcher, research assistants, and supervising professors to build consensus in the language, coding, and concepts of data. All data were equally considered in the initial analytic coding procedure, with further refining techniques addressed in the *Research Instrument, Data Collection, and Qualitative Analyses* sub-section of this paper.

Qualitative methodology, specifically grounded theory, allows the opportunity to investigate diverse topics, assess various psychological processes, and investigate several topics in which psychologists and clinicians have focused interests (Chamberlain, 1999). Another strength is that grounded theory is a very adaptive and flexible approach with different methodological directions (Chamberlain, 1999). Because of this, grounded

theory is a promising approach for health and psychological research and can be utilized through adaptation for particular research needs (Chamberlain, 1999).

Grounded theory was chosen for this project because of its rise in health services and health policy research, particularly emphasizing openness of uncovering information from what is intended on being addressed and what actually emerges from the data (Sofaer, 2002). Focus groups and interviews are now standards in developing valid and reliable survey instruments, particularly in assessing patient experiences (Sofaer, 2002). This feature allows grounded theory methodology to highlight and identify unknown domains of stress and coping. This feature is particularly applicable in uncovering the unknown and unaddressed areas of how stress, coping, and living with HIV are specifically related. Additionally, grounded theory allows for a richer understanding of complex phenomena; it also allows the opportunity for voices that are rarely heard to come to focus (Sofaer, 1999). Research recommends the use of qualitative and quantitative methods in tandem to best address gaps in understanding healthcare and psychological phenomena (Sofaer, 1999; Sofaer, 2002). In uncovering the unknown areas of stress and coping, through qualitative research, grounded theory allows for this project to serve as a foundation for future research in developing a quantitative measure to assess HIV and stress.

Participants, Population, and Sample

Participants were over the age of 18 and participated in individual semi-structured interviews aimed at assessing specific types of stress, and stressful events that are pertinent to PLH. The Institutional Review Board (IRB) of Texas State University approved all methods and procedures for this project. This study includes a total of 20

participants, consisting of 12 PLH and 8 individuals who work primarily with clients who are living with HIV. The variety of participants in the individual interviews provides diversity to the contribution to the overall sample of each individuals' participation, as well as to foster a more comprehensive look at patient perspective and provider perspective of what it is like to live with HIV.

Recruitment was done through AIDS Services of Austin, clinics and organizations in Austin, Texas as well as through Community Action Inc. of San Marcos, Texas. Recruitment for this project consisted of research informational flyers posted at HIV resource centers in the greater Austin and San Marcos areas, as well as outreaching to HIV organizations through social media (Facebook) and emailing HIV resource centers with the recruitment flyer for the project. Participants consisted of a variety of people who live with HIV, HIV healthcare providers, and those who work closely with HIV, such as HIV counselors or community service members. In return for participation in the individual interviews, participants were thanked for their time and compensated with a \$15 Amazon Gift Card. The choice of a gift card was made to safeguard the possibility of participants using direct cash as a way of engaging in dangerous or health-compromising behaviors commonly associated with HIV, such as increased risk for drug use or risky sexual behaviors. Participants were also given a copy of the recruitment flyer, which includes the researcher's email, in the case they would like to contact the researcher about the results of the study. For the current study, theoretical sampling was used in that data collection and analysis initially overlapped; however, concepts and themes emerged and reached saturation without requiring continuing further recruitment into the middle and end of the data analysis process.

Research Instruments, Data Collection, and Qualitative Analyses

The researcher engaged participants in semi-structured interviews, with each individual interview recorded on an audio-recording device. Within semi-structured interviews, conversations typically address a set of questions designed to cover specific topics of interest, however the conversation is free to vary and often changes between participants (Fylan, 2005). Because of this, semi-structured interviews have a great deal of possibilities of exploration, from answering simple questions to undergoing a diversity of directions in covering all areas to be addressed (Fylan, 2005). Conversations were supervised and guided by the researcher to delve into useful information while remaining on topic. This method was utilized to enable each participant to provide maximum potential for expressing individual thoughts, focusing on answering outstanding research questions, and allowing for emerging information to be disclosed. Interview questions were asked in a way to elicit open-ended responses, and interviews were conducted in either designated conference-style room or private office. During the interview process, only the researcher and the participant were in the designated room for data collection, to maintain confidentiality and foster a comfortable environment for data collection on this sensitive subject. Participants were free to speak as much or as little about each topic as they felt comfortable, and were able to choose to not answer on any specific topic they wished without penalty. Audio playback was then transcribed onto a Microsoft Word document for partial coding.

Qualitative analysis proceeded in three stages: open coding, axial coding, and selective coding. Coding is essentially a process of defining what a selection of data are about through an assigned label, or code (Charmaz, 2003). Here, transcriptions were

coded through open coding technique of coding line-by-line, by sentiment, and by sentence. Open coding is defined as the process of fracturing, examining, comparing, conceptualizing, and categorizing data (Kendall, 1999). Coding line-by-line allows researchers to build analysis from the ground up, and helps refrain from imputing personal motives or bias into collected data (Charmaz, 2003). For the purposes of this study, coding by sentiment may include coding a selection of several sentences or words to capture a comprehensive and embodied thought or notion. Data was interpreted verbatim as well as through conceptual and metaphorical meaning to properly code the main idea of each quotation. Conceptual and metaphorical meaning include an examination of how language is used figuratively, visually, or symbolically as an approach to responding to the question asked (Saldaña, 2015). It is important to note that codes were not mutually exclusive to specific questions and are expected to commonly re-occur throughout the coding process. This allows coding to overlap and potential for a quotation to have multiple codes and suffice to represent multiple themes that occur within the qualitative analyses.

From here, the transcriptions were uploaded to NVivo for axial and selective coding. Axial coding is described in qualitative research as assembling together data after open coding through developed connections in context, conditions, and strategies between open codes (Kendall, 1999). While open coding separates data into specific categories, axial coding is a process of regrouping these codes and sub-codes through shared connections (Kendall, 1999). Lastly was selective coding, which involves selecting a core category that accounts for the most variation of the main idea all other codes are centered around and integrated with (Kendall, 1999). With the use of these

coding procedures, NVivo software was used to find major themes. Here, major not only means frequent, but also per consensus through co-coders, significant and revealing of dimensions that answer the research question. These major themes will comprise items of a future questionnaire to be developed. The questionnaire will allow researchers to assess the pervasiveness and generalizability of the themes, with particular focus on how living with HIV plays a role in overall perceptions of stress.

During all aspects of the coding process, the researcher and one of three co-coders refined codes and created a consensus of coding. The researcher was involved in coding each transcript, with each secondary coding divided among the three co-coders. Consensus was achieved through simultaneously coding, creating a codebook of common themes and reoccurring themes, and having a co-coder agree or challenge discrepancies between codes and the codebook. If any coding discrepancies occurred, the researcher and co-coder discussed the content of the transcript, the codes in question, and developed a consensus on the code. If a consensus could not be met, a third co-coder was included in developing a consensus. Once codes and themes were identified, a coding schema outlining coping and stress was created to visualize how PLH experience stress and cope with the underlying mechanisms of stress. Furthermore, note-taking by coders helped merge and eliminate ideas and formalize definition of and connections between concepts as they emerged and developed. Research questions were used to initiate studies while constructed themes assisted in answering the research questions.

Research Question and Hypotheses

This study attempted to answer several research questions addressing what it is like to live with HIV and how living with HIV might play a role in overall perceived

stress for PLH. First, this study aimed to determine what it means to be HIV positive as an identity. Second, this study sought to determine how HIV management may affect and intrude in life. Third, this study attempted to assess what aspects of life are perceived as most stressful to PLH. A fourth aim of this study was to answer how individuals with HIV may cope with stress. A fifth aim of this study was to describe how living with HIV affects family relationships, interpersonal relationships, and intimate relationships. Finally, this study sought to describe how HIV may affect how someone may view themselves as an individual. With these research questions in mind, this study utilized both PLH and people who work directly with PLH to address our questions.

In general, it was hypothesized that main themes of stress from interpersonal relationships, health, and finances would emerge. This was expected because, as previously stated, PLH are confronted with disclosing their status to others, and due to the fact that HIV is a chronic illness that requires continuous and intensive treatment. Since a vast proportion of PLH have lower socioeconomic status, it is plausible to assume that stress over finances would be found in these interviews. Specifically, it was hypothesized that individuals living with HIV and living in public housing would express dissatisfaction and stress from their housing situation due to environmental factors out of their control. It is also hypothesized that recreational drug/alcohol users become more frequent users after an HIV+ diagnosis due to feeling overwhelmed. Additionally, being HIV+ may trigger a constraint circle of decreased ability to get work, maintain work, and pay for necessities. Financial issues, such as medical comorbidities and inability to work, would contribute to a lower ability to actively cope. Lastly, it was hypothesized that HIV

disclosure would cause stress; however, a positive reception of disclosing can bring empowerment.

Relevance to Clinical and Health Psychology

This study has significance in the realms of both clinical and health psychology. To begin with, the survey that is to be developed from this study could have clinical significance. If it is found that stress is related to health compromising behaviors, the scale developed from this study could be used in clinical settings and the results could inform HIV healthcare providers of increased susceptibility to health compromising behaviors as a result of stress. This is important because as of now, there is no clinically practical survey that could be used as a part of initial paperwork for HIV clinics. In 2002, Pakenham and Rinaldis created the HIV/AIDS Stress Scale, however this measure was developed through modifying a preexisting checklist of HIV-related problems and tested in cohort of only gay and bisexual men living with HIV of South East Queensland and northern New South Wales, Australia. The development of the HIV/AIDS Stress Scale shows important progress in development of HIV/AIDS research, however the methodological development of the scale leaves room for refining and further improving a measurement assessing stress in PLH. Thus, the results of this study will be used in creating a measure designed to assess stress related to HIV.

Secondly, upon conducting the literature review for this study, it was noted that limited research exists regarding PLH in the South, specifically in Texas. Any results from this study could be deemed as fruitful and help to further contribute to the psychological understanding of a marginalized group in an understudied geographical area.

CHAPTER III

RESULTS

This section includes a qualitative review of overall results found in this study as well as a section dedicated to participant demographic information. Originally, the study aimed to assess 1) individual perspectives of what it means to be HIV+ 2) how HIV management affects and intrudes into life, 3) what aspects of living with HIV cause the most stress, 4) coping strategies for living with HIV, 5) substance use in living with HIV, 6) how living with HIV affects self-perception, and 7) how living with HIV affects familial, interpersonal, and intimate relationships. Narratives show much overlap in answering research questions and further revealed themes of 1) whether and how various housing situations affect overall stress for PLH, including government subsidized housing and non-government subsidized housing, 2) when and why PLH resort to drug/alcohol use to cope with stress, 3) how financial ability affects overall stress, and 4) how stress and coping differ between relationship types. During analysis, a fifth construct emerged: 5) personal/individual stressors and coping.

Demographic Results

A total of 20 participants were involved in this study, including 12 PLH as well as 8 individuals who work primarily with PLH. To maintain confidentiality of participants, limited demographic information was collected. However, participants of this project varied with regard to age, gender and ethnicity. The average age of an HIV+ individual utilizing services at these resource centers was 49 years old. It is also important to note that these HIV resource centers where participants were sampled have primarily indigent

clients. The 12 participants who were PLH were primarily male (66.7%), with 2 female and 2 transgender female participants. Participants who were PLH were also primarily African-American (58.3%), with smaller proportions of Caucasian and Latino/a participants.

With regards to HIV professionals, demographic descriptive analysis showed that our sample was primarily Hispanic/Latino (50%) and male (75%). Additionally, the HIV professionals had an average of 11.13(9.63) years working within the HIV field. It is also important to note that two of the eight HIV professionals also disclosed during the interview process that they themselves are diagnosed as HIV+. HIV professionals also varied with regard to their job title, consisting of 1 program manager, 1 counselor, 1 health insurance specialist, 1 prevention program specialist, and 4 case managers.

Qualitative Results

Analysis showed the emergence of five themes: *Housing Strain, Engagement in Substances Use, Limited Financial Abilities, Relationship Dynamics, and Internal Pressures and Psychosocial Resiliency*. Overall, housing costs and quality caused mental and employment stress in PLH by being financially taxing and providing unsatisfactory conditions for living. Engagement in substance use was described as a familiar coping resource for some, and a recreational activity for others. Rationalizing substance use as methods of relaxation was also not uncommon. Financial abilities were affected by HIV symptoms impeding ability to work and negative side effects of medication preventing ability to generate income, furthering a constraint cycle of not being able to gain employment and inability to fund necessities. Furthermore, financial aid was also seen as

a stressor by requiring recipients to maintain strict parameters for qualification, yet often not providing enough aid to fund all necessities. Because of this, participants often felt a battle of their own hierarchy of basic needs (e.g. food, rent, medication).

Within relationships, HIV can be seen as something that can strengthen and weaken bonds with friends, families, and intimate partners. A unique stressor of mandatory vs. selective disclosure was reported for disclosing HIV status to intimate partners compared to non-intimate relationships. Lastly, several personal stressors that were unique to each individual were often reported as a personal gain or psychosocial resiliency. Specifically, participants reported changing their self-views, finding meaning and happiness in life, and viewing themselves as a stronger individual due to living with HIV.

Theme 1: Housing Strain

The first theme was *Housing Strain* and emerged from the data as a global view of housing circumstances that fostered the growth of stress. This first theme showed how housing situations influence the perception of stress for PLH. This theme represents the negative experiences PLH endure with regard to housing situations, and how these negative experiences contribute to the growth of stress. Many individuals expressed dissatisfaction with government subsidized housing, due to limited choice in living environment and unsatisfactory living conditions. One participant described his/her experiences with government subsidized housing below:

“How I ended up in housing? It wasn’t a choice where I could live, you know.

And for me, being poor, my income was low you know. They just put you in

places. You don't know where you're living so that can be stressful. Because you don't know what kind of part of the neighborhood you're gonna end up. That's stressful and when you deal with other peoples' habits. That's stressful. When you have a neighbor that is a chain smoker and her nasty habit is coming into your environment, it's very stressful and very unhealthy for me. So fighting the struggle to get this person to stop is a constant battle with legal aid, and housing does all these laws that we're supposed to follow but they don't enforce them."

Individuals living with HIV who live in government subsidized housing expressed dissatisfaction with their housing circumstances. This individual expressed their dissatisfaction with the controllability of his/her environment, stating that the initial choice of placement and uncontrollable environmental intrusions contribute to their overall dissatisfaction. Furthermore, this individual also is struggling with housing authority to follow rules and guidelines required by the law and describes their housing situation as a "constant battle." Others, like this individual, expressed encountering unpleasant neighbors, inadequate choice in housing placement, and various other environmental factors that may contribute to the overall dissatisfaction and overall stress experienced by certain PLH.

It is also possible that unfavorable housing, in general, could be a significant stressor for many individuals living with HIV, regardless of whether the person is living in government subsidized housing or not. This suggests that HIV scope of care might not be addressing all aspects of HIV-related stressors in HIV+ individuals. One HIV care

provider described his/her experiences with clients experiencing stress from housing situations below:

“Individuals who don't have, let's just say who are low income, very low income for them, the stress is really profound. Their stress is really around the economics of day-to-day living, especially if they are in care and now a days people at low income can be in care that's necessarily solve their housing problem. I have clients and have had clients in the past who are medically stable but they are homeless. Medically stable but they are living in a housing situation with people who are unkind whether that's domestic violence intimate partner violence.”

The concept of housing posed several pathways in which stress can become involved in the day-to-day lives of PLH. As this participant stated, stress regarding housing situation can stem from not having a home, maintaining a home, and the home environment. Also, this participant suggested that through his/her interaction with clients, that those PLH who experience financial challenge may have many of the same stressors as HIV- (HIV negative) individuals, but perceive the significance of these stressors at heightened levels. Furthermore, this quotation shows how stressors touch on many domains and themes; they are not mutually exclusive to each theme outlined in this paper.

Many individuals stated that financial difficulties were among one of the more stressful events experienced by PLH. These financial shortcomings also enhanced stress experienced from housing situations, and the individual's ability to fix their housing situation. It is possible that many PLH experience a cycle partly where financial abilities

affect housing situations, and thus housing situations affect financial abilities. Below is one participant's account of how finances and financial abilities affect housing capabilities:

"It's hard to live on the amount of money I have, get every month. It's only \$862 a month and if it wasn't for my husband busting his ass. It's... it's been tough. It's been very tough. You can't find apartments or even have a vehicle with you and your spouse being on disability. It's, it's very tough. You get shitty apartments you know a shitty landlord, people. Just shitty apartments period."

Here, the participant mentioned how housing authority provides sub-par facilities and requires interactions with unfavorable individuals. Additionally, the participant mentioned being on a fixed income, due to being on disability, which makes housing situations even more difficult. These housing situations also interfere with ability to maintain a reliable vehicle, which could in turn affect the possibility of acquiring and maintaining employment, accessibility to means of maintaining housing, accessibility to seeking medical treatment, and much more. This possibility is explored later on in a subsequent theme.

Theme 2: Engagement in Substance Use

The second theme was *Engagement in Substance Use* and emerged from data through accounts of when and why individuals utilize substances/drugs as a method of coping, or general engagement in substances. Regarding the second theme, PLH who used substances in the past also used substances as a current method of coping. It is possible that individuals used substances because they were something familiar to them,

when use was a coping mechanism previously utilized in the past. This theme outlined how PLH engaged in substance use as a method of coping with regard to past, present, and future. One participant described his/her interactions with clients who cope with substance and alcohol use:

“What I find more often is that people fall back on the coping strategies that they have always used, and a lot of times that's getting away whether that's through drugs, through alcohol, through sex. Whatever ways because they're just getting away. It's an escape so the coping mechanisms continue or they go in and out of this coping.”

This participant detailed interaction with clients who have had a history using substances as a previous coping mechanism. This quote explains that using substances is often an escape from whatever uncomfortable life stressors they may be experiencing, and that those who have used substances in the past were likely to use again in the future when confronted with a stressor. It is also important to note, however, that the participant mentioned his/her clients “go in and out of this coping,” suggesting that even though clients often revert to previous coping strategies, substance use is a dynamic type of strategy that can change as life stressors change as well. This suggest that PLH who have a history of coping through substance use may not always cope by using substances and may engage in other more positive coping mechanisms.

Some participants also mentioned that though they understood how engaging in substance use was something that could compromise their health, (e.g., exposing themselves to the threat of contracting HIV), they continued to engage in using

substances and alcohol. This participant described how they used substances prior to becoming HIV+:

“I kept doing what I was doing knowing that the disease was out there you know. It had been made brought to the light, but I still wanted to indulge in my drugs and so I ignored it you know. I was hardheaded, I mean you know because I was doing the things that I was doing you know I had a ready heard about it and I didn't stop doing what I was doing, which was shooting up.”

Here, the participant stated that he/she understood the dangers associated with using drugs, especially the dangers associated with intravenous drug use. However, he/she described themselves as “hardheaded” and focused on using the drugs. This participant also disclosed that he/she no longer uses drugs and also has learned to “look at things like ‘nah that ‘ain't good for you man, you don't need that.’” This is consistent with the previous quote stating that clients go “in and out of this coping [with substance use].”

It is also important to note that several participants mentioned that they currently continue to engage in substance and alcohol use as a method of coping with stress and unhappiness with current life situations, even though they are aware of its harmful possibilities. Below is one participant’s account of their personal struggle with substance use:

“Well, when I was working, I wouldn’t drink every day. I would only drink on my days off. Now that I don’t have a job, I find myself drinking every freaking day, every day. And [NAME REDACTED] saying, ‘How do you get the money if you don’t have a job? How do you get the money?’ From friends, it’s there from their

table for me. But I woke up this morning, and it's like 'I'm doing it again.' And I start crying, like I don't need it every night because I can't function the way I want to in the morning. So yeah it's sad, but I know once I get back on my feet, I won't be acting a fool drinking every freaking day."

This participant described how not having employment contributed to his/her negative feelings, promoting their desire to drink. Through the participant's personal account of his/her interaction with alcohol, it is clear that they were aware of the negative effects it causes to his/her life, however they continued to perpetuate the cycle of coping with drugs/alcohol and often relied on financial assistance from friends to purchase alcohol.

One alternate explanation could be explored through participants' reporting that using substances was more for purposes of relaxation and for calming, rather than as a coping response to stress. Because of this, a tendency to rationalize and minimize alcohol/drug use was also found. Below is an example of how participants may rationalize the use of alcohol:

"Yeah well I ain't gonna say I'm an alcoholic. But I guess if you take a drink down every day you just about an alcoholic. But I don't drink a whole lot. I'm a liquor person, I like me something to sip on you know?"

Here, the participant showed an understanding of his/her own frequency of alcohol use, which may not necessarily be problematic. It is interesting to note, however, that the participant mentioned their daily alcohol intake might as well classify them as a perceived alcoholic.

Several participants who work closely with the HIV+ population also mentioned how substance use within the HIV+ community remains an issue for some individuals. One participant described his/her experiences with HIV+ clients who use substances below:

“They say, ‘This is what I do. I cope this is how I wind down.’ I do know I have clients that are on meth yeah smoke marijuana. I have clients that you know they use other drugs that are not legal in the state of Texas. So there you go. You have those still.”

When asked directly if drinking alcohol was used as a response to life stressors, several mentioned that drinking was “not stress it’s just relaxing” and more of a “to relax and have fun thing.” These responses suggest that participants themselves might minimize the severity of drinking alcohol, or the severity of their own drinking. It is possible that daily drinking to “wind down” along with the use of other substances could pose threat to individual health and progression of HIV virus within the body.

While some participants mentioned the use of a single substance, for example solely drinking alcohol, others mentioned engagement in polysubstance use. Participants often mentioned a long history of substance use, with onset occurring as a response to stress or for purely recreational purposes. One participant described his/her positive experiences of personal growth and coping with substances below:

“I was an alcoholic from age 14 to 47 I think, and I just, I used to juggle my substances so I wouldn't be addicted to any certain one. And this kind of way of my life has been for learning things, learning to cope. I did a lot of psychedelics,

but I did everything else too. Psychedelics are more therapeutic I think than some of the other things I did.”

Here, the use of substances and drugs was outlined as more of learning or stepping-stones of learning how to cope with stressors. Specifically, the participant described how personal use of psychedelics was therapeutically more beneficial than other drugs. The positive experiences with psychedelics can be seen as a rationalization of use, for being “therapeutic”; However, it is also important to note that the use of psychedelics in a chronic illness context has been researched in patients living with chronic pain, anxiety in cancer patients, as well as enhancing the end of life process for terminal patients (Sessa, 2005). Little to no research has been conducted regarding how psychedelics may play role in stress reduction in PLH specifically.

Theme 3: Limited Financial Abilities

The third theme was *Limited Financial Abilities* and manifested as accounts of when and how finances contribute to overall growth of stress. Regarding the third theme, financial abilities affected overall stress by creating a constrained circle of one’s ability to get work, maintain work, and pay for necessities when experiencing a financial or medical emergency. A case manager for an HIV/AIDS service provider shared his/her view of how HIV contributes to this circle:

“The stress all of a sudden is working full-time. And then the expectations of coming to AIDS services to meet with case managers, going to medical appointments frequently on a new diagnosis...you know, just navigating the system. And then if you have mental health issues on top of that and those

appointments also. So I think maintaining a job and then being afraid of losing your job because you have to take time off for all these appointments can be a huge stressor.”

Here, the case manager described how many individuals who get an HIV+ diagnosis are often confronted with the added stress of living with a chronic illness, needing to navigate their new healthcare system and confront a new disease. The participant mentioned that a new diagnosis often needs much attention, frequent medical appointments and meetings with HIV/AIDS service providers. This attention required of their illness may put an added stress on their work life. It is possible that this demand of healthcare needs added to the stress associated with maintaining work life may surpass an individuals’ threshold and ultimately cost the individual their job.

Many HIV/AIDS professionals expressed similar concerns through client experiences with regard to how living with HIV affects finances and work opportunities. This participant mentioned how the body’s interaction with medication affects the potential to work and ultimately financial capabilities:

“So if it cannot fight off infection, you're gonna have another problem. And that is what basically ends up happening. And so as, when that happens, I kind of, it kind of throws a monkey wrench in their lives when they’re not able to work and provide for themselves, financially. So at that point we advise them to apply for disability and see if they’re able to qualify for that.”

Here, the participant suggested that if medication shows to be ineffective, of if the individual were to eventually develop a resistance to medication, certain PLH may not be

able to work, thus limiting income, and further restrict the capability of carrying on day-to-day activities. Because these hardships were very closely related to living with HIV, many were advised to seek financial assistance through disability services. Participants also mentioned how not having sufficient financial abilities affected emotional well-being as well as inability to fund a financial or medical emergency. One participant described his/her struggle with finances and assisting his/her daughter with intensive cancer treatments below:

“I need a job in order to help be there for her and take care of her. Yeah, that’s driving me crazy to where yesterday, I went to Lady Bird Lake, and I walked and I walked and I walked by the water, and I cried and I cried and I cried. I need a job. I keep telling Lord ‘Please get me this job, I need this job to get me back on track.’ And I don’t want to lose it because I need to take care of my daughter. I gotta be here for my girl.”

Here, the participant described how he/she is unable to help fund their daughter’s medical treatment, thus affecting their own emotional well-being. The participant stated “I don’t want to lose it”, meaning they do not want to lose control of his/her emotions and psychological wellbeing. Because of this, the participant assumed responsibility in needing to assist their daughter by using absolutes such as “need to take care” and “gotta be here.”

Additionally, financial issues attributed to medical comorbidities and inability to work contributes to a lowered ability to actively cope. Symptoms can create work absences and inability to perform job function, and can also give PLH a perception of

them having the inability to obtain a job. One participant described his/her complex medical conditions due to living with HIV:

“Well I have a lot of appointments. I mean, I've had this a long time, you know. My body's just kind of deteriorated. I have a body of a 60-year-old, and I'm only 38, so the bones in my body, I mean they hurt. I see a neurologist because I've got migraines and so all these health problems that I have. It weighs onto the fact that I probably wouldn't go through this if I wasn't HIV positive.”

Here, the participant described how HIV had brought on several medical complications; furthermore, he/she mentioned that attending appointments for these medical issues is time consuming and emotionally taxing. Within this quotation, the participant also denoted a sense of resentment or regret towards their HIV+ status for complicating their life.

Another participant showed how medical symptoms or medication side effects had affected their clients' ability to acquire and maintain a job:

“It's gonna depend on a lot on how bad they are, health-wise. You know because if they're having symptoms of such as ongoing diarrhea, vomiting, nausea, then they're not gonna be able to get out of bed to go to work. And so we've had quite a few clients who have lost their jobs because they're not able to get out of bed.”

Symptoms of HIV caused significant impairment in the overall ability to perform a job. Negative side effects from medication also caused significant inability to perform one's job. The absences from work due to HIV-related symptoms and/or medication side effects created a strain in the work environment and ultimately cause the individual to

lose his/her job, furthering the financial stress experienced by PLH. The deterioration of the body and the symptoms associated with HIV contributed to the overall difficulties surrounding acquiring and maintaining a job, and ultimately the financial abilities of the individual experiencing these issues. From these two quotes, it can be noted that HIV can impact physical functioning to the point where appropriate work would be difficult to find and maintain.

As stated before, many PLH applied for disability services to provide financial assistance. Disability aid qualified HIV+ people for fixed income and social services, however it also restricted the amount of extra income that the individual can receive outside of disability services. One participant described below how financial assistance has served as a stressor to his/her life:

“If you are on disability, you only are allowed like 20 hours to work. Can't make over a certain amount of money every month and it's, it's a lot. It's very stressful, more stressful than you would think.”

Like this participant, other individuals described that receiving this aid also may serve as a double-edged sword. Many PLH who can work, those whose HIV symptoms or negative medication side effects no longer cause significant impairment, described difficulty in finding employment that can satisfy the parameters associated with receiving financial assistance. With a lack of ability in satisfying the parameters of financial assistance, being on fixed income may have compromised the ability to meet all their needs and can function as a stressor of its own. Adhering to the parameters to receive this aid helped financially, but added a component of stress into daily life.

Lastly, it is also important to note that for individuals experiencing financial hardships, financial responsibilities competed with one another, making it a treatment versus hierarchy of needs battle.

“I don’t have enough money to pay my utilities. I don’t have enough money to pay my rent. I don’t have enough money you know to get hygiene stuff, you know, things that are important. I feel that. And not luxuries, you know. They’re necessities. And even the medication is a necessity. But it’s I either pay my utilities, or I pay my medications so I can continue living a more comfortable life.”

This participant described that by following the parameters required to receive financial assistance, he/she was left in a financial battle of creating a hierarchy of purchasing basic necessities. When necessities are compromised, it is possible that overall quality of life and health in general can decline. This also suggested that for many individuals needing to create a hierarchy of necessities, several necessities have been ignored, which can have impact of the individual life of someone living with HIV.

Theme 4: Relationship Dynamics

The fourth theme, *Relationship Dynamics*, appeared through how, when, and why HIV acted as an influence for positive and negative change in the relationships PLH have with others. Regarding the fourth research question, it was found that disclosing HIV status would prove stressful for all three relationship types, because disclosure deprived them of control of the future of the relationships. HIV-related stigma from others was often based on a misunderstanding and ignorance surrounding how HIV is transmitted,

commonly thought that HIV is transmitted through any physical contact with HIV+ individuals. One participant described some of the challenges associated with disclosing an HIV+ status:

“Well everybody’s afraid of what other people would think, and it was considered a deadly disease, you know. ‘Hey they got the AIDS, they got it they got it,’ you know. It was like kind of hush-hush you know. And [people] probably felt scared to talk about it, you know. They were afraid of death, afraid of what people might think.”

This quote outlined several of the negative views individuals have surrounding HIV and how these negative views may serve as barriers to disclosing an HIV+ status. Among these barriers were fear of what others might think, confronting an uninformed view of HIV, as well as fear of negative treatment from others if HIV status is disclosed.

Because of negative views surrounding HIV, PLH were often confronted with the stress of selectively disclosing their HIV status and taking preventative measures to ensure that their HIV status is not accidentally disclosed. Because of this, many individuals felt isolation and additional stress stemming from balancing their disclosure. On participant described his/her experiences regarding balancing disclosure:

“Like I said, you get to know somebody. You want to give them, you know, the full info. But then they’ll say something and, you know, just kind of it be [you need to] wait before you divulge anything to make you say that they got a good cover. Because I thought this was a person that was going to, you know, be a friend and stuff like that. But, you know, they still on that stupid about HIV you know.”

This participant described the process of selective disclosure as a constant testing of the waters of the relationship before full disclosure. Here, others' ignorance regarding HIV was also highlighted as a barrier to disclosing HIV status. If someone is "still on that stupid" with regard to HIV, this individual would not disclose their HIV status and would not include them as a friend within their social circle.

There was also a unique stress to disclosing HIV status to an intimate partner, as it was often seen as a mandatory disclosure versus a disclosure done through choice. When talking about the stress of disclosing to an intimate partner, many participants stated they "have" to disclose rather than choosing who they would disclose to. One participant's account of the stress associated with disclosing his HIV status to an intimate partner is outlined below:

"I'm a man. I love women, and I have a problem with that now by being HIV. Because if the woman is not HIV and I am. And I have to tell her, especially if she's interested in me, it makes it. That's been a real difficult thing in my life, being able to tell another mate that I'm HIV and knowing that they are not."

Here, the participant described how being HIV+ had served as a problem with regard to establishing and maintaining intimate relationships. Within intimate relationships, this participant, as well as others, described HIV disclosure as something that is mandatory and something that is difficult to do. It is important to note, however, that HIV disclosure remained an unspoken topic for many individuals living with HIV and engaging in sexual intercourse. Many participants of the study explained that disclosing an HIV+ status could hinder and dampen the relationship. However, it is important to note that within HIV serocongruent and serodiscordant intimate

relationships, accepting HIV status would often strengthen the quality of the relationship. HIV serocongruence refers to intimate relationships where all partners are HIV+, while serodiscordant relationships refer to intimate relationships where at least one partner's HIV status was not consistent with another's status.

“They have found that it brings them closer to that other person. Because now there is the sense that life, life can be potentially cut short and or that for someone to be so courageous as to share something so potentially catastrophic with me makes me special. The person that you're speaking to special or that person has such an understanding of the circumstances that you've been living your life that this is not was not outside the realm of possibility.”

For some individuals, such as those described by the quotation above, disclosing an HIV+ status strengthened the quality of the relationship by putting life into perspective. Knowing that there was potential for a life to be cut short and knowing that HIV disclosure had possibility to be detrimental to the relationship, the relationship could strengthen when positively received and accepted. This shared experience between those involved in the relationship served to strengthen the relationship, particularly if both individuals are undergoing the same HIV related care, both by means of management (ART) and by means of prevention though pre-exposure prophylaxis (or PrEP), as expressed by other participants.

Disclosing was a source of support and comfort to cope with HIV, however an HIV+ diagnosis had also negatively changed the relationship quality for some, particularly within familial relationships. Within the interview process, several

individuals stated that their relationship with their family changed as a result of disclosing their HIV status. Many others also stated that they have yet to disclose their HIV status due to fear of the reactions from the family. An HIV service provider described below how clients may struggle in disclosing to family:

“They live in a household, but they can't tell anybody because it might get them put out or yeah, just a lot of things could go wrong because they told that they had HIV. So they just keep it to themselves. They hide it, you know. It's stressful. It's constantly stress because they feel like they can't be honest about what they're living with. And a lot of times you have families that don't even know other family members living in their house are sick because they just feel like that support won't come from them. And they don't want to ruffle feathers and get kicked out, so they don't even talk about it. They just keep it to themselves.”

This participant suggested that many PLH chose not to disclose their HIV status to their family partly purely due to personal choice, and to a greater part due to fear of attitudes and outcomes from disclosing. Because of this heightened risk for more to go “wrong,” some PLH chose not to disclose and risk not receiving proper care. This suggested that the fear one has regarding disclosing HIV status to family has the potential to be so great that one would rather struggle through the illness rather than risking damaging the relationship.

After disclosing, others often treated HIV+ individuals differently and negatively through enforced specific rules and guidelines for the HIV+ person. For those living with HIV, the label of being HIV+ restricted the availability and motivation to socialize and

engage in some activities with relationships. One individual who works closely with PLH described their clients' negative experiences below:

“One of the ladies, she and her family, she always has to eat off plates because she has HIV. She never said she would never be in that situation in her home, with paper plates, so it's really about the rejection. It's about the shame. It's about the consequences and those can be all the way from eating off of paper plates to actually somebody who's gonna hit you. So what I find is that these are some of the stresses the people talk about its the stress of rejection, the stress of shame, the stress of stigma, the stress of being put out the emotional consequence of someone yelling at you that you did something bad that it's all your fault. nd often times that is the go-to feeling.”

Here, the participant described how his/her client and their family were now treated differently by their extended family due to their HIV+ status. The participant also mentioned that consequences of disclosure, for example the stress of shame, rejection, and stigma, were often so great that the HIV+ individual often reluctantly tolerated the negative treatment rather than risk the possibility of exasperating those to whom they have disclosed. Ignorance surrounding HIV transmission and fear of contamination were primarily what promoted negative treatment from others, as shown through this quotation as well as through other quotations.

Many members of family, interpersonal, and intimate relationships were unaware of what being HIV+ means and how to treat someone who is HIV+. Because of this, the

HIV+ individual was often seen as the educator within these various relationships. One HIV provider described how clients may be the educator in relationships:

“They're also in the role where anytime they want to have an emotional connection or intimate relationship or sex, they're probably going to have to educate the person that they are having sex with about HIV. It's like, ‘Oh I want to have sex, but man I just don't feel like being professor HIV for 20-30 minutes again.’ So it's like, I think it's, it's all sorts of being rejected for the billionth time. So it's a huge. I'd put that at number one for the stresses that people with HIV feel.”

For many HIV+ individuals, becoming the educator of HIV both inside the family dynamic and outside the family dynamic added an additional stressor to their daily lives. This participant described how HIV+ individuals often assumed the role of the educator prior to and during sexual interactions. As the participant described, many may feel a reluctance to become the “professor HIV,” and are confronted with the stress of either unenthusiastically becoming the educator, or not disclosing their HIV+ status prior to engaging in sexual acts.

With regards to friendships and family, disclosing can bring a cut in contact when negatively received, however strengthened and created new bonds when positively received. One HIV professional described their clients' experiences in how disclosure had been both positive and negative:

“I've definitely seen families come in with that patient or client and support them through the process because they were too stressed out or too nervous to really

deal with it themselves. So it's just one of those situations that will or benefit and the ones that are just disastrous and sad and horrendous. It can really affect someone and then the persons choice and experience disclosing that information to their family can be hugely stressful too because when they have to disclose that to their [other] family members.”

This quotation showed how the role of family support for PLH varied from person to person. The participant described increased support for some clients from disclosing their HIV status to their family; and he/she also described how disclosure of an HIV+ status brought negative experiences from family members for others. It is also important to note that the participant mentioned how disclosing to family also influenced disclosure to other family members.

Theme 5: Internal Pressures and Psychosocial Resiliency

Lastly, the fifth theme, *Internal Pressures and Psychosocial Resiliency*, emerged as internal stressors and changes in life due to being HIV+. This fifth construct that emerged showed that HIV+ individuals often had a negative self-image and viewed themselves as tainted as a result of being HIV+. Often these individuals described their feelings about living with HIV as they “would not wish this disease upon anyone”. Several also described living with HIV as a learning process of fully understanding how it was to truly live with HIV:

“I mean yeah cause when I found out about it, I got told this at clinic. I told him, ‘Oh great I have fricking HIV. I’m never gonna get into a relationship ever again.’ He says, ‘No, you will have a boyfriend someday.’ I said, ‘No I won’t. Who’d

want to sleep with me?’ And he’s older, He goes, ‘Trust me. You’ll get a relationship down the road. You just gotta absorb all the information, because you just found out what you’re living with.’ Sure enough I got one, and I don’t want to lose this one. I don’t know. God works in mysterious ways. I got with this one, and I hope we stay together for quite some time.”

Interactions with the physician served as a comforting support for this participant after he/she experienced their initial diagnosis. By talking through and processing the initial diagnosis with his/her physician, the participant described being able to begin to learn what it means to be HIV+ and how that transitions to daily life.

Many individuals who were HIV+ reported utilizing religion and spirituality in prayer to cope with daily stressors. It is important to note that the majority of participants described utilizing religion or spirituality as a method of combatting stress. Religion as a coping mechanism often was used to relieve the stress of finding a relationship:

“All I can do is take one day at a time and pray and pray that God continues to smile on my life because I don’t think there’d be somebody else that would stick with me, living with what I have.”

Here, the participant described his/her connection with God as complex but comforting. He/she utilizes religion to cope with relationship stress; this includes the stress of finding an intimate/romantic relationship as well as finding the type of relationship where he/she can find emotional comfort.

Because religion and spirituality can be used in seeking a placement of emotional comfort, many describe their relationship with God itself as an emotional comfort. Thus,

religion and spirituality were also utilized when feeling like life is overwhelming and feeling intolerable desperation.

“But it’s gotten to a point where you discovered [that you’re] gonna get to the point where you can’t take it no more and this and that. I just put everything in God’s hand and everything in it’s own part and everything.”

This participant described a point in life where he/she felt overwhelming distress and reached a point of realization of intolerability. He/she described accepting the loss of controllability of life and allowed God to guide them through every aspect. Religion and spirituality were also utilized as a method of finding purpose in life and day to day actions with others:

“I was like, ‘Lord what is my purpose?’ And now I know it's that what I've been through go out there and talk about it [HIV].”

These three quotations showed several participants utilized religion and spirituality to combat stressors encountered in life. Religion and spirituality were also used to build hope, overcome the feeling of being overwhelmed, and through finding purpose in life.

After overcoming the initial shock of being diagnosed as HIV+, individuals had a positive outlook of both their HIV status and management, and lower their overall stress perception. It is interestingly noted that many individuals had a positive self-regard and self-view of themselves as a result of the HIV status. Many individuals claimed that HIV has made them stronger as a person and more favorable in their eyes.

“I think it’s probably made me a stronger person. I mean...it’s made me a stronger person in a sense that I’m able to deal with it. It was hard to deal with it at first. But I think because I have so many friends that have passed away with HIV that it wasn’t as hard because I think from very young I was always like very well informed. So I was never really scared of HIV. I wasn’t really scared of people with HIV.”

By experiencing friends dying from HIV, this participant described a personal transformation to where living with HIV has made them a psychologically stronger person and more able to cope with their chronic illness.

Living with HIV is known to be a stressful experience, and many individuals felt as though, once HIV is managed, they were now survivors of what HIV could have possibly done to their body.

“I’m a survivor and you know, I changed my reality sick convenience so I can make things work for me and I manage too.”

This participant described actively taking the steps to change their life and his/her decisions to improve their present and future. It is also important to note that many individuals maintained a positive outlook on life regarding their HIV+ status. When asked how HIV influences their outlook of their future, one participant responded:

“It’s just made me stronger. I’ve lived through it, you know. I don’t fear it. I’ve never feared it. I really have always said it, you know, it wouldn’t kill me, and I don’t know if it’s an attitude or throwing the kitchen sink at it or that I’m a

vegetarian. And some people say marijuana fixes it, you know. Who knows, you know? But I'm here, and I'm going to be here. And I've got 30 more years to go.”

This quotation showed a strong sense of resiliency through stress and positive outlook of HIV management, HIV treatment, and his/her future life in living as an HIV+ person. The participants described living with HIV as a part of his/her own personal development and demonstrated an overall positive outlook towards his/her future life, regardless of what added complications or stressors HIV may introduce.

Data-Driven Conceptual Model

Though not specific to grounded theory, one important strategy commonly associated with grounded theory is the use of a diagram to assist in theory development and in helping visualize the interplay of data. Conceptual modeling may be used as a method for illustrating the data at the completion of the selective stage of coding (Bernard & Ryan, 2009). Through selective coding, we developed a schema for a conceptual model regarding specific sources of stress and general coping. Figure 1 illustrates how themes relate to one another through a conceptual model that describes the phenomenon of how the range of stressors and coping strategies interact. This model depicts four branches of stress found in PLH and further elaborates on the branches by stemming aspects of each branch that participants report as stress contributors. PLH respond to stress through either positive coping skills (e.g. social support) or through negative coping skills (e.g. substance use).

CHAPTER IV

DISCUSSION

The purposes of this study were to explore, through qualitative research the following issues: individual perspectives of what it means to be HIV+; how HIV management affects, and intrudes, into life; what aspects of living with HIV cause the most stress; coping strategies for living with HIV; substance use in living with HIV; how living with HIV affects self-perception; and how living with HIV affects familial, interpersonal, and intimate relationships. Another purpose of this study was to create a foundation for developing a clinically practical scale to assess stress relating to living with HIV, which will be completed in future work. The ultimate goal of this project was to establish this foundation for this second phase as well as to highlight specific stressors PLH encounter. This chapter reviews the findings, compares these findings to prior research on HIV and stress, discusses limitations of the study, and provides suggestions for further research on stress and HIV.

Interaction with the data helped inform research questions through the development of 5 themes. The first theme was *Housing Strain*, which emerged from the data as a global view of housing circumstances that foster the growth of stress. The second theme was *Engagement in Substance Use* and emerged from data through accounts of when and why individuals utilize substances/drugs as a method of coping, or general engagement in substance use. The third theme was *Limited Financial Abilities* and manifested as accounts of when and how finances contribute to overall growth of stress. The fourth theme, *Relationship Dynamics*, appeared through how, when, and why HIV

acted as an influence for positive and negative change in the relationships PLH have with others. Lastly, a fifth theme emerged from the data, *Internal Pressures and Psychosocial Resiliency*, emerging from internal stressors and changes of life due to being HIV+.

The concept of housing poses several pathways where stress can manifest and become an active part of day-to-day lives for many PLH. An analysis of qualitative data suggests that some individuals experience a source of stress from the home and housing contexts. Individuals can experience stress through dissatisfaction with quality and environmental intrusions from current housing accommodations, such as neighbors and legal battles, regardless if they are living in government subsidized housing or not. Additionally, the dynamic of having unfavorable housing, no housing, or even housing where your needs are not adequately being satisfied all have potential to increase stress for PLH.

The use of substances appears primarily as a current manifestation of prior learned coping skills. That is, individuals who were familiar with substance use or had engaged in substance use in the past were also found to engage in current substance use. The data also offers an explanation for this finding. Some individuals rationalize or minimize the severity of legal and illicit substance use, although the many negative effects substance use can have for someone who is HIV+ are understood. It is possible that this rationalization of using substances, or alcohol, could guide the return to using. It would be interesting in further research to evaluate the underlying cognitive processes some individuals have surrounding substances and rationalizing their use.

Limits on financial abilities were also seen as a method or cycle to promote stress. For some individuals, limited financial abilities create a strain to acquire employment and maintain employment, however limited financial abilities also adds strain to fund necessities required for life and for gaining employment itself, such as medication, food, and rent. Because of this, some individuals are caught in a cycle of not being able to afford necessities to obtain a job, and not being able to get a job because they cannot afford the necessities. Limited financial abilities also take a toll on emotional well-being as well. Financial assistance, or “fixed income” assistance is often seen as a method of helping alleviate financial stress. Interestingly, the assistance may also serve as a stressor on its own by requiring the individuals to maintain the parameters required to receive the assistance. Because of this, many individuals receiving this financial assistance are still left unable to fund all necessities. When limited financial abilities are coupled with poor emotional well-being and comorbid medical conditions, the cycle is further intensified to where certain PLH experience a battle regarding their own hierarchy of necessities.

With regard to relationships, data showed that HIV disclosure has potential to introduce stress to the relationships, if negatively received through misunderstanding and ignorance surrounding HIV. Disclosure itself is a stressful aspect of life that PLH are confronted with, often needing to selectively disclose their status and be mindful of their words around those with whom they do not feel comfort in disclosing. When their HIV+ status is negatively received, some PLH are often treated differently, confronted with negative actions against them, and may develop an internalized negative view of themselves. However, disclosure of an HIV+ status also has potential to strengthen the relationship by means of putting life itself into perspective, allowing an intimate couple

the opportunity to engage in a shared HIV adventure of prevention, and through friends and family providing emotional support for individuals living with HIV.

The final theme incorporates internal or personal pressures and psychosocial resiliency. Here, data shows that participants often identify and incorporate HIV as a part of their own identity, but not as the complete definition of who they are. A part of this identity includes changes that occur from living with HIV. These changes can include changing life perspectives of what they gain satisfaction from in life, and an increased awareness of themselves as an HIV+ individual around others. Other changes include the acceptance of inevitable death, and acquiring a survivorship mentality towards a disease that once killed many of their friends, families, and acquaintances. Additionally, this theme shows a transition towards individuals accepting their HIV status and committing to living as an HIV+ individual. Some individuals also changed how they once viewed HIV, to where now they experience a mostly positive outlook of their life; this includes how HIV has played a role in strengthening themselves as a person physically here on Earth as well as through strengthening their soul by means of religion and spirituality.

With regard to previous research, the results of this study highlight the possibility of adherence being compromised through both financial issues and negative side effects of medication itself (Centers for Disease Control and Prevention, 2014). This is consistent with literature on barriers to adhering to HIV ART (Varni, Miller, Solomon, 2012; Zierler, Cunningham, Anderson, Nakazono, Morton, et. al., 2000; Gostin, Feldblum, & Webber 1999). The results also mirror the stress associated with disclosing

health status to others (Hackl, Somlai, Kelly, & Kalichman, 1997). However, it introduces a possibility of increased health benefit if positively received by others.

Among daily hassles, reports were similar to what is highlighted in research (Holm & Holroyd, 1992; DeLongis, Coyne, Dakof, Folkman, & Lazarus, 1982; Kanner, Coyne, Schaefer, & Lazarus, 1981; Lazarus & DeLongis, 1983, however some PLH also report a specific hassle of taking medication and confronting payment/insurance issues for HIV maintenance. With regard to coping, both maladaptive and adaptive styles of coping were found in PLH and mirror many coping mechanisms found in previous research (Armeli, Tennen, Affleck, & Krantzler 2000) as a response to negative life situations by displaying negative affect (Nel & Kagee, 2011). Substance use is consistent as a coping strategy for some PLH (Altice et. al., 2010); however, the notion of rationalization of substance use is something that research has not placed much emphasis on. It is also interestingly noted that some PLH report more positive outlook after confronting HIV related stressors. This is a concept that is fairly new to HIV literature and could prove beneficial for future research (Gonzalez et al., 2004).

In terms of the study's hypotheses, this study generally supports the majority of hypotheses outlined earlier. In general, it was hypothesized that main themes of stress from interpersonal relationships, health, and finances would be found. This was expected because, as previously stated, PLH are confronted with disclosing their status to others, and due to the fact that HIV is a chronic illness that requires continuous and prevalent treatment. Since HIV affects a much greater number of people of lower socioeconomic status (Centers for Disease Control and Prevention, 2014), it was plausible to assume that

stress over finances would be found in these interviews. Our findings support these claims; PLH expressed stress stemming from various interpersonal relationships, health consequence and maintenance, and financial ability to fund necessities of basic living. Specifically, it was hypothesized that individuals living with HIV and living in public housing would express dissatisfaction and stress from their housing situation due to environmental factors out of their control. Our findings also confirm this statement; however, it is also important to note that PLH who were not in government subsidized housing also reported housing strains from other paths (e.g. the internal housing environment and the shared concept of financial inability to fund necessities).

It was also hypothesized that recreational drug/alcohol users become more frequent users after an HIV+ diagnosis out of feeling overwhelmed. Our findings did not confirm or deny this statement, but rather showed that those who had a history or past of substance engagement were more likely to engage in substances again, as a response to stress or as a method of recreation. Additionally, being HIV+ may trigger a constraint circle of ability to get work, maintain work, and pay for necessities. Financial issues (such as medical comorbidities and inability to work) would contribute to a lower ability to actively cope. Both of these statements were supported and unveiled an internal constraint cycle of battle between one's own hierarchy of needs and for some an inability to cope with positive coping mechanisms. Lastly, it was hypothesized that HIV disclosure would cause stress; however, a positive reception of disclosing can bring empowerment. This hypothesis was also supported through participant recollections of family and

friends joining therapy sessions for some and disowning and/or treating negatively for others.

It is interesting to note, however, that the concept of adherence to medication regimen and stress associated with adhering to medication did not arise as a main domain of stress. Although participants were not asked to disclose the length of time they've been living with HIV, it is postulated that this may be due to the sampling of our participants only assessing those who have lived with HIV for many years and have well-established medication and treatment management. It is also possible that there are different stressors and different levels of stress associated at the beginning of a new HIV diagnosis, and other types of stress and stressors at later times in living with HIV. Because of this, the non-occurrence of stress specifically from medication adherence can only be suggested as a factor related to HIV diagnosis timeline.

It is also noted that the majority of the participants were primarily low income, or indigent clients. Although results from this study may not be generalizable to all PLH, it gives important insight to unique stressors for PLH who are indigent. With regard to previous research of indigent HIV community and clinical samples, the areas of unemployment (Bowleg, Teti, Malebranche, & Tschann, 2013), household and/or within-house stressors and substance use (Illangasekare, Burke, Changer, & Gielen, 2013) are found as major sources of stress for low-income PLH. Additionally, research highlights higher levels of stress associated with lower perception of social support and utilizing fewer active coping skills for lower-income PLH (Catz, Gore-Felton, & McClure, 2002). This study contributes to the literature by adding domains of stress, identifying when and

why PLH may engage in substance use, as well as identifying an internal perpetual battle of one's own hierarchy of needs. This concept has potential for further utilization in indigent PLH research and psychotherapy and also to be adapted to PLH in general; one's hierarchy of needs is unique and individual to each PLH.

Limitations

There are several limitations of this study. Participants may fake good or fake bad intentionally; meaning, participants may give untrue or unrepresentative responses to portray themselves as better or worse than they actually are. Participants also may possibly feel compelled to answer a certain way due to the nature of the study. This is a specific concern in the individual interviews, but having multiple participants and various types of people with various exposure to HIV should limit this bias. Specifically, the measures assessed only PLH. So, results from this study cannot be generalized to people not living with HIV. Results from this project can not be generalized to people living with other chronic illnesses, such as diabetes. Another potential concern is that demographic data is limited for this study, due to the nature of the topic in research. Additionally, participants from this study were sampled only from two cities. Thus, regional and cultural differences could influence the results. Future studies should look at possible regional differences in how participants respond in individual interviews, especially since most studies on HIV in the USA have been conducted on primarily the East or West Coast.

The main concern for further development of a stress measurement, as a second project, for PLH is having participants from mainly the Austin, Texas area. This may

become an issue if the stress measurement developed from this section is not generalizable enough for PLH as a whole. However, we attempted to address this issue by recruiting and interviewing individuals on different days as well as from two separate cities in the Central Texas area.

Recommendations for Future Research

This study aids in increasing the understanding of the relationship between stress and HIV by demonstrating individuals living with HIV may experience specific types of stress that are not being addressed within the traditional clinical setting. There is a deficit in the psychological literature in terms of mapping specific areas of stress or specific types of stress that PLH experience; rather, it is typically researched as generalized stress. Because of this, this study can serve as a foundation towards developing greater bodies of research that detail specifics of stress in PLH. This study also serves as a method of highlighting deficits within clinical settings in hopes of moving towards a more comprehensive setting of care and resources for PLH.

Future research should add focus to the specific areas of life where PLH experience stress and how their experience of stress may differ from those who are HIV-. Research should also question how effective clinical settings are in addressing issues encountered by PLH, in terms of psychological counseling and financial assistance programs, for example. By assessing the more focused areas of stress along with the ability of clinical settings to combat these areas of stress, it is possible to move towards a more comprehensive and efficacious psychosocial treatment of HIV.

Finally, as previously mentioned, it would be beneficial to use the information gathered from this project, in the development of a clinically utilizable scale that can

address the more specific stressors associated with living with HIV. The development of this scale also has potential for utilization in healthcare settings to better address and provide psychosocial assistance for individuals experiencing stress associated with living with HIV. Ultimately, if healthcare systems address the range of specific stressors experienced by PLH, improved quality of care to PLH could result.

Concluding Remarks

Utilizing qualitative methodology to examine the experiences of stress in PLH allows for a greater and fuller analysis and understanding regarding the lives of PLH. Though this study, along with many other studies, classifies these individuals as “People living with HIV”, qualitative research allows for a more individualized and personalized account of several “Persons living with HIV”. Though one might argue that this type of research is highly individualistic and non-representative of PLH in general, it can also be argued that this understanding of individuals can assist in the understanding of larger groups of people, particularly in something as universal as stress within a community.

Results from this study suggest an overall theme of PLH undoubtedly experiencing stress at some point in their lives, or through a chronic exposure to stress in their lives. Specifically, this study highlights the realms of housing strain, substance use, limited financial abilities, relationship dynamics, and internal pressures with psychosocial resiliency as branches of stress PLH experience. While coping ranges from individual to individual, aspects of seeking support from others and engaging in substance/drug use were not uncommon references as responses to all realms of stress. To sum up the sentiment of research findings of how stress and HIV interplay, I offer this closing passage from the data:

“But, I know. I can see it through their eyes when we, we’re having laughter together at the dinner table, I notice that they like have this look where they feel sorry for me. And I don’t want nobody to feel sorry for me, cause it is what it is. Just continue to live life. This illness ‘ain’t ‘gonna kill me! If anything is ‘gonna kill me it’s these fast, Capital Metro busses that nobody sees, that’s ‘gonna take my life out! Have fun with life, I tell people have fun with life.”

Table 1. Demographic Results for Clients: Gender

Gender	Frequency	Valid Percent
Male	8	66.7%
Female	2	16.7%
Transgender Female	2	16.7%

Table 2. Demographic Results for Clients: Ethnicity

Ethnicity	Frequency	Valid Percent
Caucasian	2	16.7%
African-American	7	58.3%
Hispanic/Latino	3	25%

Table 3. Demographic Results for HIV Professionals: Gender

Gender	Frequency	Valid Percent
Male	6	75.0%
Female	2	25.0%

Table 4. Demographic Results for HIV Professionals: Ethnicity

Ethnicity	Frequency	Valid Percent
Caucasian	3	15.0%
African-American	1	5.0%
Hispanic/Latino	4	50.0%

Table 5. Demographic Results for HIV Professionals: Job Type

Job Type	Frequency	Valid Percent
Program Manager	1	5.0%
Counselor	1	5.0%
Health Insurance Specialist	1	5.0%
Case Manager	4	20.0%
Prevention Program Specialist	1	5.0%

Table 6. Theme 1 Explanation of Theme, Codes, and Concepts

Theme and Definition	Code Name	Code Concepts
<i>Housing Strain</i> : Global view of housing circumstances that foster the growth of stress	Financial Stress	This code was used to mark any financial hardship expressed by participants. The code represents when financial strains or financial needs are difficult to be met.
	<i>Sub-code: Financial Stress: Funding Necessities</i>	This sub-code was used to identify financial stress stemming from the inability to fund necessities of living.
	Housing Stress	This code was used to mark any housing-related hardships expressed by the participant. The code represents when dissatisfaction with housing situation causes distress.
	<i>Sub-code: Housing Stress: Neighbors</i>	This sub-code was used to identify housing stress stemming from issues surrounding unfavorable neighbors.
	<i>Sub-code: Housing Stress: Quality</i>	This sub-code was used to identify housing stress stemming from issues surrounding the overall quality of housing facilities, including
	<i>Sub-code: Housing Stress: No Satisfaction</i>	This sub-code was used to identify housing stress stemming from issues surrounding individual satisfaction surrounding housing situation.

Table 7. Theme 2 Explanation of Theme, Codes, and Concepts

Theme and Definition	Code Name	Code Concepts
<i>Engagement in Substance Use</i> : When and why individuals utilize substances/drugs as a method of coping	Coping Mechanisms	This code was used to identify general coping mechanisms used in reaction to stress and stressors of life. The code represents both adaptive and maladaptive methods of coping with stress.
	Coping with Substance Use	This code was used to mark the specific instances of substance/drug use. The code represents the concept of using substances/drugs as a method of coping with stressors of life.
	<i>Sub-code: Coping with Substance Use: Current</i>	This sub-code was used to identify instances where participants indicated current substance use.
	<i>Sub-code: Coping with Substance Use: Past</i>	This sub-code was used to identify instances where participants indicated past substance use.
	<i>Sub-code: Coping with Substance Use: Rationalization of Substance Use</i>	This sub-code was used to identify when participants reported a rationalization, normalization, or softened severity of substance use.
	Using Familiar Coping Mechanisms	This code was used to mark the instances where participants revisited coping mechanisms that had been used in the past. The code represents the concept of utilizing familiar coping mechanisms as a method of coping with stressors of life.

Table 7 Continued

	Change in Coping Strategies after Diagnosis	This code was used to mark the instances where participants stated coping style and strategies changed after diagnoses. The code represents an adaptive or maladaptive change in coping after becoming HIV+.
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Table 8. Theme 3 Explanation of the Theme, Code, and Concepts

Theme and Definition	Code Name	Code Concepts
<i>Limited Financial Abilities:</i> when and how finances contribute to overall growth of stress	HIV Restrictions	This code was used to mark the instances where HIV has restricted a part of life that had once been non-restricted. This code represents how HIV is restrictive of many activities and requires several life changes.
	<i>Sub-code: HIV Restrictions: Access and Source of Healthcare</i>	This sub-code was used to identify accessibility to HIV-competent healthcare providers, availability of these providers, and how HIV associated stressors influence access and availability.
	<i>Sub-code: HIV Restrictions: Ability to Work</i>	This sub-code was used to mark inabilities or difficulties to find, maintain, or perform job duties due to HIV symptoms/maintenance.
	Financial Stress	This code was used to mark any financial hardship expressed by participants. The code represents when financial strains or financial needs are difficult to be met.
	<i>Sub-code: Financial Stress: Funding Necessities</i>	This sub-code was used to identify financial stress stemming from the inability to fund necessities of living.
	<i>Sub-code: Financial Stress: Financial Support as a Source of Stress</i>	This sub-code was used to identify distress stemming from receiving financial assistance, maintaining parameters to qualify for financial assistance, and inability of financial assistance to fully support the individual.
	HIV Management and Maintenance	This code was used to mark the instances where HIV management and maintenance of HIV has compromised financial abilities. This code represents when and how HIV care can directly affect financial abilities.

Table 8 Continued

	<i>Sub-code: HIV Management and Maintenance: Negative Medication Side Effects</i>	This sub-code was used to identify instances where negative side effects of ART or HIV-related medication limited ability to perform activities of daily living, such as working, cleaning, and other activities of daily living
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Table 9. Theme 4 Explanation of Theme, Codes, and Code Concepts

Theme and definition	Code Name	Code Concepts
<i>Relationship dynamics: how, when, and why HIV influences a change in the relationships PLH have with others</i>	Stress from HIV Disclosure	This code was used to identify the instances where an HIV+ disclosure causes distress in the individual disclosing. This code represents the stress of disclosing an HIV+ status.
	<i>Sub-code: Stress from HIV Disclosure: Unintentional</i>	This sub-code addresses instances where PLH must selectively disclose, test the waters of the relationship, and be mindful of those around them or risk unintentional/accidental disclosure of HIV+ status.
	<i>Sub-code: Stress from HIV Disclosure: Becoming the Educator</i>	This sub-code was used to mark instances where HIV+ individuals switch roles to an HIV educator, in a variety of contexts.
	Relationship Stress	This code was used to identify the instances where an HIV+ individual experiences stress in familial, interpersonal, and intimate relationships. This code represents the stress being HIV+ adds to the relationship dynamic.
	<i>Sub-code: Relationship Stress: Friends</i>	This sub-code was used to mark instances where being HIV+ introduced a stress into friendships.
	<i>Sub-code: Relationship Stress: Family</i>	This sub-code was used to mark instances where being HIV+ introduced a stress into family relationships.
	<i>Sub-code: Relationship Stress: Intimate Partner</i>	This sub-code was used to mark instances where being HIV+ introduced a stress into intimate partner encounters.

Table 9 Continued

HIV Related Stigma	This code was used to identify negative treatment, views, opinions, and concepts associated with PLH. The code represents negative and untrue beliefs and actions towards PLH.
<i>Sub-code: HIV Related Stigma: Negative Treatment from Others</i>	This sub-code was used to mark instances when participants indicate stigma of HIV from other – indicating how others feel negatively about HIV and how the feeling translates to negative actions.
<i>Sub-code: HIV Related Stigma: Internalized Stigma</i>	This sub-code was used to mark instances when participants indicate stigma of HIV from self – indicating how PLH themselves feel negatively about HIV.
Coping Mechanisms	This code was used to identify general coping mechanisms used in reaction to stress and stressors of life. The code represents both adaptive and maladaptive methods of coping with stress.
<i>Sub-code: Coping Mechanisms: Coping with Family Support</i>	This sub-code was used to mark instances when participants indicate finding comfort and confidence within familial relationships.
<i>Sub-code: Coping Mechanisms: Coping with Friendship Support</i>	This sub-code was used to mark instances when participants indicate finding comfort and confidence within friendships.

Table 9 Continued

	<i>Sub-code: Coping Mechanisms: Coping with Partner Support</i>	This sub-code was used to mark instances when participants indicate finding comfort and confidence within their partners, spouses, and intimate relationships.
	<i>Sub-code: Coping Mechanisms: Support from Others in Similar Situations</i>	This sub-code was used to mark instances when participants indicate finding comfort and confidence within other individuals living with HIV – including community groups, support groups, and HIV advocacy organizations.

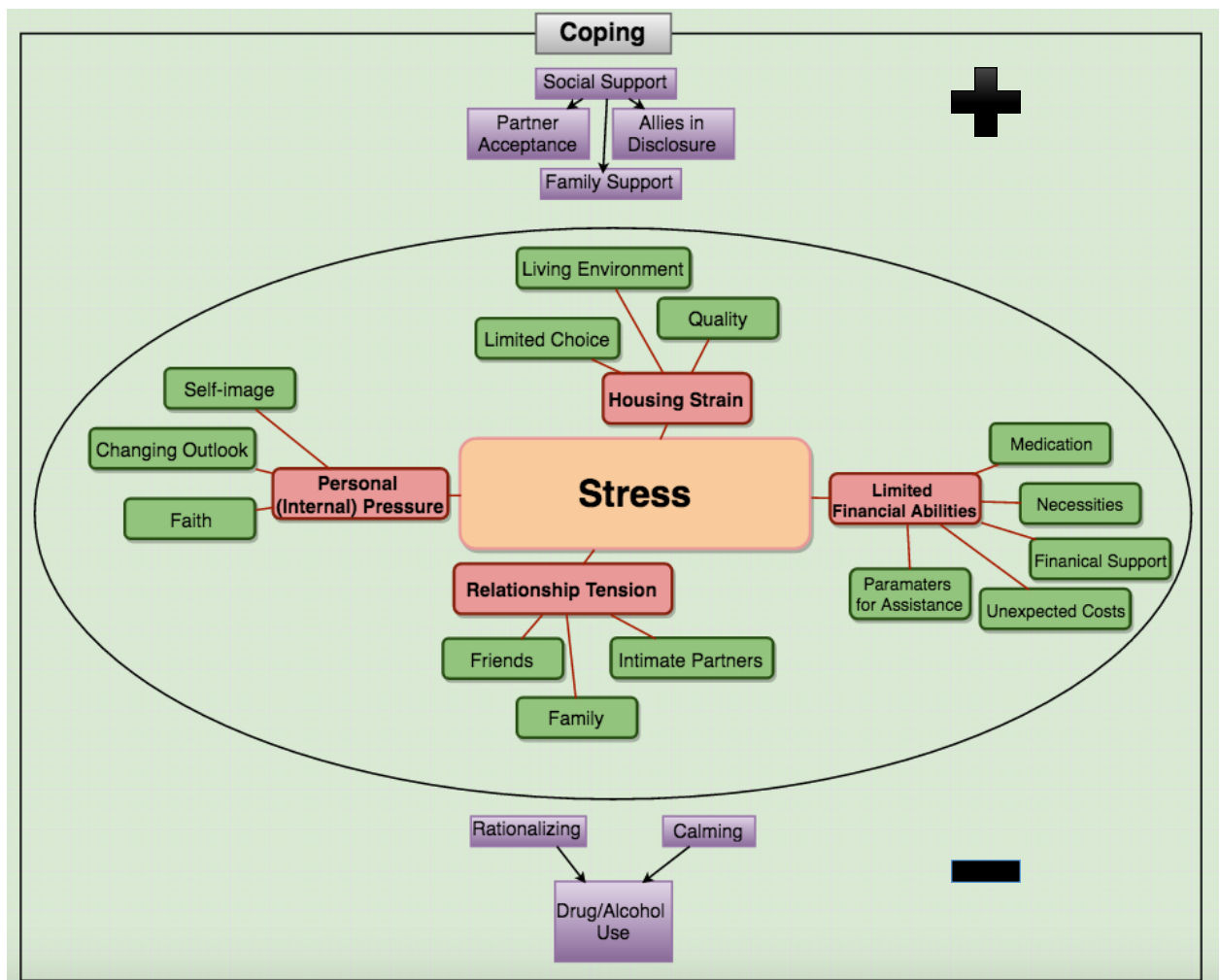
Table 10. Theme 5 Explanation of Theme, Codes, and Code Concepts

Theme and definition	Code Name	Code Concepts
<i>Internal pressures and psychosocial resiliency: internal stressors and changes of life due to being HIV+</i>	HIV as Part of Identity	This code was used to mark when participation describe HIV as a part of their identity. The code represents HIV as part of, as an aspect of, but not complete definition of identity for PLH.
	Personal Changes due to Living with HIV	This code was used to capture individual changes made by PLH after diagnosis. This code represents the constant behavioral and psychosocial adjustment towards living with HIV.
	<i>Sub-code: Personal Changes due to Living with HIV: Life Perspectives</i>	This sub-code was used to mark how living with HIV changes outlook of life and perspectives of life, life satisfaction, and importance of life.
	<i>Sub-code: Personal Changes due to Living with HIV: Self-awareness</i>	This sub-code was used to mark participants' increasing self-awareness surrounding HIV and how their HIV status affects those around them.
	<i>Sub-code: Personal Changes due to Living with HIV: No Fear of Death</i>	This sub-code was used to mark a change from fearing death and living cautiously to a freer lifestyle where death is no longer feared, but rather just accepted as fact.
	<i>Sub-code: Personal Changes due to Living with HIV: Survivor Mentality</i>	This sub-code was used to mark a survivor mindset many PLH experience, including both a positive survivorship of HIV and a survivor's guilt for those who have lost friends/family due to HIV.

Table 10 Continued

	<i>Sub-code: Personal Changes due to Living with HIV: Acceptance and Commitment</i>	This sub-code was used to mark acceptance of HIV status and commitment to living with HIV, rather than denial or shame towards HIV+ status.
	<i>Sub-code: Personal Changes due to Living with HIV: Viewing HIV as Positive</i>	This sub-code was used to mark individuals' perception of HIV as something positive that has happened to them in their lives, and as something that has made them a stronger/better person as a result.
	Resiliency Through Stress	This code was used to show when participants indicate perseverance and continues to drive through stressors in daily life. The code represents a resiliency through life stressors.
	Coping Mechanisms	This code was used to identify general coping mechanisms used in reaction to stress and stressors of life. The code represents both adaptive and maladaptive methods of coping with stress.
	<i>Sub-code: Coping Mechanisms: Religion and Spirituality</i>	This sub-code was used to mark coping with and seeking guidance through stress through use of religion, higher power, spirituality, and meditation.

Figure 1: Theoretical and Conceptual model of Stress and Coping for PLH



APPENDIX SECTION

Semi-Structured Interview Script

Thank you for agreeing to do this interview. My name is Stephen Ramos. I'm a student at TX State University conducting research to design a survey on stress, HIV, and coping. I'll be asking you questions about your personal experiences with HIV and stress. We'll be here about a half hour. Everything you tell me will be confidential. To protect your privacy, we won't connect your name with anything that you say. You don't have to respond to questions that you don't want to answer. I would like to record our discussion today to keep accurate records. Is it all right with you if I audiotape the interview?

Patients/Clients

1. Tell me what it is like to live with HIV (What it **means** to be HIV positive)
2. How does HIV / managing HIV (txt) **affect your life** (financial, work, satisfaction, daily hassles)
3. What causes you most **stress** (daily hassles)
4. How do you **cope** with stress
 - a. Substance use?
 - b. Describe a typical coping strategy: After a stressful day, I...
5. Talk to me about your **relationships** (probe for problems, cause; familial, friendship, and intimate)
6. How does HIV affect how you **see yourself**? How other see you?

HIV Professionals

1. What do your patients/ clients say it is like to live with HIV (what it means to be HIV positive)
2. How does HIV / managing HIV (txt) **affect their life** (financial, work, satisfaction, daily hassles)
3. How does HIV affect how they **see themselves**? How others see them?
4. What causes them most **stress** (daily hassles)
5. How do they **cope** with stress
 - a. Substance use?
6. Talk to me about their **relationships** (probe for problems, cause; familial and intimate)

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