

STIGMA, SPIRITUALITY AND PSYCHOLOGICAL QUALITY OF LIFE IN PEOPLE
LIVING WITH HIV: A MIXED METHODS APPROACH

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HIV is a potentially fatal virus that affects over 1,148,200 people in the United States. Due to the minority status that comes with living with HIV, PLH (people living with HIV) often encounter various aspects of stigma due to HIV, which contributes to suppressed overall psychological quality of life (PQOL). While the relationship between stigma and PQOL in PLH is well documented, little research examines mediators of this relationship. We hypothesized that spirituality (as measured by sense of peace, forgiveness of self and perceived fulfillment of life's goal) mediates the relationship between stigma and PQOL (as measured by depression, mental health and stress). We used an explanatory sequential mixed methods design which utilizes two distinct phases of the research process: quantitative (QUANT) analysis followed by qualitative (QUAL) analysis. Results of the QUANT phase suggest spirituality is a partial mediator in the relationship between stigma and PQOL in PLH. In the QUAL phase, we interviewed 15 PLH to elaborate on the relationships between the three constructs. We found PLH endorsed personalized stigma most frequently. Similarly, our results also indicate PLH experience stress, depression and anxiety as a result of their HIV status. Lastly, participant's interviewed most commonly described their spiritual beliefs as relating to religion or God, which is in contrast to how spirituality was conceptualized in the quantitative portion of our study. In all, QUAL results confirmed QUANT findings, with the one main difference between how spirituality was conceptualized between the

QUANT and QUAL qualitative portions of our study. Results highlight the importance of clinicians inquiring about PLH's PQOL, experiences of stigma and spiritual beliefs.

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CHAPTER I INTRODUCTION

What is HIV?

According to the Centers for Disease Control and Prevention (CDC; 2014), the human immunodeficiency virus (HIV) is the virus that can lead to acquired immunodeficiency syndrome (AIDS). HIV affects specific cells of the immune system, called CD4 cells, or T cells. Over time, HIV destroys many of these cells and the body can no longer fight infection, which leads to the development of AIDS. In Western countries, the median time from infection of HIV to the development of AIDS is 10 to 12 years (CDC, 2014). HIV has a well-documented progression, which untreated is almost always fatal. The first stage of HIV is known as “acute infection” and occurs within two to four weeks after infection (CDC, 2014). At this time, the newly infected person experiences flu-like symptoms, such as fever, headache, tiredness, etc. This stage is also known as “acute retroviral syndrome.” During the first stage, large amounts of HIV are produced in the body. The virus uses CD4 cells to make copies of itself while simultaneously destroying these cells in the process. The likelihood of spreading HIV is the greatest during this stage since the amount of HIV in the blood is very high. Eventually, the immune response brings the amount of virus in the blood down to a stable level, at which point, the CD4 count will begin to increase, but not return to its baseline levels (CDC, 2014).

During the second stage, known as clinical latency, HIV is still active, but reproduces at low levels, and symptoms of HIV may not be present. People who receive antiretroviral therapy (ART) may live in this stage for several decades (CDC, 2014). For those who do not take ART, this period can last up to a decade. However, some people

may progress through this stage at a faster rate. Even though highly active antiretroviral therapy (HAART) has the ability to decrease viral load and increase T-cells, not all people who meet the criteria for ART are prescribed HAART. For example, people who are not adherent are often not prescribed HAART because poor adherence can lead to resistance to that medication (McNaghten, Hanson, Dworkin & Jones, 2003).

Furthermore, factors such as alcohol or drug use, mental health status, and missing outpatient care may influence HAART prescription. In particular, women and PLH with alcohol abuse/dependence are prescribed HAART at lower rates than men and non-alcoholics. Similarly, PLH who contracted HIV through heterosexual contact are more likely to be prescribed HAART than men who have sex with men (MSM; McNaghten, Hanson, Dworkin & Jones, 2003). This discrepancy may be explained by stigma and discrimination of sexual minorities from health care providers. Overall, McNaghten et al. (2003) examined PLH in more than 100 hospitals and clinics and found that of the 9,530 people eligible for HAART prescription, only 5,456 PLH were prescribed HAART.

It is important to note that HIV can still be transmitted during the clinical latency stage (and all stages) even if ART is used; although ART does reduce the likelihood of transmission. Toward the middle and end of this stage, viral load increases, CD4 count drops, and symptoms of HIV infection may begin (CDC, 2014).

The final stage of infection is AIDS. This is the stage that occurs when the immune system is severely weakened and vulnerable to infections and infection-related cancers (i.e., opportunistic illnesses). AIDS is diagnosed when the CD4 cell count falls below 200 cells per cubic millimeter of blood (200 cells/mm³) or if one or more opportunistic illnesses develop (regardless of CD4 count; CDC, 2014). Without

treatment, people diagnosed with AIDS typically survive about 3 years. However, some opportunistic infections reduce life expectancy to about one year (CDC, 2014).

Prevalence/Incidence

At the end of 2009, approximately 1,148,200 people aged 13 years and older were living with HIV in the United States (CDC, 2014). The CDC estimates that approximately 50,000 people are diagnosed with HIV each year. In 2010, an estimated 47,500 people were diagnosed. Minority groups such as African Americans, Latinos, and gay and bisexual men of all race and ethnicities continue to be disproportionately affected. Of the 47,500 new diagnoses in 2010, the majority were European American men who have sex with men (MSM; CDC, 2012, see Table 1 for most affected sub populations).

Table 1

2010 Estimates of New Diagnoses of HIV by Subgroup

Sub Populations	Number Newly Diagnosed
European American MSM	11,200
African American MSM	10,600
Hispanic/Latino MSM	6,700
African American Heterosexual Women	5,300
African American Heterosexual Men	2,700
European American Heterosexual Women	1,300
Hispanic/Latino Heterosexual Women	1,200
African American Male Intravenous Drug Users	1,100
African American Female Intravenous Drug Users	850

Of the 197,090 diagnoses of HIV infection from 2008-2011, the majority were African American (47%; see Table 2).

Table 2

2010 Estimates of New Diagnoses of HIV by Ethnicity/Race

Ethnicity	% Newly Diagnosed
African American	47%
European American	28%
Hispanic/Latino	21%
Asian	2%
Multiracial	2%
Native American/Alaska Native	<1%
Native Hawaiian/other Pacific Islander	<1%

The most common method of transmission differs between men and women. For men, the breakdown of transmission is as follows: 78% male-to-male sexual contact, 12% heterosexual contact, 6% injection drug use, 4% male-to-male sexual contact and injection drug use, and <1% other. Women, in contrast, show a different pattern of transmission: 86% heterosexual contact, 14% injection drug use (CDC, 2014).

CHAPTER II

REVIEW OF THE LITERATURE

Quality of Life in People living with HIV

People living with HIV (PLH) face many stressors including medication management and adherence, physiological changes and stigma. Currently, no cure for HIV/AIDS exists and PLH require a lifetime of treatment. The goal of HIV treatment is to reduce the amount of virus in a person's body and prevent destruction of the immune system. While new antiretroviral treatments improve survival, the durability of the therapeutic effect is uncertain and severe side effects are common (Hays et al., 2000). HIV-related symptoms related to the underlying disease and side effects of anti-retroviral medications affect a wide-range of well-being. Of the 21 anti-HIV medications approved by the US Food and Drug Administration (FDA) for the treatment of HIV, all cause negative side effects, which range from mild to life-threatening (US Department of Health and Human Services, 2005). Some of the common major side effects are: hepatotoxicity, hyperglycemia, hyperlipidemia, lactic acidosis, lipodystrophy, neuropathy, osteonecrosis/osteoporosis, osteopenia and skin rash. *Hepatotoxicity* is a general term for liver damage, which can cause nausea, vomiting, abdominal pain, loss of appetite, diarrhea, feeling tired or weak and jaundice. *Hyperglycemia* occurs when a higher than usual level of glucose is in the blood, and results in increased urination, excessive thirst or hunger, and unexplained weight loss. *Hyperlipidemia* is an elevated level of fat in the blood and increases the risk of heart disease and pancreatitis. *Lactic Acidosis* is a result of too much lactate in the blood and low blood pH, because the blood contains too much acid. Symptoms of lactic acidosis include nausea, unexplained

tiredness, shortness of breath, rapid breathing, cold or blue hands and feet, abnormal heart beat and weight loss. The two types of *lipodystrophy* include (1) *lipoatrophy*, in which fat is lost from particular areas of the body, and (2) *hyperadiposity*, in which fat builds up in particular areas of the body. *Osteonecrosis* (bone death), *osteopenia* (i.e., when the bones lose minerals and become less dense) and *osteoporosis* can result in bone fractures. Taken together, side effects of medication and symptoms of the disease contribute to poor quality of life. Side effects are also associated with greater ER visits, hospitalizations, HIV/AIDS related physician visits, outpatient clinic visits and counseling visits (daCosta DiBonaventura et al., 2012). With regard to employment, side effects of anti-retroviral therapy are associated with absenteeism and work impairment (daCosta DiBonaventura, Gupta, Cho & Mrus, 2012).

Other than physical health symptoms, PLH also exhibit worse mental health symptoms than members of the general public. For example, a meta-analysis found that PLH are almost twice as likely to be diagnosed with a major depressive disorder than those who are HIV-negative (Ciesla & Roberts, 2001). Similarly, rates of PTSD in PLH range from 22-60%, (Gore-Felton & Koopman, 2002; Sledjeski, Delahaty & Bogart, 2005) while only 7% of US adults exhibit symptoms of PTSD (Kessler, Chiu, Demler, Merikangas & Walters, 2005).

Minority Stress Theory

The minority stress theory may partially explain why PLH have poorer quality of life than those who are not HIV-positive. The minority stress theory, proposed by Meyer (2003), provides insight into how rejection/discrimination, as a result of being a minority,

can impact quality of life for PLH. While Meyer (2003) originally applied the minority stress model to sexual minorities, this paper will apply Meyer's model to PLH.

Sociologist Louis Wirth defined a minority group as "a group of people who, because of their physical or cultural characteristics are singled out from others in the society in which they live for differential and unequal treatment, and who, therefore, regard themselves as objects of collective discrimination" (Wirth, 1945, p. 347).

Similarly, the Americans with Disabilities Act (ADA) considers HIV/AIDS a physical disability and therefore protects PLH (U.S. Department of Justice). Based on this information, PLH are considered to be a minority group. Therefore, the minority stress model (2003) originally intended for lesbian, gay and bisexual people, can also be applied to PLH.

Minority stress can be identified as the excess stress experienced by individuals from stigmatized social categories as a result of their minority position (Meyer, 2003). Minority stress stems from the contrast between minority and dominant values, such that the minority person's cultural norms do not reflect the majority group (Meyer 2003). Also, as a result of their minority status, group members are more readily exposed to negative life events including prejudice, stigma, discrimination and violence. Lazarus and Folkman (1984) explain that the core of all social stress results from conflict between individuals and their experience of society. Not being accepted can be damaging to one's mental health, especially since the social environment helps people organize their experiences. Similarly, negativity from other can result in negativity towards oneself.

Meyer (2003) explains that minority stress is: (a) unique in that it is additional stress than what most individuals who are not minorities; (b) chronic; and (c) socially based since it is related to the social environment. Since PLH are members of a minority group, they also experience a stressful environment, which can contribute to mental health problems.

HIV Stigma

According to Meyer (2003), the largest reason PLH experience reduced quality of life is stigma and discrimination. In their meta-analysis of rates of depression, anxiety and stigma in PLH receiving antiretroviral therapy, Lowther, Selman, Harding and Higginson (2014) found that 42% to 83% of PLH experience some type of stigma. This includes discrimination from friends, family or community members and also internalized feelings of guilt and shame associated with their HIV diagnosis.

Therefore, it is important to understand the varying dimensions of HIV stigma and its implications. HIV stigma, known as social discrediting and devaluation associated with HIV (Goffman, 1963), occurs within a power structure and is a result of labeling, stereotyping, status loss and discrimination (Mahajan, 2008). HIV stigma maintains and perpetuates social inequalities, especially those associated with class, race, gender and sexuality (Parker & Aggleton, 2003). Herek (1999) describes four characteristics which explain why HIV is so highly stigmatized. First, HIV is a disease that is perceived as the fault of the HIV-positive person since the primary modes of transmission are behaviors that are considered voluntary and avoidable. Second, HIV is perceived as a condition that is unalterable and fatal, although the advent of HAART (highly active antiretroviral therapy) has started to change the perception of HIV to a chronic illness. Third, medical

conditions that are contagious have greater stigma attached to them. Lastly, conditions that are visible to others, such as in the advanced stages of AIDS, are more stigmatized. In addition, many PLH are also members of another minority group (e.g., sexual minorities, ethnic minorities and/or intravenous drug users), which provide another layer of stigma and discrimination.

Earnshaw and Chaudoir (2009) propose an HIV Stigma Framework which suggests that PLH experience internalized, anticipated and enacted HIV stigma. Internalized HIV stigma is the incorporation of society's negative feelings and beliefs and applying them to the self. Many PLH endorse negative feelings and beliefs about HIV from the perspective of a person living without HIV (Earnshaw & Chaudoir, 2009). The process of confronting these feelings and beliefs can result in internalized stigma. In contrast to internalized stigma, anticipated and enacted stigma require experience with others (Earnshaw & Chaudoir, 2009). Anticipated HIV stigma is expecting discrimination, stereotyping and prejudice from others in the future. Enacted HIV stigma is the actual discrimination, stereotyping and prejudice from others due to an HIV-positive status. Earnshaw, Smith, Chaudoir, Amico and Copenhaver (2013) found that internalized HIV stigma has the strongest associations with indicators of behavioral health and well-being (i.e., greater helplessness regarding HIV, lower acceptance of HIV and lower perceived benefits of HIV), greater days in medical care gaps and greater likelihood of non-adherence. Anticipated HIV stigma is associated with greater likelihood of chronic illness comorbidity, and lower mental health and social support. Enacted HIV stigma is associated with greater likelihood of having a CD4 cell count lower than 200 (Earnshaw & Chaudoir, 2009).

Pascoe and Smart Richman (2009) suggest a process whereby stigma and discrimination lead to poor mental health. Chronic discrimination depletes a person's resources (e.g., coping skills) and lowers their ability to handle new stressors. The experience of discrimination is a stressor that broadly impacts health. Stressors that are uncontrollable and unpredictable (e.g., HIV stigma) are particularly harmful to health. Several models conceptualize discrimination as a social stressor that initiates a series of physiological responses, such as elevated blood pressure, heart rate and cortisol secretions. Over time, these elevated physiological responses can have a severe impact on health (Pascoe & Smart Richman, 2009). Others suggest that repeated exposure to discrimination prepares the body to be more physically reactive in stressful or potentially stressful situations (Guyll, Matthews & Bromberger, 2001). In addition to a sustained activation of the stress response, discrimination may affect health by decreasing resources for self-control and may result in participation in unhealthy behaviors (e.g., smoking, alcohol use; Landrine & Klonoff, 1996; Bennett, Wolin, Robinson, Fowler, & Edwards, 2005) and non-participation in healthy behaviors (e.g., condom use, medication adherence; Yoshikawa, Wilson, Chae & Cheng, 2004). Furthermore, HIV stigma is related to poor mental and physical health. Major and O'Brien (2005) found perceived HIV-related discrimination is associated with greater symptoms of depression and PTSD in HIV-positive black men who have sex with men (MSM), a population disproportionately affected by HIV. Human immunodeficiency virus (HIV) can be thought of as a persistent stressor (Major & O'Brien, 2005; Link & Phelan, 2006) that contributes to negative mood states such as distress, anxiety, depression, lower self-esteem and self-worth (Meyer, 2003; Major & O'Brien, 2005).

While many researchers suggest that stigma directly contributes to poor mental health (Meyer, 2003; Major & O'Brien, 2005), limited research examines the relationship between stigma, spirituality and quality of life. We hypothesize that a mediator in the relationship between stigma and quality of life for PLH is spirituality.

Spirituality

Definitions

Before understanding the interconnections between stigma, spirituality and quality of life, it is important to first define spirituality. The literature is replete with a variety of perspective and assumptions regarding the definition of spirituality, which makes conceptualizations of spirituality particularly difficult. Some authors define spirituality based on the perspective of organized religion with specific beliefs and practices, while others define spirituality as based on an elusive and subjective experience (Thoresen, 1999). Spirituality can be conceptualized as a search or quest for the unknown, the sacred in life and beyond and a search for purpose and meaning (Thoresen, 1999). Certain components of spirituality are not measurable, as they extend beyond the physical limits of time and space, while other aspects are readily observable (e.g. spiritual practices). Other definitions and conceptualizations of spirituality focus on relationships, such as the sacred in life or one's Higher Power (Miller & Thoresen, 2003). Unifying themes among conceptualizations of spirituality include include a sense of meaning and purpose in life, connectedness to the self, the environment or a higher power and belief in a unifying force (Zullig, Ward & Horn, 2006).

In discussions of spirituality, it is also important to distinguish spirituality from religiosity. While certain aspects of these two constructs certainly overlap, there are also

important differences. For example, religion is often based on an organized belief system with set rituals and practices and beliefs are typically learned in places of worship (Zullig, Ward & Horn, 2006). On the other hand, spirituality is a way of being that can be learned anywhere without requirement of formal religious practices (Zullig, Warn & Horn, 2006). Although some believe that religiosity suggests and implies spirituality, religiosity does not guarantee spirituality (Chandler, Holden & Kolander, 1992). Conversely, some people define and express their spirituality through their religion.

Dimensions of Spirituality

Overall, spirituality is difficult to define, as clear-cut boundaries do not exist, which makes forming a tight operational definition difficult. Regardless, the assumption that this means spirituality should not be studied has led to a gap in research on spirituality (Miller & Thoresen, 2003). Therefore, even though a clear definition of spirituality is difficult to achieve, it is still important to attempt to explore constructs which science may not fully understand.

Spirituality and HIV

The majority of PLH report that spirituality is an important factor in their lives, as most indicate some sense of meaning/purpose and deriving comfort from their spiritual beliefs (Cotton et al., 2006). After a diagnosis of HIV/AIDS, PLH often reflect on their lives and illness from a spiritual perspective (Tarakeshwar, Khan & Sikkema, 2006). In fact, Ironson et al. (2006) found that 45% of PLH report an increase in spirituality after receiving their diagnosis. Higher levels of spirituality are also associated with a greater likelihood of feeling life has improved since receiving an HIV/AIDS diagnosis (Szaflarski

et al., 2006). For example, spirituality increased the reason for PLH to increase their self-care, such as increased adherence to HAART medications. For some participants, self-care also included seeking forgiveness from God/Higher Power and learning to forgive themselves and family/friends.

Interestingly, spirituality/religion can play a dual role as both a coping mechanism and a stressor for PLH. For example, Kremer, Ironson & Kaplan (2009) found that spiritual beliefs impact the view of HIV as a positive or negative turning point. PLH who experience an increase in spirituality perceive HIV as a positive turning point. On the other hand, PLH who experience a decline in spirituality view HIV as a negative turning point. Similarly, a positive view of God is associated with slower rate of disease progression, while a negative view of God is associated with a quicker rate of disease progression.

In order to obtain a greater understanding of how PLH use spirituality, Tarakeshwar et al. (2006) interviewed 20 PLH about their spiritual life. Most PLH expressed a relationship with God /Higher Power since childhood. Approximately half of the participants reported they drifted away from their religion/spiritual beliefs before their diagnosis of HIV. Of particular importance was the finding that for all participants a diagnosis of HIV triggered participants to reflect upon their relationship with God or their Higher Power. Similarly, Cotton et al. (2006) interviewed 450 PLH about their spiritual/religious life and found that 88% found at least a little comfort in their faith or spiritual beliefs and 75% believed that their diagnosis strengthened their faith at least a little (Cotton et al., 2006). Tarakeshwar et al. (2006) also found that almost all participants appraised their God or Higher Power as a benevolent influence and

reported gratefulness for their blessings, even if the blessing was a lesson in the form of HIV. For example, one participant was quoted as saying, "I'm stronger and maybe that's why God chose me as opposed to somebody else" (Tarakeshwar et al., 2006, p. 63).

For many a diagnosis of HIV shifts the purpose of life and life's meaning. For example, Dunbar, Mueller, Medina and Wolf (1998), found that many women find new meaning and create new goals in their life after an HIV diagnosis, such as an increase in connection with their spiritual selves and greater meaning in their spiritual lives. Tarakeshwar et al. (2006) also found that life's goals shift from more individually-oriented goals (e.g., career, financial and social achievement) to inward-looking aspirations (e.g., being a better mother, living in the moment, etc.). These inward looking aspirations also largely include a desire to maintain and enhance family relationships. Family relationships also provided PLH with a reason to live and a sense of purpose. For PLH with children, their diagnosis allows them the opportunity to look outside of themselves (e.g., through the eyes of their children). Women also report being more honest in their relationships with others, which even includes ending relationships that do not align with their new goals and aspirations (Dunbar et al., 1998). Families also function as social support for PLH. This support includes not only reminders of medications and appointments, but also acceptance of their spiritual life (Tarakeshwar et al., 2006).

While many studies related to HIV and spirituality are descriptive or exploratory, a few intervention studies are reported. For example, Borman et al. (2006) conducted an intervention in which 93 PLH were randomly assigned to silently repeat a spiritual mantra throughout the day or to a control group. Those in the treatment condition were

provided with information on using and choosing a mantram. Other practices to enhance mantram repetition were also used including one-pointed attention and mindfulness. Participants in the attention control group watched videotapes on HIV-topics including medication, treatment issues, wasting syndrome and nutrition. PLH in the mantra group reported reductions in trait anger and intrusive thoughts, as well as increases in quality of life, spiritual connectedness, spiritual faith, sense of meaning or peace and spiritual well-being in comparison to the control group. Furthermore, Margolin, Avants and Arnold (2005) randomly assigned PLH who were using illicit drugs to receive acupuncture alone or acupuncture with spiritual group therapy. PLH in the group that received acupuncture and spiritual group therapy reported reductions in depression and anxiety and greater drug abstinence than PLH who received acupuncture alone.

Results suggest that interventions that include spirituality need to consider a notion of spirituality that goes beyond organized religion, church/synagogue/etc attendance, prayer and reading of religious texts. These interventions should include both the positive aspects of spirituality as well as the spiritual struggles that individuals with HIV may experience.

Spirituality and QOL for PLH

While many PLH report an increase in spirituality after being diagnosed with HIV, many also indicate an associated increase in quality of life. Greater levels of spirituality are associated with health outcomes such as fewer mental health problems, fewer reported HIV-related symptoms, fewer medical conditions and better overall health related quality of life in PLH (Cotton et al., 2006; Cuevas, Vance, Viamonte, Lee &

South, 2010). Specifically in women living with HIV, engagement in spiritual activities is associated with decreased emotional stress (Sowell et al., 2000), lower depression and greater optimism (Simoni & Ortiz, 2003).

According to Ironson et al. (2002), long-term survivors of AIDS (i.e., people who survived two times the median survival time expected for those with AIDS) were significantly higher on religious behavior than a comparison group. Similarly, private religious or spiritual feelings (e.g., faith or compassion for others) as well as public religious involvement were both associated with long-term survival. Sense of peace (i.e., serenity, spiritual comfort, security and sense of well-being) and faith were related to lower cortisol, which suggests that spiritual beliefs may have physiological benefits. Sense of peace and faith were also associated with optimism, lower hopelessness, less distress and anxiety.

While some researchers (McCullough et al., 2000) speculate the positive effects of spirituality on quality of life are due to social support derived from a religious community, Ironson et al. (2002) found that private aspects of religious/spirituality (i.e., faith) were associated with health. This suggests that the relationship between religion on health is not primarily accounted for by social support. Furthermore, even after Ironson et al. (2002) controlled for social support the relationship between religious behavior and health remained significant. Ironson et. al (2002) speculate that greater religiousness/spirituality affects health through lowering cortisol levels in PLH. Additionally, a recent study suggests that independent of medication adherence, substance abuse and social support, the use of positive spirituality/religiousness to cope with HIV predicted survival over 17 years (Ironson, Kremer, & Lucette; 2016). PLH who

specifically used spiritual practices, spiritual reframing, over-coming spiritual guilt, spiritual gratitude and spiritual empowerment were two to four times more likely survive over the course of 17 years.

Another key question addressed by Ironson (2002) was whether those with AIDS who survived longer were more religious prior to their diagnosis. Both the long term AIDS survivors and the comparison group were asked about their religiousness and spirituality at different times in their lives, including the year prior to their HIV diagnosis and the year after diagnosis. The long-term survivors were more religious in the year preceding their diagnosis than the comparison group. In addition, only the long-term survivors reported a significant increase in their spirituality/religiousness the year after receiving their diagnosis. No further increase in spirituality/religiousness was reported after the long-term survivors received a diagnosis of AIDS. These findings suggest PLH experience the biggest increase in spirituality/religiousness in the year after receiving an HIV diagnosis. In sum, the long-term survivors were more spiritual/religious to begin with and also became more spiritual/religious when they received an HIV diagnosis. Therefore, when PLH are first diagnosed with HIV, they may turn to their spiritual beliefs as a way to cope with their diagnosis; however, if PLH were not spiritual to begin with, they may rely on other resources as ways to cope.

Conversely, Ironson et al. (2002) also found that religion-based judgmentalness is negatively associated with survival. Religion can be deleterious to mental health, particularly if a person uses negative religious coping, which can be defined as seeing a crisis as punishment from God or calling into question God's power or love (Pargament, Koenig & Perez, 2000). These negative effects of religion on attitudes and affect are

particularly important for PLH. In fact, a minority of ministers, generally those older and less well educated, believe that PLH deserve their illness and that their illness is a punishment from God (Crawford, Allison, Robinson, & Samaryk, 1992). Kaldjian, Jekel and Friedland (1998) found that 17% of an AIDS sample felt that their illness represented punishment from God.

Other researchers examined two types of religious coping techniques: positive religious coping and spiritual struggle (Trevino et al., 2010). Positive religious coping can be referred to as methods which reflect a secure relationship with God/Higher Power, a belief in life's larger meaning and a sense of spiritual connectedness with others. Those who use positive religious coping techniques search for social support, look for religious messages in life and/or use rituals (e.g. prayer, participation in a religious organization). Spiritual struggle, on the other hand, is an expression of conflict, question and doubt in matters of faith, religion and God/Higher Power. Spiritual struggle often results in added stress. Positive religious coping and spiritual struggle are not mutually exclusive and a person can employ both types of coping during times of stress. Trevino et al. (2010) investigated the long-term effects of spiritual coping/spiritual struggle on PLH. The short-term outcomes of positive religious coping were greater self-esteem and spirituality. As expected, spiritual struggle resulted in poorer quality of life, higher levels of HIV symptoms and higher level of depressive symptoms. Similarly, the longitudinal data (12-18 months after receiving HIV diagnosis) suggest a positive relationship between positive spiritual coping and well-being. In addition, PLH who use positive religious coping demonstrate improvements in well-being over time, whereas PLH who report spiritual struggle experience declines over time (Trevino, 2010). At this

time, no research is documented on the way atheists or PLH without spiritual/religious beliefs cope with an HIV-diagnosis.

Spirituality, Stigma and Quality of Life

Few researchers examine the relationship between spirituality, stigma and psychological quality of life. However, Chaurdoir, Norton, Earnshaw, Moneyham, Mugavero, & Hiers (2012) found that spiritual peace moderates the relationship between high, but not low levels, of HIV stigma and depression. As previously stated, the relationship between stigma and a decrease in various aspects of quality of life (e.g., depression, etc) is well documented. However, no research, to date, examines how stigma influences spirituality, and therefore, psychological quality of life. We hypothesize that stigma is negatively associated with spirituality, such that as HIV stigma increases, spirituality decreases. Furthermore, we also hypothesize that spirituality and psychological quality of life are positively associated such that as spirituality increases, psychological QOL also increases.

Research Question and Hypotheses

According to the minority stress model, minorities (e.g., PLH) experience stigma and discrimination that leads to adverse health outcomes, such as increased and chronic stress (Meyer, 2003). Spirituality is one multidimensional construct which may help to explain the relationship between stigma and psychological QOL. Using the minority stress model as a template, we hypothesize that spirituality mediates the relationship between stigma and psychological QOL. Figure 2 below depicts the hypothesized relationship between these three constructs (stigma, spirituality and psychological QOL).

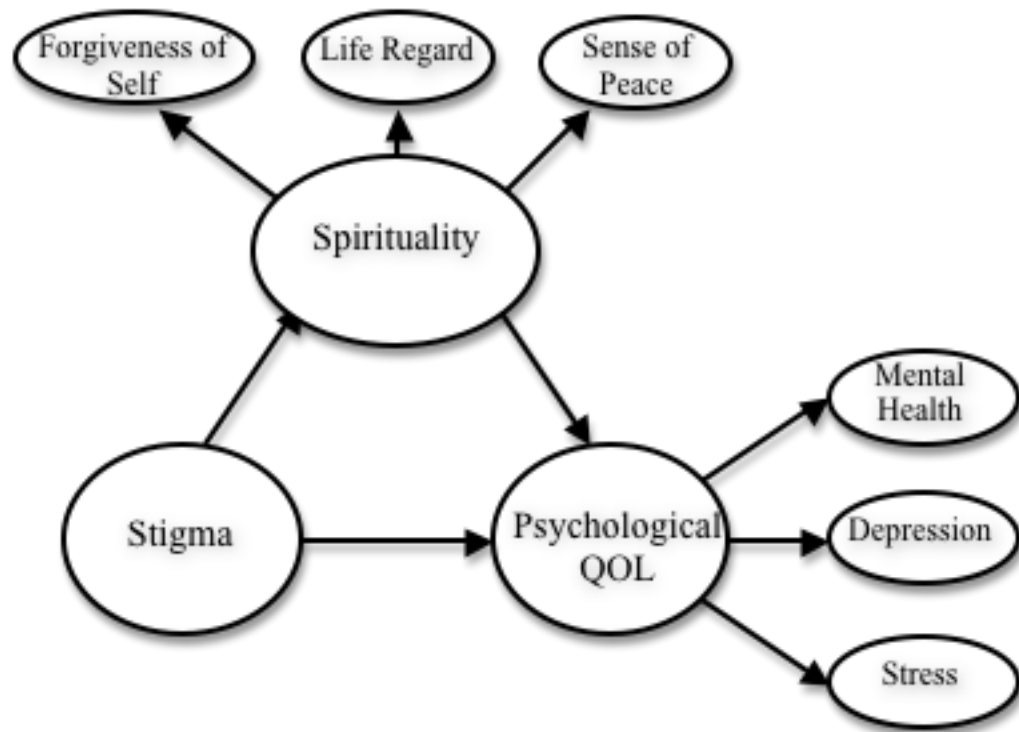


Figure 1. Stigma, spirituality, quality of life (SSQoL) model.

Within this model, we define spirituality as a multidimensional construct that contributes to forgiveness of self, perceived fulfillment of life's goals, and sense of peace. These aspects of spirituality are chosen based on Tarakeshwar and colleagues' (2006) identification of how PLH define and employ spirituality in coping with their HIV diagnosis. The latent construct psychological QOL is defined as being composed of and contributing to mental health, depression and perceived stress. The HIV stigma scale we use to assess stigma is also composed of questions that assess the multiple types of stigma: enacted stigma, disclosure concerns, negative self-esteem and concern with public attitudes. We hypothesize that stigma is associated with reduced spirituality (i.e., forgiveness of self, perceived fulfillment of goals and sense of peace) and thereby is

associated with reduced overall psychological quality of life (as measured by depression, mental health and stress).

In order to evaluate our study aims and purpose, stigma, spirituality and psychological quality of life are modeled together (see figure above) to understand the interdependencies between these constructs when acting in concert with one another. To delineate the efficacy of our model, the following hypotheses will be tested.

1. Stigma is negatively associated with psychological QOL.
2. Stigma is negatively associated with spirituality.
3. Spirituality is positively associated with psychological QOL.
4. The relationship between stigma and psychological QOL is mediated by spirituality.

Another aim of our study is to examine how PLH qualitatively define spirituality, HIV-stigma and PQOL, as well as how they view the relationships between these three constructs. This information would elaborate on the findings from our quantitative data and help us further understand how PLH conceptualize spirituality, HIV-stigma and PQOL. Qualitative data will also provide rich and meaningful information to elaborate on how PLH view the relationships between these three constructs.

CHAPTER III

METHODOLOGY

Study Design

To answer this study's research questions, we used a mixed-methods approach. Through this approach, we collect, analyze and mix or integrate both quantitative and qualitative data into one single study. In our study, we used a sequential explanatory mixed methods design. This design consists of two distinct phases: quantitative followed by qualitative. In this design, we analyzed the quantitative data. Second, we collected and analyzed the qualitative data to help explain and elaborate upon, the quantitative results. The qualitative phase builds on the quantitative phase, and thus the two approaches are connected in the intermediate stage of the study. The rationale for this approach is that the quantitative results help provide a general understanding of the research problem, while the qualitative data helps explain those results by exploring participants' reactions and views in more depth (Ivankova, Creswell & Stick, 2006).

In the two-phase approach of our study (Figure 2; Ivankova, Creswell & Stick, 2006), we first analyzed our data quantitatively using a PLS approach to SEM. Based on the results of our analysis, we created an interview protocol and conducted interviews with PLH who were matched on age, ethnicity and education to participants who completed the quantitative portion of this study. The number of participants depended on data saturation, which is the point at which no new or relevant information emerges from the qualitative interviews. This number is also reflective of previous research with an explanatory sequential mixed method designs (Barclay, Ripat, & Mayo, 2014; Barclay-Goddard, Ripat & Mayo, 2012; Ptaff, Baxter, Jack and Ploeg, 2014). We

then completed a qualitative follow-up approach to explain the results of our quantitative analyses in more detail. The reason for mixing both types of data is that neither the quantitative nor qualitative methods are sufficient by themselves to capture the trends and details of a situation, such as the complex issues of stigma and spirituality in PLH. When used together, quantitative and qualitative methods complement each other and provide a more complete picture of a complex research problem. Furthermore, since the area of HIV and spirituality is new and emerging, a mixed methods approach will give us a more complete picture of this complex relationship.

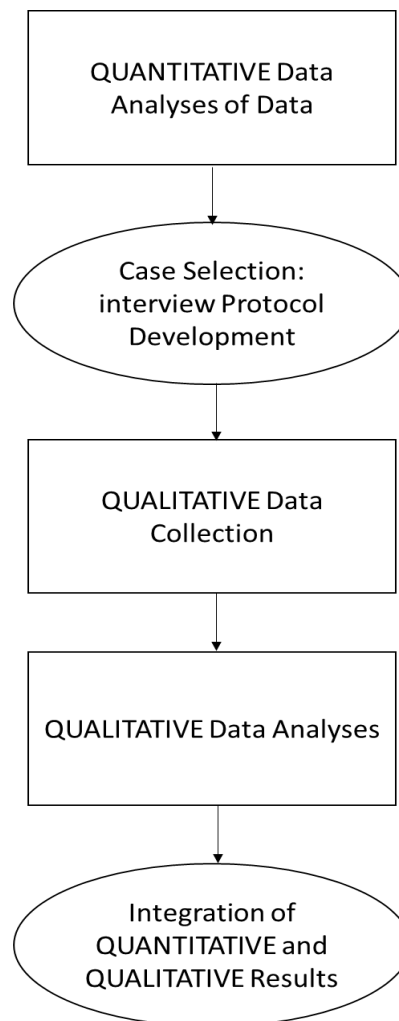


Figure 2. Model of mixed methods sequential exploratory design

Participants

Quantitative Participants

For the quantitative portion of this study, the appropriate institutional review board approved our study. Written informed consent was obtained from all participants prior to participation. Participants were offered \$15 as incentive to participate in the study. Individuals 18 or older that identified as having HIV or AIDS were recruited in 2002 as part of a larger project that examined how HIV-related stigma is associated with health outcomes and health related behavior. Recruitment was solicited through local community-based organizations and HIV service providers, such as UT Southwestern Medical Center and AIDS Services of North Texas. We used a cross-sectional correlational design and examined self-report data from questionnaires. Our diverse sample was stratified based on gender and consisted of 179 participants. Our sample consists of 95 males, 81 females, and 3 transgender participants. The average age of participants was 41.4 (SD = 8.4), and their average education was 12.5 years (SD = 2.5). Fifty-two percent of participants were African American, 35% were European American, 9% were Hispanic/Latino and 4% were classified as Other Ethnicity. Approximately 69% of participants earned less than \$10,000 per year, 16% earned between \$10,000 and \$19,000, 11% earned between \$20,000 and \$39,000 and 4% earned above \$40,000.

Qualitative Participants

For the qualitative portion of our study, the appropriate institutional review board also approved this portion of our study. We recruited participants from local AIDS service organizations (ASO's), including Resource Center Dallas and the AIDS

Outreach Center via flyers. Our participants were matched on the age, ethnicity and education of participants who completed the quantitative portion of this study (Table 3). The number of participants interviewed reflected similar studies that used an explanatory sequential mixed methods design (Barclay, Ripat, & Mayo, 2014; Barclay-Goddard, Ripat & Mayo, 2012; Ptaff, Baxter, Jack and Ploeg, 2014) and was also dependent on data saturation – the point at which no new data, themes or codes were obtained. Data saturation was met when new information obtained through interviews produced little or no change to the codebook. Approximately 20 participants endorsed interest in participating; 15 were ultimately selected based on data saturation and participant matching. We offered these participants \$20 as incentive for participation in the study (Guest, Bunce & Johnson, 2006).

Table 3

Participants

Ethnicity	Quantitative Participants		Qualitative Participants	
	N	Percentage	N	Percentage
European American	63	35.2%	4	26.7%
African American	93	52.0%	7	46.7%
Latino/a	16	8.9%	4	26.7%
Other Ethnicity	7	3.9%		
Gender	N	Percentage	N	Percentage
Male	95	53.1%	8	53.3%
Female	81	45.3%	7	46.7%
Transgender	3	1.7%		

	M	SD	Range	M	SD	Range
Age	41.4	8.4	19-68	46.3	10.1	26-68
Education (years)	12.5	2.5	6-22	13.3	2.0	11-18
	Range	N	%	M	SD	Range
Income*	<10K	121	67.6%	\$7,533	\$7,927	\$0-\$21K
	10K–19K	29	16.2%			
	20K-39K	19	10.6%			
	40K-59K	4	2.2			
	60K-79K	3	1.7			

*Income was measured differently between the quantitative and qualitative portions of our study. In the quantitative portion, participants indicated the amount they earned based on a range. In the qualitative portion, participants indicated the exact amount of money earned in a given year.

Data Analyses

Quantitative Analyses

Measures

Participants from the quantitative phase completed items on demographic characteristics, as well as items on health and wellness, medical issues, barriers to health and health disparities in PLH. Data on psychosocial and behavioral factors such as social support, stress and coping, pro-health and health seeking behaviors were also collected.

Medical Outcomes Study HIV Health Survey: Mental Health (MOS-HIV). The MOS-HIV is a 30-item measure designed to assess quality of life in PLH. The mental health subscale assesses feelings of anxiety and depression. This Likert-type scale

consists of six items and ranges from 1 (*all of the time*) to 6 (*none of the time*), with higher scores indicating higher mental health. Examples items include “During the past 4 weeks have you been a nervous person?” and “During the past 4 weeks have you felt so down in the dumps that nothing could cheer you up?” Internal consistency/reliability for the mental health subscale ranges from 0.91 to 0.94 (Revicki, Sorensen & Wu, 1998). Furthermore, multitrait analyses support the convergent and discriminant construct validity of each subscale (Wu, Rubin, & Matthews, 1991).

Perceived Stress Scale (PSS). We will measure stress using the Perceived Stress Scale (Cohen, Karmack & Mermelstein, 1983). The PSS measures the degree to which situations are perceived as stressful. This 10-item scale ranges from 1 (*never*) to 5 (*very often*), with higher scores indicating higher amounts of perceived stress. Example items include, “In the last month, how often have you been upset because of something that happened unexpectedly?” and “In the last month, how often have you felt that things were going your way?” Internal consistency/reliability ranges from 0.84 to 0.86, and test re-test reliability is approximately 0.85 (Cohen, Karmack & Mermelstein, 1983). The PSS demonstrates adequate concurrent and predictive validity (Cohen, Karmack & Mermelstein, 1983).

Center for Epidemiological Studies Depression Scale (CESD). We will use the CESD to measure depression (Radloff, 1977). This 20-item measure ranges from 1 (*rarely or none of the time*) to 4 (*most of the time*) with high scores indicating high depression. Example items include, “I felt that everything I did was an effort” and “*I had crying spells.*” A total score of 16 or greater suggests clinical depression. Internal

consistency reliability estimates ranged from 0.85 to 0.90 (Radloff, 1977). Radloff (1977) indicated the CESD demonstrates adequate discriminant validity.

HIV Stigma Scale (HSS). Stigma will be measured using the HIV Stigma Scale (Berger, Ferrans & Lashley, 2001). This 40-item measure ranges from 1 (*strongly disagree*) to 4 (*strongly agree*). Example items include, “I have been hurt by how people reacted to learning I have HIV,” and “Since I have HIV, I worry about people discriminating against me.” Coefficient alpha was estimated at 0.96 (Berger, Ferrans & Lashley, 2001). The HSS demonstrated good construct and discriminant validity (Berger, Ferrans & Lashley, 2001).

Ironson-Woods Spirituality Scale: Sense of Peace (IWSRI). We will measure sense of peace using the Sense of Peace subscale of the Ironson-Woods Spirituality Index (Ironson et al., 2002). We chose this subscale as it measures the notion that life has meaning. This 25-item likert type scale ranges from 1 (*strongly agree*) to 5 (*strongly disagree*), with higher scores indicating higher sense of peace. Examples of items on this subscale include, “My beliefs give meaning to my life” and “My beliefs help me feel I have a relationship or a connection with a higher form or being.” Ironson et al. (2002) report an internal consistency reliability of 0.94 and test-retest coefficient of 0.76. The Ironson Woods Spirituality/Religiousness Index also demonstrates adequate convergent and discriminant validity (Ironson et al., 2002).

Extended Life Regard Index: Fulfillment (ELRI). The Fulfillment subscale of the Life Regard Index was measured to assess the degree to which an individual sees himself/herself as having fulfilled or being in the process of fulfilling life’s goals. This 28-item scale ranges from 1 (*strongly disagree*) to 5 (*strongly agree*). Example items

include, “Living is deeply fulfilling” and “I really feel good about my life.” Cronbach’s alpha ranged between 0.83 and 0.92 and the measure demonstrated adequate convergent validity (Harris & Standard, 2001).

Heartland Forgiveness Scale: Forgiveness of Self (HFS). We will measure forgiveness using the forgiveness of self (FOS) subscale of the HFS (Thompson, Snyder & Hoffman, 2005). We chose this subscale because forgiveness of self appears to be more strongly related to aspects of mental health such as depression, anxiety and anger when compared to forgiveness of others (Mauger, Perry, Freeman, Grove, McBride & McKinney, 1992). This eight-item likert-type subscale ranges from 1 (*almost always false of me*) to 7 (*almost always true of me*), with higher scores indicating higher forgiveness of self. Examples of items on this subscale include “Although I feel badly at first when I mess up, over time I can give myself some slack” and “Learning from bad things I’ve done helps me get over them.” Thompson et al. (2005) report test-retest reliability coefficient of 0.69 and internal consistency reliability between 0.72 and 0.76 across studies. The HFS also demonstrates adequate convergent validity (Thompson et al., 2005).

Univariate, Bivariate and Multivariate Analyses

We used a partial least squares (PLS) approach to structural equation modeling (SEM) to answer the majority of our hypotheses. Before explaining in detail the way in which we analyzed our data in each phase (quantitative and qualitative), it is important to note that like other SEM methods, PLS approaches cannot generally be taken as evidence of causation (Kline, 2011). In fact, according to Kline (2011), no statistical technique can prove causality in non-experimental designs, such as ours. Because a

true causal model is rarely known in the behavioral sciences, we can hypothesize a causal model, and then test that model with sample data. The model may or may not fit the data, but through SEM-based approaches, we cannot claim that our model or any paths within our model are proven. The fact that SEM does not prove or suggest causality is important to note throughout this paper, especially when seemingly causal language is used.

Prior to structural equation analyses, initial data analyses were conducted to examine the data for outliers and missing values. Results of Little's MCAR test ($\chi^2 = 305.18$, $df = 112$, $p < 0.05$) suggest data were missing at random (MAR). We removed participants with missing data as well as those who were significant outliers as a result of data entry error. Cronbach's alpha was calculated for each subscale used in our model, and because structural equation modeling relies heavily upon the assumptions of univariate and multivariate normality, these modeling assumptions were validated.

After exploring and cleaning our data, we conducted several statistical analyses to better describe our data. We conducted univariate analyses to examine our demographic variables and measures. Next, we calculated the range and average age, income and education level of our participants. Finally, we determined the average scores, ranges and reliabilities of each of our measures. We also conducted multivariate analyses. For example, we conducted several exploratory ANOVAs, with appropriate Bonferonni adjustments, to examine differences in our measures in gay, lesbian and bisexual participants, as well as African American, European American, Hispanic/Latino and Other Ethnicity participants. Planned comparisons were used to determine if significant differences exist.

Next, structural equations modeling was used to analyze the relationships between the latent constructs that characterize the effect of stigma on quality of life indicants in the context of spirituality for PLH. We developed an *a priori* Stigma Spirituality Mental Health (SSQoL) model (Figure 2) based on Meyer's (2003) minority stress model. In the SSQoL model, stigma acts as an antecedent causal factor process, which is associated with decreased spirituality and, therefore, decreased psychological QOL. Stigma was measured by the HIV Stigma Scale (HSS). Spirituality was measured by forgiveness of self (HFS), life regard (ELRI) and sense of peace (IWSI). Psychological QOL includes mental health (MOS-HIV), depression (CESD) and stress (PSS). As specified, our model predicts that the relationship between stigma and psychological QOL will be mediated by spirituality. We tested our SSQoL model using cross-sectional data to evaluate our study's aims and hypotheses.

The data was analyzed using structural equation modeling (SEM); however, the sample size is not large enough to satisfy the power requirements associated with covariance-based SEM approaches. Therefore, a partial least squares (PLS) approach to SEM was used to test the model's overall significance. PLS allows researchers to test model parameters and structural paths like covariance-based SEM. Covariance-based SEM approaches use maximum likelihood estimation to obtain model parameters and PLS uses a component based least squares method. PLS focuses on the strength of the individual component relationships instead of the overall fit of the proposed model to observe covariance's among the variables. Another advantage of PLS is it avoids many of the restrictive assumptions associated with covariance-based techniques such as large sample sizes and multivariate normal data distributions.

PLS models are evaluated in two stages: first we conducted an assessment of the measurement model, followed by an evaluation of the structural model. The measurement model in PLS was evaluated by examining its internal reliability, convergent validity and discriminant validity. PLS uses an algorithm that calculates an inner model, which includes the latent variables with their hypothesized relationships, and an outer model, consisting of the measurement model of the manifest variables. An iterative procedure of bootstrapping was conducted to establish path significances. This procedure generates 500 sub-samples of cases randomly selected, with replacement, from the original data. Path coefficients were then generated. Path significances were generated using *t*-statistics.

Mediation was tested for Hypothesis 4 by using the total direct and indirect effects in a path analysis of our model. Similarly, path analyses were used to confirm the directionalities specified by Hypotheses 1, 2 and 3. The factor loadings for the manifest variables that define psychological QOL were used to quantify how spirituality affects the relationship between stigma and psychological QOL. Additionally, the factor loadings for the variables that define spirituality were examined in light of an individual's experienced stigma. While factor loadings, in general, provide useful information about the relative importance of the underlying observed variables, the most salient aspects of the SEM analyses are the resulting parameters for each pathway in our model.

Qualitative Data Analyses

Case Selection/Interview Protocol Development

Following the quantitative data analyses, we obtained IRB approval from the University of North Texas to conduct the qualitative phase. Then, we created an

interview protocol. We did not create the interview protocol until the quantitative phase was completed, so that the questions generated were based on the results of our quantitative analyses. In order to most closely match the participants from the quantitative phase to the qualitative phase, the participants were matched on the age, ethnicity and education of participants who completed the quantitative portion of this study.

The content of the interview protocol was grounded in the quantitative results from the first phase of the study. For example, since spirituality mediated the relationship between stigma and psychological QOL, we based our questions around that finding. In particular, we asked participants about their experience with HIV stigma, how they use and define spirituality to cope with their diagnosis, and how stigma and spirituality influence their overall psychological QOL (Appendix A). Since the goal of the qualitative phase is to explore and elaborate on the results of the statistical tests, the qualitative data helps explain how PLH define and use spirituality as well as how spirituality is associated with stigma and psychological QOL.

At the beginning of our interview protocol, we asked basic background information, such as the participant's age, gender, sex, ethnicity, sexual orientation, time since diagnosis, religious/spiritual background, etc. We then asked questions based on Jacob and Furgerson's (2012) recommendations. Jacob and Furgerson (2012) highlight the importance of asking open-ended questions in the interview protocol. Furthermore, they recommend researchers begin with easy questions and then, as rapport develops between the interviewer and participant, ask more difficult questions. We also had a list of prompts and probe, such as "can you give me an

example,” to encourage participants to elaborate on specific questions.

Qualitative Data Collection/Analyses

Each interview was audio-taped and transcribed verbatim by two separate researchers. This created two written transcripts for each participant. We reviewed each participant's two transcripts to check for agreement. Once the transcripts were in agreement, we created a final transcript for each participant that was whole and accurate. If the transcripts were not in agreement, transcribers met to discuss the inconsistencies. In order to analyze each final transcript, we constructed a coding sheet using a grounded theory approach. Grounded theory is a type of qualitative research that involves collecting data (e.g., interviews), identifying categories or themes, connecting the categories or themes, and generating a theory that explains a phenomena. Therefore, the theory that is generated comes from a process that is grounded in the data (Glaser & Strauss, 1967).

To create the coding sheet, two separate researchers were first trained to code the transcripts. Each researcher then read through two final transcripts and reviewed the questions and generated a list of themes and subthemes. These two researchers then compared the lists of themes and subthemes and consolidated the list into one coding sheet (Appendix B). Once the coding sheet was developed, we trained two coders to read through a set of two new transcripts to code each using the coding sheet through Coding Analysis Toolkit (CAT). CAT is a web-based suite of Computer Assisted/Aided Qualitative Data Analysis Software (CAQDAS) tools. CAQDAS offers tools that assist with qualitative research including transcription analysis, coding and text interpretation. CAT was used as a platform to assist in coding transcripts. After

these two researchers read and coded a new set of two transcripts using the coding sheet, the researchers again met to discuss the agreement of each final transcript as well as changes to the coding sheet. Once the coding sheet was finalized (Appendix B), additional researchers were trained on coding using CAT and coded the final transcripts. The researchers then met again to agree upon the coding of each additional final transcript. Using CAT, we calculated Cohen's kappa, a statistic of inter-coder agreement, for each final transcript. Researchers continued to discuss coding of the final transcripts until a significant agreement ($\text{kappa} > .80$) was achieved (Landis & Koch, 1977).

Once coding was complete, the final transcripts were transferred to ATLAS.ti ©, a computer assisted data analysis software (CAQDAS) program. ATLAS.ti © is one of the leading CAQDAS programs in qualitative data analysis of field notes, interviews, text documents, etc (Barry, 1998). Once the final transcripts were entered into ATLAS.ti ©, each section of coded text was extracted into a separate text document for review. We then read through each coded text document and identified emerging themes by examining and comparing the text that corresponds to each code. Specifically, we examined patterns as well as regularities and irregularities to determine the content of what was discussed within each code. For example, for the code "Personal Definition/Description of Spirituality," we read through extracted piece of text under this code to identify and describe how participants defined and described their spiritual beliefs and practices. For this code in particular, we identified that participants commonly discussed religion, creation of their own spiritual identity based on a religious tradition and purpose/kindness/the Golden Rule.

Integration of Quantitative and Qualitative Results

In the explanatory sequential mixed methods design, the quantitative and qualitative phases are integrated in two places in the study: (1) early in the research process in development of the interview questions and (2) at the interpretation phase (in the discussion section). The integration of the quantitative and qualitative findings portions of our study first happens following analysis of our quantitative findings. The quantitative guide the data collection for the qualitative portion (e.g., the qualitative participants are matched with the quantitative participants). The results from the quantitative portion also inform the questions that are created for the interview. For example, we found spirituality mediates the relationship between HIV-stigma and PQOL (refer to results section) in the quantitative portion of our study. Therefore, we asked interview questions to clarify the types of stigma PLH experience including concerns with public attitudes about people with HIV, personalized stigma, disclosure concerns and negative self-image. We also asked questions around PLH's emotional experiences since being diagnosed with HIV including what makes them feel stressed, depressed and anxious as well as the frequency of their negative emotional experiences. In order to determine how PLH utilize spirituality, we asked participants to describe their spiritual beliefs and practices. Finally, since we determined spirituality mediates the relationship between HIV-stigma and PQOL, we asked participants to describe how HIV-stigma affects their spiritual beliefs (and vice versa), as well as how their spiritual beliefs affect their emotions. For example, we asked participants, "How has your spirituality affected your mental health/emotional wellbeing?" as well as "How does HIV-stigma affect your spiritual beliefs?". Similarly, PLH were also asked to share

how stigma influences their psychological quality of life. Through asking PLH questions about their spirituality, experiences with stigma and psychological QOL, we gained a deeper understanding of the interactions between these constructs and how they influence the lives of PLH than we could through quantitative analyses alone.

The quantitative and qualitative phases are later integrated in the discussion section of this paper where we interpret the outcomes of the entire study. We compare the results from both portions of our study in the discussion section. Specifically, we integrate our findings by returning to our research questions and determining whether our data (quantitative and qualitative) support our hypotheses. Again, the qualitative data provides more detail and elaborates on the results of the quantitative portion. We also highlight similarities and differences in the discussion section between what participants reported in the quantitative portion in comparison to the qualitative portion of our study.

CHAPTER IV

RESULTS

Quantitative Results

Univariate Statistics

A univariate analysis was conducted to examine each measure (HIV Stigma Scale, Heartland Forgiveness Scale, Extended Life Regard Index, Ironson-Woods Spirituality/Religiosity Index, Medical Outcomes Study HIV Health Survey, Center for Epidemiological Studies Depression Scale, Perceived Stress Scale; Table 4). As can be seen in Table 4, several measures demonstrated a restriction in range. For example, the HIV-stigma scale shows a floor effect in that participants commonly endorsed lower levels of stigma on this scale and no participants endorsed the maximum level of stigma, as measured by this scale. The CES-D and PSS also showed a slight restriction in range. Reliability for all measures, except HFS, was acceptable. Reliability for the HFS was poor (Cronbach's alpha = 0.54), which may be a result of this scale's low number of items, as this scale is made up of only eight questions. Pallant (2011) suggests Cronbach alpha values are quite sensitive to the number of items in the scale. With short scales, especially those less than ten items, it is common to achieve a low Cronbach's alpha, such as 0.50. In this case, Pallant (2011) suggests it may be more appropriate to report the average inter-item correlation for the items. An optimal range for the inter-item correlation is between 0.2 and 0.4 (Pallant, 2011). The average inter-item correlation for the HFS scale is 0.27. Therefore, we decided to keep the HFS in our model.

Table 4

Mean and Standard Deviation and Range

Scale	Mean	SD	Actual Range	Possible Range	Reliability
MOS-HIV	23.8	6.1	8-35	6-36	0.77
CES-D	23.0	13.2	0-55	0-60	0.92
PSS	20.0	6.5	4-40	0-40	0.70
IWSRI	41.0	9.0	9-45	9-45	0.98
HFS	36.0	7.4	10-56	8-56	0.54
LRIR	31.1	6.2	15-42	14-42	0.88
HSS	80.0	19.6	35-127	30-180	0.96

Bivariate Statistics

We conducted a bivariate correlation analysis to determine relationships among variables to obtain a better understanding of our sample (Table 5). The diagonal cells represent the square root of the average variance extracted (AVE), which is necessary information to establish discriminant validity (see section below: Structural Equation Modeling).

Table 5

Bivariate Correlations

Scale	1.	2.	3.	4.	5.	6.	7.
1. MOS-HIV	0.69						
2. CES-D	-0.80**	0.68					
3. PSS	-0.65**	0.64**	0.81				
4. IWSRI	0.11	-0.01	0.02	0.99			
5. HFS	0.47**	-0.49**	-0.40**	0.11	0.79		
6. ELRI	0.51**	-0.59**	-0.43**	0.05	0.45**	0.56	
7. HSS	-0.29**	0.26**	0.27**	-0.03	-0.27**	-0.22**	0.64

* $p < 0.05$ ** $p < 0.01$

Multivariate Statistics.

We conducted several ANOVAs. We examined differences on scales that comprise the stigma, spirituality and PQOL latent constructs in gay, lesbian and bisexual participants; male, female and transgender participants; and African American, European American, Hispanic/Latino and Other Ethnicity participants. Planned comparisons were used to determine if significant differences exist. Participants scored significantly different from each other on the MOS-HIV $F(3, 175) = 2.82, p < 0.05$).

European Americans ($M = 24.9, SD = 6.23$) scored significantly higher on the MOS-HIV scale than did Other Ethnicity ($M = 18.3, SD = 7.2$), $p < 0.05$. We found no significant differences between African Americans, European Americans, Hispanics/Latinos, and Other Ethnicity participants on the PSS ($F(3, 178) = 0.18, p = 0.91$), CESD ($F(3, 178) = 2.22, p = 0.87$), IWSOP ($F(3, 178) = 0.47, p = 0.71$), LRIR ($F(3, 178) = 0.74, p = 0.53$),

HFS ($F(3, 178) = 1.89, p = 0.13$), and the HSS ($F(3, 178) = 0.32, p = 0.81$).

We also conducted exploratory ANOVAs to examine differences between gay men, bisexuals and heterosexuals on each measure. There were no lesbians in our study. Our results indicate no significant differences between gay men, bisexuals and heterosexuals on the MOS-HIV ($F(2, 178) = 1.52, p = 0.22$), the PSS ($F(2, 178) = 1.28, p = 0.30$), CESD ($F(2, 178) = 1.40, p = 0.25$), IWSOP ($F(2, 178) = 1.25, p = 0.29$), LRIR ($F(2, 178) = 1.14, p = 0.32$), HFS ($F(2, 178) = 0.81, p = 0.46$), and the HSS ($F(2, 178) = 1.07, p = 0.35$).

Lastly, we conducted exploratory ANOVAs to determine differences between men, women and transgender participants on our measures. We found significant differences between genders on the PSS ($F(2, 178) = 4.31, p < 0.05$). Women ($M = 21.40, SD = 6.01$) scored significantly higher on the PSS than men ($M = 18.98, SD = 6.60$), $p < 0.05$. Our results show no significant differences between men, women and transgender participants on the MOS-HIV ($F(2, 178) = 1.52, p = 0.22$), CESD ($F(2, 178) = 0.31, p = 0.73$), IWSOP ($F(2, 178) = 0.36, p = 0.70$), LRIR ($F(2, 178) = 1.14, p = 0.32$), HFS ($F(2, 178) = 0.84, p = 0.43$), and the HSS ($F(2, 178) = 0.27, p = 0.76$).

Structure Equation Model.

The psychometric properties of the data are evaluated by examining the factor structure (Table 6) which includes the reliability, convergent and discriminant validity of the indicators. As recommended, the composite reliability and Cronbach's alpha coefficient (with the exception of the HFS-FOS, however, inter-item correlation was acceptable) are larger than 0.70, which suggests an adequate level of internal consistency. As can be seen for some items, the composite reliability and Cronbach's

alpha are somewhat discrepant. Cronbach's alpha is often criticized as being a lower bound and underestimating true reliability (Peterson & Kim, 2013). In order to examine the factor structure, we conducted confirmatory factor analyses through PLS. Each item that was not significant at the 0.05 level was removed from analyses in a stepwise fashion, such that we removed one item at a time and then examined item's loading and significance. For example, two items were removed from the HSS, four items were removed from the HFS-FOS and three items were removed from the PSS. As can be seen in Table 6, once the four items were removed from the HFS-FOS, Cronbach's alpha improved drastically (from 0.54 to 0.79). The following items were removed from the HFS-FOS: Question 1 ("Although I feel badly at first when I mess up, over time I can give myself some slack), Question 3, Learning from bad things I've done helps me get over them"), Question 5 ("With time I am understanding of myself for mistakes I've made.") and Question 22 ("When I am wronged, I act like everything is OK so that people won't think I'm bitter or petty.) Even though some items loaded below the recommended level of 0.70, those that were significant at the 0.05 level were retained in analyses, as they were statistically significant. The Average Variance Extracted (AVE) for most constructs was above 0.40. AVE measures the average variance of measures accounted for by the construct. Taken together, the item loadings and AVE suggest sufficient convergent validity.

Discriminant validity was established since the smallest square root of the AVE is 0.56, which is larger than all but one correlation (i.e., the correlation between MOS-HIV and CESD was 0.80) between constructs and all items loaded most heavily on their intended construct. In sum, the psychometric properties of internal consistency,

convergent validity and discriminant validity were all demonstrated. Therefore, evaluation of the structural model was warranted.

Table 6

Reliability and Validity

Construct	Items	Mean	S.D.	Composite Reliability	Cronbach Alpha	AVE
<u>STIGMA (HSS)</u>	38	94.20	25.37	0.96	0.96	0.43
<u>SPIRITUALITY</u>						
HFS-FOS	4	17.53	6.30	0.87	0.79	0.63
LRIR	14	31.2	6.30	0.87	0.84	0.32
IWSOP	9	36.25	9.50	0.99	0.98	0.99
<u>PQOL</u>						
MOS-HIV	6	23.76	6.12	0.83	0.76	0.47
PSS	7	14.01	6.12	0.90	0.81	0.66
CESD	20	21.66	13.05	0.94	0.93	0.46

Table 7 show the path coefficients for the model. Each path coefficient was significant at the 0.05 level. The direct path between stigma and PQOL was significant (coefficient = -0.35, $t = 3.48$) and stigma explained 12% of the variance in PQOL. The path between stigma and spirituality was also significant (coefficient = -0.34, $t = 3.33$) and stigma explained 11.7% of the variance in spirituality. The path from stigma and spirituality to PQOL was also significant (coefficient = -0.48, $t = 3.67$). Together, stigma and spirituality explained 31.8% of the variance in PQOL. In order to test for mediation in the model, the Sobel test was used. The Sobel test indicated spirituality mediates the

relationship between stigma and PQOL (Sobel = 3.05, $SE = 0.05$, $p < 0.01$). The direct relationship between stigma and PQOL was statistically significant, but when the mediator (spirituality) was added, the indirect relationship was reduced. Since the indirect relationship is still statistically significant (coefficient = -0.18, $t = 1.67$), spirituality is considered a partial mediator in the relationship between spirituality and PQOL.

Table 7

Path Coefficients and t-scores

Path	β	t	p
Stigma → PQOL (direct)	-0.35	3.48	<.001
Stigma → PQOL (indirect)	-0.18	1.67	0.04
Stigma → Spirituality	-0.34	3.33	<.001
Spirituality → PQOL	0.48	3.67	<.001
Spirituality → IWSI	0.43	2.65	.004
Spirituality → HFS	0.54	4.04	<.001
Spirituality → LRIR	0.92	28.53	<.001
PQOL → MOS-HIV	-0.85	27.55	<.001
PQOL → CESD	0.96	132.49	<.001
PQOL → PSS	0.70	10.59	<.001

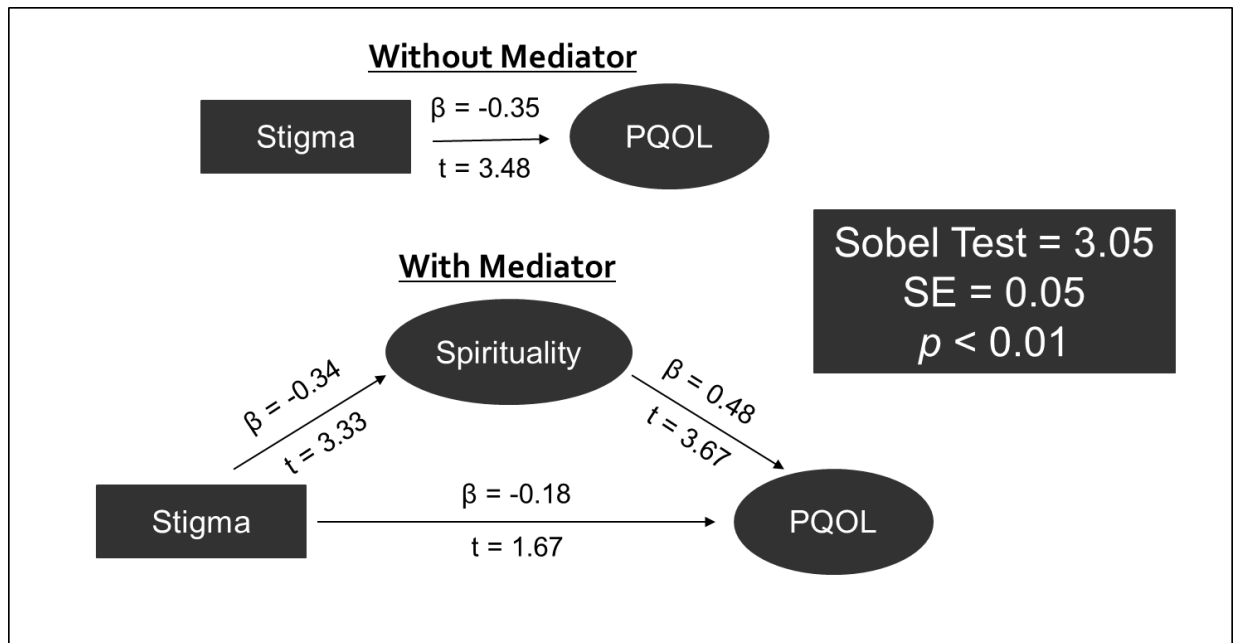


Figure 3. Mediation model.

Qualitative Results

The mixed method approach allows us to cross-validate findings as well as generate complementary findings. Through the use of an open-ended interview format, PLH's experiences of stigma, spirituality and PQOL were captured. The audiotapes were transcribed verbatim by two separate researchers. Written transcripts were then reviewed for accuracy by listening to the tapes while rereading transcripts. Transcripts were then coded using the process listed above in the section titled "*Qualitative Data Collection/Analyses*". Ten themes were identified using this process (see Appendix B: Code Sheet). Using CAT, we calculated a statistic of inter-coder agreement for the final transcripts (Cohen's kappa = 0.87), which is indicative of acceptable interrater agreement (Landis & Koch, 1977).

Themes

We identified ten themes using grounded theory (see Appendix B: Code Sheet).

Each theme fell under the construct of either HIV-stigma (personalized stigma, disclosure concerns, negative self-image, and concern with public attitudes about HIV), PQOL (stress/depression/anxiety due to HIV and other sources of psychological distress) or spirituality (personal definition/description of spirituality, spirituality and mental health, negative impact of spirituality on experience of living with HIV, positive impact of spirituality on experience of living with HIV). As can be seen below, each theme is clustered under a given construct (HIV-Stigma, PQOL and Spirituality) in order to provide further elaboration and clarification on the results of the quantitative portion of our study. The constructs elaborated upon in the qualitative portion overlap with the constructs evaluated in the quantitative portion of our study, and we clustered our themes in this way for ease of comparison with the quantitative findings. In the sections below, we discuss each of the ten themes in more detail. Of the ten themes, the most commonly discussed themes were: personalized stigma, stress/depression/anxiety due to HIV and positive impact of spirituality on experience of living with HIV (Figure 5).

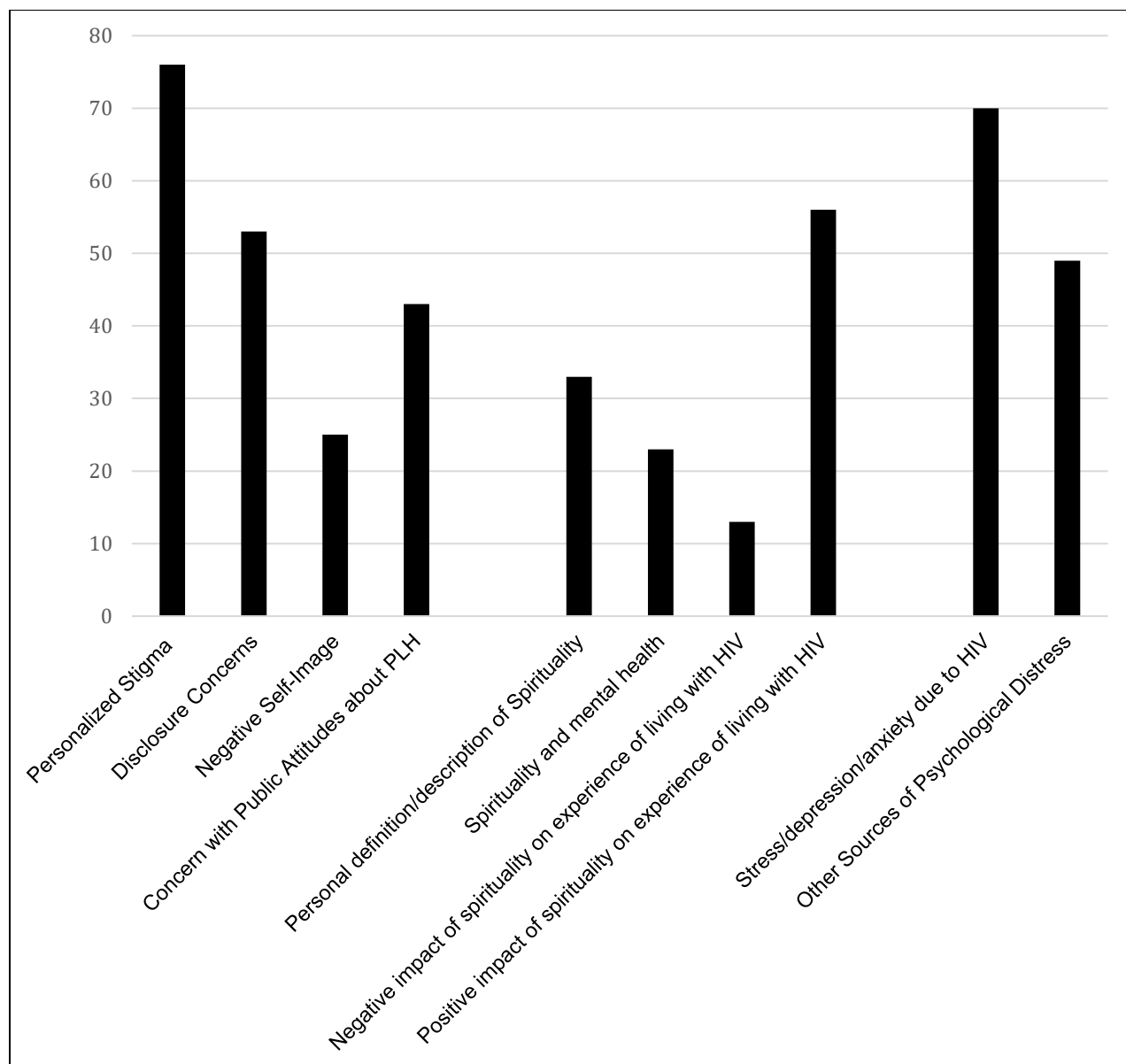


Figure 4. Frequency of themes.

HIV-Stigma

Four themes under the construct of HIV Stigma were identified: personalized stigma, negative self-Image, disclosure concerns and concerns with public attitudes about PLH. These themes were also used for ease of comparison to our quantitative results, as they match the subscales on the HIV Stigma Scale. Of these four themes, PLH most commonly discussed personalized stigma (Figure 6).

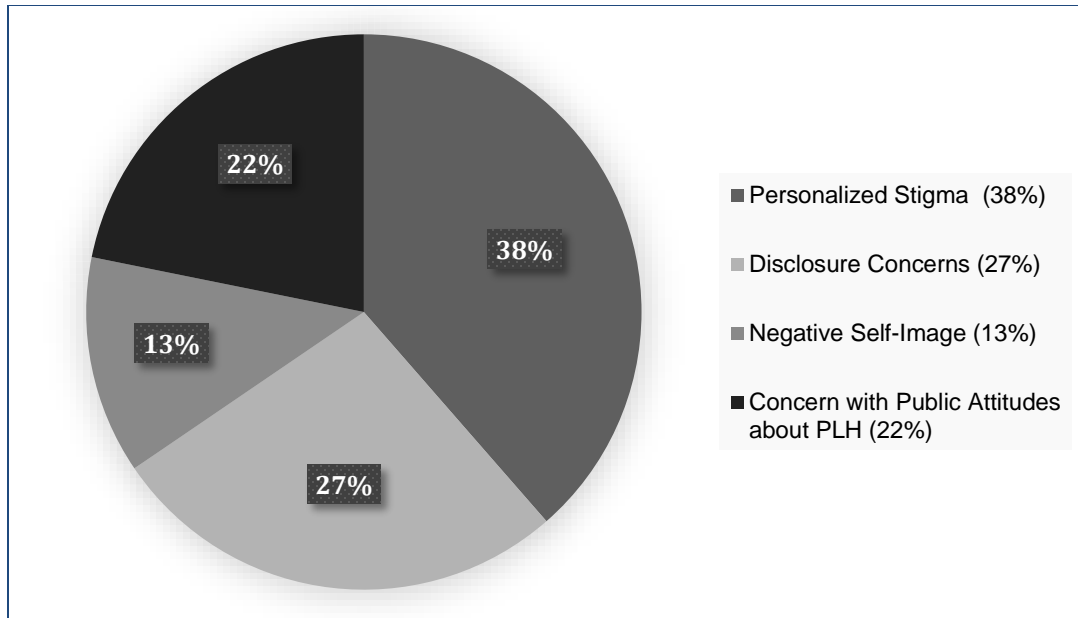


Figure 5. HIV stigma.

Theme 1: Personalized Stigma. Personalized stigma refers to the consequences of others knowing about one’s HIV status including experiences or fears of rejection, loss of friends and avoidance of others. All participants endorsed some type of personalized stigma. Participants commonly reported two themes (1) fears of rejection, and (2) experiences of stigma. First, participants noted their fears of rejection and discrimination. Specifically, respondent’s discussed fears of isolation, negative judgments, ostracism, and changes in relationships, to name a few. For example, one participant reported fears that his ex-wife would not let him see his son if she knew he was HIV-positive. Another participant stated, “The main concern... they are going to turn me away or I am going to be treated poorly, or for lack of a better word, like trash.” Another participant who had not disclosed his HIV-status to anyone other than his medical team discussed his fears associated with potential ramifications of disclosure and stated,

You’ll be by yourself one day and you’ll be like man, why did I tell them, they’re

probably already talking about me now or something, you know, you don't want to have them thoughts put in, you're already stressed and that adding more and it's just constantly building... then they tell everybody in the neighborhood or their friends and that's it.. It's best not tell unless you really have to do it, that's the best way to keep everything from being, keep it as normal as possible unless you don't have a choice, that's the only way.

Lastly, another participant endorsed fears of his wife leaving him as a result of his HIV-status and reported, "I was crying and could hardly talk and tell her because, as soon as I tell her, she's going to pack her bags and leave."

Participants also discussed their actual experiences of discrimination and shared examples of discrimination from family, friends, co-workers as well as health care workers. Some participants discussed reactions by family members. One respondent shared that after disclosing her status to her family,

There was more frequent cleaning of the bathroom utensils and so forth, but then everyone kind of looked at it and said well we don't think you would pass anything on to us... but for the sake of the family and the fact that we have little ones in the house, we cleaned more often.

Other participants shared that after their disclosure, people threatened to tell the public. One participant shared his experience and stated the person he disclosed to "threatened to publicly disclose it, you know like put it on paper and go run sticking it on flagpoles." Many other participants discussed how their relationships changed after they disclosed. For example, three participants discussed feeling as if there was a barrier or a wall that went up once they disclosed. One respondent, who also identified as gay,

shared, “it’s like they put a wall there, enough to communicate with you... pretty much it’s gay is one wall that goes... HIV is another wall, a divider between. We’ll go this far, but not this far.” Another participant shared a similar reaction and indicated others “kind of shun you, but in a secret way. Like not letting you know out front, but it’s kind of like a couple steps back once you disclose something like that.” Lastly, many participants also shared negative experiences with medical staff. For example, one participant stated he went to his primary care physician after being exposed to HIV and was told, “I’m not going to test you. Go to the damned health department.” This participant, who was diagnosed in the early 2000’s, was then told by the Health Department, “We just asked one thing of you and that’s that you never have sex again’... so for 10 years almost, no more like five years, I didn’t.”

Theme 2: Negative Self-Image. The negative self-image subscale captures feelings of shame, guilt, feeling unclean, and self-deprecation. Eighty percent of participants discussed negative self-image. Respondent’s commonly endorsed feelings of shame, self-deprecation, and as if their diagnosis was a punishment as a result of “bad” behavior in the past. To begin with, 53% of respondents discussing feelings of shame. One participant discussed frustration with the lack of support surrounding his HIV diagnosis and compared his experience to that of those diagnosed with cancer. He shared his belief that people with cancer are able to ask for help, whereas those with HIV, as a result of the way it is transmitted, are unable to discuss this. He stated, “because of how it’s transmitted, there’s shame attached to it so you don’t want to put yourself out there.” Other participants shared their own feeling of shame. Specifically, one participant reported,

When I look back on some of the things... some of the high risk areas that I put myself in, I feel really ashamed of myself because I was thinking with my lower nature instead of my higher nature.

Another participant who had been diagnosed many years ago reflected on his view of himself after he was diagnosed. He stated, "In the beginning when I was first diagnosed, I felt... guilt, shame, and... regret." He later reported, "We are HIV-positive. It's nothing to be proud of."

Other than shame, 33% of participants shared statements reflective of self-deprecation. Participants discussed feelings of low self-esteem, unworthiness and disappointment of self. One respondent shared, "how much lower can it get... seems like [I'm] always doing something wrong or something, [I'm] always doing something to mess up my life." Another person shared feeling like a "used piece of meat." Another shared "some part of me is still insecure about my worth, and I'm still working on feeling worthy enough or secure enough about myself, even though I know I'm HIV-positive."

Lastly, 20% of participants endorsed feeling as if their diagnosis was a punishment as a result of prior actions. One participant reported, "My HIV was because I was sinning or because I was homosexual or it's God's punishment on me." Another indicated he had to accept his "punishment" since he was "living a very promiscuous lifestyle. I was an addict and I was in a relationship with a drug dealer." Lastly, one respondent shared her reactions following her diagnosis and stated, "Initially I probably felt like damaged goods. I was damaged goods to begin with... maybe that's why I set myself up for this diagnosis."

Theme 3: Disclosure Concerns. Disclosure concerns focuses on issues of telling others about their HIV status including controlling information, keeping HIV status a secret, worrying others know of HIV-status or others would share their information. Ninety three percent of participants discussed disclosure related concerns. Specifically, respondents discussed protecting self through non-disclosure or silence (which we will label as “protective silence”) and attempts to conceal their status. To being with, participants discussed the concept of protective silence, which most participants used at one time or another after their diagnosis. Some participants were eventually able to disclose their status to others, while others had not yet disclosed their status to anyone outside of their medical team. Some participants shared they feared they would be unable to manage their own emotions related to potential rejections if they disclosed. For example, one man who had not disclosed his status to anyone other than medical providers shared,

That’s something I really can’t do. I can’t really talk about it around my people. It’d be too much, I don’t think I could do it... I’d have to not see them again if I told them... I couldn’t do it. I couldn’t do it. Never... No way.

Another participant shared, “You don’t disclose your status basically. I don’t think it’s necessary to do that. You take the right treatment and you move on with your life. Unless it’s necessary that you really have to disclose it.” Yet, other participants reported they do not share their HIV-status with others unless it is deemed necessary. For example, one respondent asked, “Why would I bring it up in a conversation that I’m HIV-positive?” Another participant stated,

As far as disclosure goes, it’s a need to know basis, that’s only if we’re going to

enter an intimate basis with each other or as I need something where you're my only contact like if something happens to me.

Another participant reflected, "It takes a little time to figure out if you can trust this person with information." Lastly, another participant indicated, "I'm real cautious about that myself and letting people know, whether I'm really close with them or not. It's only a very few confidants besides my family."

Participants also shared the ways in which they attempt to conceal their HIV-status including hiding medication, not taking their medication in front of others, etc.

One participant shared,

Well first of all I make sure that any type of literature at my home, my medication, whatever, period, is not anywhere open, but it's secure. I think it's more like turning into a phobia that I protect things that I cover things up, keep things turned over where it's like even if I'm reading information about something that's come out that's new or breakthrough with somebody dealing with medical stuff, I tend to hide that because, oh he must have AIDS, that why he's reading stuff like that... But at least I'm not leaving myself... with a window open for someone to look in a find something like that.

Other participants reflected on their attempts to conceal their HIV-status and indicated, "I hide my mail. I hide all my pain. When I get my medication, all the paperwork that comes with my medication I hide it and put it away." Another participant shared she had strokes in the past and tells her friends and family that all her medical appointments are related to her stroke, not her HIV-status. She indicated, "Everybody thinks because I've had strokes that's the reason I go to the doctor so often, so that's a plus for me because

I had three strokes, that's the issues so they don't know that I have the HIV." Other participants shared they put themselves at risk in order to conceal their status by changing the way they take their medication or avoiding going to HIV clinics. One participant shared, "I take my medication in the middle of the night with a flashlight... being closed doors." Another participant indicated he avoided being seen going to HIV clinics and stated, "In the beginning I used to try to stay away from the place."

Theme 4: Concerns with Public Attitudes about PLH. Concerns with public attitudes reflects attitudes of others related to discrimination and social discomfort with HIV. Participants discussed both negative and positive attitudes of the public, lack of education and stereotyping. To begin with, many participants shared their beliefs of the public's attitudes toward PLH. Most participants reported feeling as if the public had mainly negative beliefs of HIV. For example, one participant shared the public perceives PLH as "sexual predators, they want them different, they do not want them near them, that's what I think. They don't want that type of stuff around them." Another participant reported the public perception of HIV is "something dirty and terrible." Some participants reflected on differences in perception depending on geographical location. One participant indicated, "the South tends to be more homophobic than other areas of the country, or they are more HIV phobic. They're afraid if you sneeze you are going to catch it." Another participant reflected differences in perception based on geography and noted, "Dallas, I see as more compassionate versus anti." Other participant's shared their beliefs of how HIV is now viewed more positively in comparison to the late 1990's and early 2000's. For example, one participant noted, "I think that before when the epidemic started was very anti. I believe it's a little more accepting than before."

Another participant shared, “It’s growing a little more tolerant I think. It’s growing in certain areas where there is more education. In some cases it just doesn’t pack the same fear wallop that it used to.”

Fifty-three percent of participants also spoke to the lack of education contributing to negative attitudes and misconceptions of people living with HIV. One woman shared, I believe they don’t understand (the public). I think that they think if you’re HIV that you’re just automatically getting ready to die and that it’s a disease that is going to kill you and if they get near you then you’re going to get them sick as well. If they drink after you, or if you... touch them they may feel like you’re going to give HIV to them.

Another participant shared the public is “ignorant... uneducated... and they don’t understand.” However, as previously stated, many participants also believe the public is becoming more accepting of PLH. One participant shared that since HIV is no longer perceived as a “death sentence,” the public now incorrectly perceives HIV as being “easy to deal with.” This participant shared she spoke with a young woman who was engaging in “high risk behavior” and was told “HIV is the new diabetes. You know if there’s anything wrong they got retroviral drugs and everything you can get on.”

Lastly, participants discussed the common assumptions and stereotypes the public has about PLH, including beliefs that PLH are “gay,” “drug users,” “unclean,” “dirty” and “promiscuous.” One participant indicated she contracted HIV after being “raped” and stated the public perceives PLH as being at fault due to “promiscuity.”

Another participant shared, “[They think] it’s a gay disease and we get it because we’re gay and we shouldn’t be doing things that we do and therefore we have it and therefore

we die.” Another participant shared this belief and stated, “Number one [belief]... they’re all gay.” Other participants shared the public believes “you had to be doing something real bad to get that.” Another participant indicated she perceives the public’s perception of PLH as, “They all use drugs... they must have done something to get it... it’s their fault.” Finally, another participant shared the public believes, “It is preventable... you must have been doing something dirty in order to get it.”

Spirituality

Participants also responded to questions about their spiritual beliefs and practices, definitions of spirituality as well as how their spiritual beliefs impact HIV-stigma and mental health. Four themes under the construct of spirituality were identified: personal definition/description of spirituality, spirituality and mental health, negative impact of spirituality on experience of living with HIV, and positive impact of spirituality on experience of living with HIV. Of these four themes, PLH most commonly discussed the positive impact of spirituality on experience of living with HIV (Figure 7: Spirituality).

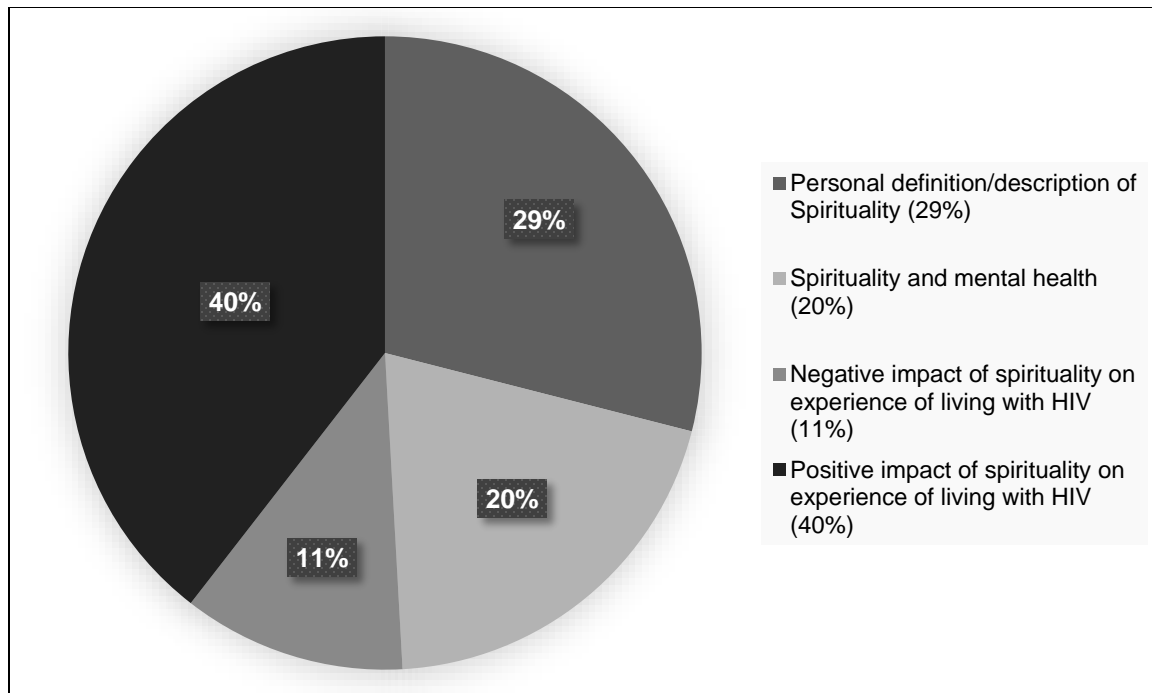


Figure 6. Spirituality.

Theme 5: Personal Definition/Description of Spirituality. PLH described the many ways in which they defined and described their spiritual beliefs and practices. When describing their spiritual beliefs, respondents tended to fall into one of three categories: (1) commitment to a particular religious tradition, (2) creation of their own spiritual identity based on a religious tradition(s), or (3) purpose/kindness/the Golden rule (no reference to religion). Eighty-seven percent of participants referred to God or religion when defining their spiritual beliefs and practices. Participants identified their spiritual/religious beliefs as: Christian/Non-denominational (N = 10), Baptist (N = 2), Catholic (N = 1), Catholic/Jewish (N = 1), and Spiritual but not Religious (N = 1). Seven participants described their spiritual beliefs as stemming from a particular religious tradition, but stated they formulated their own spiritual identity over time which may or may not be consistent with some beliefs of their religious tradition. For example, one participant responded, “I want to be a religious person, and I also want to enjoy things

on the side, like beer.” Another participant reported she identifies as Christian, but also indicated she is greatly influenced by other religious texts. She reported, “I still have a Koran and a Torah and I read them just as regularly as I do the Bible and I have been to worship at a temple and a synagogue, I have fasted, I have prayed.” Another woman identified as having “Jewish Catholic roots” and stated she was raised in the Lutheran church, but also attended Jewish synagogue as a child, which influenced her belief system. This participant shared how she distinguishes spirituality and religion and stated, “Religion is for people who are afraid to go to hell, and spirituality is for people who have been to hell and don’t want to go back.” Another participant shared she identifies as “Christ-centered” but not religious. She further clarified by sharing,

I’ve thought of myself as a woman of God with integrity, strength. I honor God in my life with my body, with my health, and all part of myself I honor God... but did God create everything in my life? No, the choices I made did.

Another participant who did not identify as religious shared

I think that I was put here to help people and... as long as I am not being selfish and as long as I am making an impact on the world as far as being there for my children or helping somebody in need... I still think treating people how you want to be treated... I believe in killing people with kindness.

Participants also shared how they practice their spiritual beliefs. Eighty percent of participants reported they utilize formal practices as an expression of their belief system. Forty percent of respondents indicated they use informal practices as a way to demonstrate their spiritual beliefs. Formal practices included attendance at church/synagogue/temple/etc, prayer, meditation, reading religious texts, listening to

spiritual teachings and fasting. One participant shared, “Before I lost my sight I would read my Bible, but now I pray, that’s the basic thing I do is pray, especially when I need strength or when I feel like I can’t make it anymore.” Another respondent shared, “sometimes I still fast, but as a Christian... I make sure to pray... I go to church.” Finally, another participant shared she reads the Bible and has a “specific guide for what scriptures to read that day or what topics if I just want specific topics, definitely prayer and meditation, just meditating and taking a moment to relax.” Of the respondents who utilize informal practices as a spiritual expression, they reported they help others, give, follow the Golden Rule and show kindness and love. One participant indicated,

I do things I feel like I need to do or should do even when others aren’t looking. You know because I feel like my higher power is always... looking, and my higher power’s the only person that I really want to please.

Another respondent shared, “I try to follow the Golden Rule – do unto others as you would have them do unto you. I pay it forward. Do a good deed for someone... random acts of kindness.” Lastly, another participant shared she shows “kindness, respect, caring, overall it’s just love... But let someone you know that you do give a damn.”

Theme 6: Positive Impact of Spirituality on experience of Living with HIV. Since research shows that many PLH note both positive and negative experiences of spirituality/religiosity, we also identified negative impact of spirituality on experience of living with HIV and positive impact of spirituality on experience of living with HIV as themes. Figure 6 demonstrates respondents more frequently discussed the positive impact of spirituality. In fact, all 15 participants reported positive experiences associated with their spiritual beliefs and practices. However, Sixty percent of respondents also

discussed the negative impact of their spirituality on their experience of living with HIV.

With regard to the positive impact of spirituality on experience of living with HIV theme, participants indicated their spirituality has helped them face challenges, increased their social support, enhanced their view of self, increased their sense of hope, purpose and meaning in life, enhanced forgiveness of self and created a sense of peace.

Almost all (93%) participants indicated their spirituality helps them face challenges and obstacles including coping with stigma and discrimination as well as mental health problems (discussed further in the section below: *Spirituality and Mental Health*). For example, one participant shared spirituality is the only way to cope with HIV stigma. He stated, “If you don’t you’d probably go crazy or something because you don’t like feeling you’re being discriminated.” Another participant indicated her spiritual beliefs make her “want to thrive to do better.” With regard to coping with HIV stigma, one participant stated his spirituality “makes you understand people, and the HIV is just one part of this walk of your life. There’s still more that’s going to be challenging and other things that you’re going to encounter, but [spirituality] helps with that.”

Seventy three percent of participants shared their spirituality increased their sense of hope, meaning and purpose in life. One participant shared he believed HIV was “given to me for me to learn from that and to share with others, to help others.” Another respondent indicated,

I prayed and something came to me. It said, you know this disease isn’t going to kill you. You’re diagnosed with it for a reason, and I was. I’m an advocate for it and I make great decisions and help others in that direction as well.

Similarly, another participant shared that as a result of her spiritual beliefs,

I've learned to look at it like a gift because things that were so important to me then are less important to me now. I'm more interested in being the best person I can be and working on my relationship with my higher power.

Finally, one participant stated spirituality gave

meaning to my life... for a year I was a train wreck and today I am centered, I know where I am going in life and actually I have goals in my life that I have set, I have hope and a future that I set for my life.

Participants also discussed the positive impact their spiritual beliefs had on sense of self. Forty percent of participants discussed an increase in their view of self as a result of their spiritual beliefs. For example, one participant shared her spiritual beliefs helped her "learn to love and respect [herself] a little more." Another participant shared that as a result of her HIV diagnosis and spiritual beliefs, she is "here to live life, please God and to love myself." She also indicated,

Because of my diagnosis, because of almost dying, I got into a relationship with God and have a wonderful support system, I have a wonderful life.. I've just been really able to build character off of that foundation and learn who I am.

Twenty-seven percent of participants described the positive impact their spiritual beliefs have on their overall sense of peace. For example, one participant shared their spirituality "gives me peace in knowing that above all I have support in my Savior." Another participant shared her spirituality "keeps me peaceful and calm emotionally." Lastly, one participant described his spiritual beliefs as a "safe haven." He stated, "when I'm in the spiritual realm... that's what I can go to and no one can discriminate to you or

tell you that you're not worthy... It's mine and it's me and him."

Theme 7: Negative Impact of Spirituality on experience of Living with HIV. In contrast to the many positive spiritual experiences reported by PLH, a number of respondents also noted the negative impacts that spirituality can have on the experience of living with HIV. Of note, all negative experiences were associated with religious beliefs, a subset of spirituality. Participants reflected on three negative experiences associated with their religious beliefs: (1) negative view of self, (2) view of HIV as a punishment and (3) stigma/discrimination from their church/faith.

To begin, twenty percent of participants noted experiencing a negative view of self as a result of their religious beliefs. For example, one participant stated, "I feel I possibly might still go to hell... at best, Purgatory, or maybe somewhere in between and; therefore, my soul may never be at rest and that kind of thing. Do I think I'm going to heaven? No." Another participant shared she experienced guilt and shame associated with her HIV status as a result of her religious beliefs. Yet another respondent indicated, "You know those lepers that were shunned or whatever. I'm one of those, but I'm still walking and still here."

Twenty-seven percent of participants discussed their HIV-status as a punishment from God. For example, one participant indicated, "I did something wrong, it's my fault... I'm being punished because of my lifestyle." Another stated, "My HIV was because I was sinning or because I was a homosexual or it's God's punishment on me." Similarly, another respondent indicated, "I feel that because of my fornication or adultery which lead to the HIV and AIDS, that is more or less my punishment while living on earth."

Finally, 33% of participants noted experiences of stigma and discrimination from

their faith communities. For example, one participant indicated HIV/AIDS is not acknowledged or discussed in her church. Another participant expressed fear associated with disclosing to his preacher because, “I wouldn’t know if they would let me back in the church.” Finally, one participant who volunteers with her church group at homeless shelters was informed the church keeps extra hand sanitizer “in case you come into contact with someone with AIDS.”

Theme 8: Spirituality and Mental Health. Participant’s also discussed the many ways in which spirituality impacts their mental health. Participants either reflected on their increase in positivity and outlook or the decrease in stress associated with their spiritual beliefs.

To begin with, 53% of participants attributed a decrease in distress (depression, suicidality, stress, etc.) to their spiritual beliefs. For example, one participant explained, “Before I became Christian I was depressed and suicidal and on a lot of psych meds and now that where I am today, I am off of psych meds for six years and I don’t think about suicide. I’m not depressed.”

Another participant shared her experience of spirituality and indicated her spirituality gives her a reason to live. One other participant reflected, “If I didn’t have my spiritual life, I don’t know if I would be as sane as I am right now.”

Other than decrease in depressive symptoms, suicidality and stress, participants also noted an increase in positivity and outlook on life as a result of their spirituality. For example, one respondent noted, “Sometimes you have feelings come over you and you feel happy because it’s from up above, from God and when those feelings get inside you, you’re just happy and you feel it, it helps you somehow.” Another respondent

shared similar beliefs and stated, “I think spirituality is just about the only way to be happy.” Finally, another respondent stated her spirituality made her “more confident and it’s helped to keep my self-esteem to a level.”

Psychological Quality of Life

Lastly, participants responded to questions about their emotions since being diagnosed with HIV, the frequency of their stress/depression/anxiety and the perceived causes of their mental health symptoms. Two themes were identified under the construct of psychological quality of life: stress/depression/anxiety due to HIV and other sources of psychological distress. Participants most commonly attributed their psychological distress to HIV (Figure 8: Psychological Quality of Life).

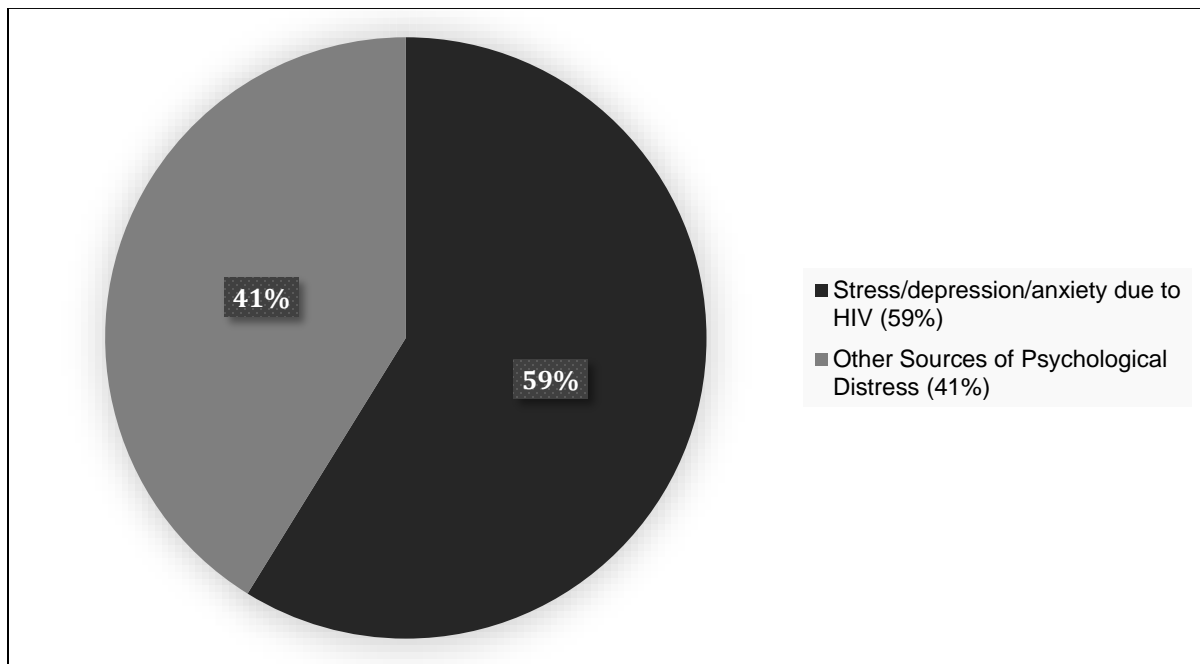


Figure 7: Psychological QOL.

Theme 9: Stress/Depression/Anxiety due to HIV. Within the theme of stress/depression/anxiety due to HIV, participants shared their emotional reactions to their HIV-status, the frequency of their mental health symptoms, as well as how their

mental health has changed and shifted over time. 100% of participants reported experiencing stress, depression, anxiety and/or anger associated with HIV at one time in their lives. More specifically, Forty-seven percent of participants discussed experiences with depression and three participants endorsed suicidal ideation, two of which made a suicide attempts. For example, one participant stated,

When I was first diagnosed... I didn't care anymore, so I figured I'd use needles and hopefully kill myself quicker and OD and that was how sick I was in my mind, but I was so sick all the time I would cry in and out of the [inpatient psychiatric unit] for suicide. I just didn't know how to cope. I thought it was death. All I knew what that people died from AIDS.

Another participant shared, "When I first got diagnosed, I thought it was the end of the world for me. It took me to a negative aspect of life." Yet another participant described her depressive symptoms as being in a state of "fluidity." She stated, "It can evolve. It can go from depression to stress."

Forty percent of participants discussed experiences with anxiety. Many participant's described their initial reactions to their HIV-status as worried and afraid. One participant stated, "For me, it started off with fear." Another participant shared, "My fear and stress and anxiety is mostly fear about the unknown" aspects of her HIV-status. Lastly, another participant described her experience of living with HIV as, "Nerve racking, disturbing, especially when I see my friends dying off and moving away."

Participant's also shared how often they experienced psychological distress as a result of their HIV-status. Twenty percent of participants shared they experienced stress/depression/anxiety "every day." One participant shared he experiences stress

associated with his HIV “all the time.” He further clarified, “You can’t help it really... I don’t know who wouldn’t be stressed because this ordeal. You really have to take care of yourself.” Another participant shared when he was first diagnosed he experienced stress/depression/anxiety “on a daily basis.” He then reflected on the time immediately after his HIV diagnosis and stated,

I would find myself saying... ‘You’d do that too if you were HIV-positive’ or ‘You would feel like that’ or you know ‘You would act that way if you were HIV-positive.’ I attributed my drug use to that a lot.

However, many participants also discussed a change in their mental health following their diagnosis. For example one participant reflected on his change in perspective over the course of living with HIV. He shared he experienced stress/depression/anxiety as a result of his HIV status “in the beginning, a lot.” He then stated,

But now, I don’t feel stress behind it...There’s been some big changes... You know there was a time, if me and you were sitting here talking right now, Oh man, at that stage in the beginning... I couldn’t have enough things to say, but that took time. Like I said a lot of time to develop that because... it affected me over the years... in different ways.

After being asked how often he experiences stress/anxiety/depression due to his HIV status, one participant shared,

Initially for the first couple years, I couldn’t talk to anybody. At work, even though I had very very close friends and I got very close to wanting to say something, I didn’t. The first couple years were real tough and then I started the drug use and

then that was another whole thing. Then my emotions and my everything was distorted so I was living in a haze. I was trying to cover up that depression or whatever that just made things worse.

That participant then went on to say,

Now, I feel the opposite. I've accepted it. I've been educated more now because of the medications and again talking with those in the... groups, what they've been through and knowing how they managed to be alive when they were told that they were going to die in a few years.

Finally, another person shared how their perception of HIV has changed over time. He stated,

I was depressed at first. I was suicidal. I didn't want to live when I was first diagnosed with HIV. I definitely didn't want to live. I tried to commit suicide a couple times. And from there, today, it's completely different... my emotional mind is stable. I focus more on the positive part of it.

Theme 10: Other Sources of Psychological Distress. Participants also discussed sources, other than HIV, which contribute to psychological distress. Fifty-three participant of respondents endorsed financial difficulties, 67% of participants discussed stress due to their relationships with their family and friends, 60% of respondents shared a history of mental health difficulties prior to their HIV diagnosis and 40% of participant's discussed experiencing health problems other than HIV. One participant shared his experiences with stress as a result of financial difficulties and stated, "Finances are one (source of stress) because you're on a fixed income... Healthcare doesn't seem to come fast enough when you need to address something... not being

able to go to work anywhere like you were before.” Another participant shared his distress is a result of “unemployment” and not living in his own place.

Participants also shared much of their distress relates to their history of mental health problems, trauma, and substance use. For example, one participant shared, “I had to tiptoe around my house because my father was an alcoholic. He was emotionally and physically abusive.” Lastly, several participants shared their stress is related to health difficulties other than HIV. In fact, many participants shared they struggle with diabetes more than with their HIV. However, participants also attribute their health problems to their HIV diagnosis. For example, one participant shared,

HIV... made some of those other traits worse... like we're talking Godzilla kind of worse... I've dealt with HIV for the last 24/25 years and this was back then I said, 'I've had more problems with the diabetes and everything else, but that was one of the side doors HIV opened.

CHAPTER V

DISCUSSION

The purpose of this study was to explore the experiences of HIV-stigma, spirituality and psychological quality of life (PQOL) in people living with HIV (PLH). We utilized an explanatory sequential mixed methods design, whereby we integrated both quantitative and qualitative data into one single mixed-methods study. This design utilizes two distinct phases: quantitative analyses followed by qualitative analyses. In the two-phase approach of our study, we first analyzed our data quantitatively using a PLS approach to SEM. Based on the results of our analysis, we created an interview protocol and conducted interviews with PLH who were matched on age, ethnicity and education of participants. The quantitative data was used to analyze and explore the relationships between HIV-stigma, spirituality and PQOL in PLH. The qualitative data helps explain those results by exploring participants' reactions and views in more depth (Ivankova, Creswell & Stick, 2006).

The major finding of this study is spirituality mediates the relationship between HIV-stigma and PQOL. This essentially suggests that HIV-stigma leads to an associated reduction in spirituality, which is correlated with a decrease in PQOL. Before continuing, it is important to note that while we hypothesized a causal model in SEM and then tested that model by using our sample data, causality cannot be assumed through SEM-based approaches. This is especially important to note when seemingly causal language is used. In order to further understand the relationships between these variables, we will next review the similarities and differences in how these three constructs (HIV-stigma, spirituality and PQOL) were conceptualized and defined in the

quantitative portion of our study in comparison to what was reported in the qualitative portion of our study.

HIV-Stigma

For the quantitative portion of our study, we measured HIV-stigma using the HIV-Stigma Scale which assesses four different types of stigma: personalized stigma, negative self-image, disclosure concerns and public attitudes. Participants in the quantitative portion of our study report a range of experiences with HIV-stigma, with some participants endorsing very little stigma and other endorsing a high level of stigma. However, results of the HIV-Stigma Scale show a floor effect in that most participants actually endorsed lower amounts of stigma, and no participants reported the maximum amount of stigma (as measured by this scale).

With regard to stigma, the results of our qualitative study are very similar to what was described in the quantitative portion of our study. Participants endorsed a range of experiences of stigma. In order to easily compare the results of our quantitative findings with the results of our qualitative findings, we identified these four main themes of stigma in our interviews of PLH: personalized stigma, negative self-image, disclosure concerns and concerns with public attitudes about PLH. Of these four types of stigma, PLH most commonly endorsed and discussed personalized stigma, which they further elaborated and defined as fears of rejection and actual experiences of stigma. PLH also shared their concerns with public attitudes about HIV and noted perceptions of both positive and negative attitudes; however, participants more commonly discussed negative public attitudes. Many PLH also perceive the public as being uneducated when it comes to HIV, especially regarding mode of transmission. They also shared that the

public often incorrectly believes PLH often fit a certain stereotype such as being gay, promiscuous and drug users. Another area of stigma often endorsed by PLH is negative self-image. Our respondents discussed three main types of negative self-image including feelings of shame, self-deprecation and punishment. Lastly, PLH shared concerns related to disclosure and discussed their attempts to conceal their status and non-disclosure (“protective silence”).

Overall, both quantitative and qualitative findings support the position that HIV stigma is multidimensional construct that can manifest in ways that are associated with internal processes such as personalized stigma and negative self-image as well as processes that are socially intertwined including public attitudes. PLH in both groups describe a range of experiences related to stigma, with some respondents reporting very little stigma and other respondents experiencing significant discrimination and negative self-image as a result of their HIV-status. Results also highlight the complex process of disclosure and the wide variety of ways in which disclosure occurs.

Psychological Quality of Life

We conceptualized PQOL as being comprised of stress (as measured by the Perceived Stress Scale; PSS), depression (as measured by the Center of Epidemiological Studies Depression Scale; CESD), and general mental health (as measured by the mental health subscale of the MOS-HIV) for the quantitative portion of our study. Results suggest participants endorsed the full range of depression, stress, and general mental health problems. We also found European Americans endorse significantly less stress than Other Ethnicity (members from a minority group other than European American, African American and Latino/a). These findings could be explained

by the minority stress model which suggests minorities experience stress in excess to the everyday stress experienced by non-minorities as a result of stigma and discrimination (Meyer, 2003). In addition, women report significantly greater stress than men. Matud (2004) explains that women experience significantly greater chronic stress and minor daily stressors than men. We found no differences between gay men, bisexuals and heterosexuals in their experience of PQOL.

Similar to the quantitative portion of our study, participants from the qualitative portion also endorsed a range of depression, anxiety and general mental health concerns. With regard to PQOL, two main themes were identified including (1) stress/depression/anxiety as a result of HIV and (2) other sources of psychological distress. All participants interviewed endorsed experiences of stress, depression, anxiety and/or anger associated with their HIV at one point in their lives. This is consistent with the results of the quantitative portion of our study. Our qualitative results provided more detail and elaboration on PQOL in PLH. Specifically, three participants shared they considered or attempted suicide due to their HIV-status. Participants also discussed their experiences of psychological distress as a result of difficulties in their relationships with friends and family, a history of mental health difficulties and health problems other than HIV. Our results also suggest many PLH experience an initial increase in their psychological distress after being diagnosed with HIV due to shock, fears of death and stigma. However, many PLH experience a change in their perspective over time due to an increase in support as well as acceptance of their diagnosis. Some PLH even perceive HIV as having a positive impact on their lives.

In sum, these findings are similar to previous research which suggests HIV is a

persistent stressor that contributes to negative mood states including distress, anxiety, depression, lower self-esteem and self-worth (Meyer, 2003; Major & O'Brien, 2005).

Spirituality

For the quantitative portion of our study, we conceptualized spirituality as being comprised of sense of peace (as measured by the sense of peace subscale of the Ironson-Woods Spirituality Scale; IWSRI), the extent to which a person feels fulfilled or being in the process of fulfilling life's goals (as measured by the Fulfillment subscale of the Extended Life Regard Index, ELRI) and forgiveness of self (as measured by the Forgiveness of Self subscale of the Heartland Forgiveness Scale, HFS). Participants in the quantitative portion of our study endorsed experiencing a full range of sense of peace, fulfillment and forgiveness of self.

For the qualitative portion of our study, participants identified four main themes under the Spirituality construct including: Personal definition/description of spirituality, spirituality and mental health, negative impact of spirituality on experience of living with HIV and positive impact of spirituality on experience of HIV. Interestingly, while we attempted to utilize a broader and more inclusive definition of spirituality in the quantitative portion of our study, most PLH who were interviewed (93%) made reference to God or religion when discussing their spiritual beliefs and practices. When describing their spiritual beliefs, participants discussed commitment to a particular religious tradition, creation of their own spirituality based on a religious tradition or made no reference to religion and discussed purpose/kindness/the Golden rule. Only two participants discussed factors unrelated to religion when describing their spiritual beliefs, suggesting that most PLH in our sample use their religious beliefs as an

expression of their spirituality.

While many religious traditions are historically discriminatory to PLH, PLH most frequently discuss the positive impact of spirituality. PLH reported their spirituality increases their ability to face challenges, increases their social support, enhances purpose and meaning in life, contributes forgiveness of self and establishes a sense of peace. In addition to these positive experiences, some PLH (27%) experience a negative impact of their religious beliefs on their sense of self. For example, some PLH view their HIV-diagnosis as punishment from God. Others experience stigma and discrimination from their church or faith group.

The location in which this study took place may help explain why PLH most commonly defined their spiritual beliefs through connection with God and their religious affiliation. The Dallas-Fort Worth Metroplex is part of what is generally considered the “Bible Belt,” a part of the country (the southeastern and southcentral United States) in which socially conservative evangelical Protestantism plays a strong role in society and politics. In general, Christian church attendance is generally higher in the Bible Belt than the nation’s average. In fact, DFW ranked as the top Bible-minded city in Texas in a survey conducted by the American Bible Society between 2005 and 2012 (Barna Group).

HIV-Stigma, PQOL and Spirituality (Hypotheses 1-3)

We found support for each of our first three hypotheses in the quantitative analyses. To begin with, stigma is negatively correlated with PQOL (Hypothesis 1). Interviews with PLH elaborate on this finding and describe experiences of stigma that may be associated with decreased PQOL. For example, all PLH in our study reported

experiences of personalized stigma including fears of rejection and actual experiences of stigma (enacted stigma). Most PLH also endorse disclosure concerns, negative self-image and concerns regarding the public's attitude of PLH. Each type of stigma (internalized, anticipated and enacted) is associated with a reduction in PQOL, including greater helplessness regarding HIV, lower acceptance of HIV, and lower mental health and social support (Earnshaw & Chaudoir; 2009).

According to Meyer's (2003) framework, the largest reason PLH experience low PQOL is stigma. PLH may have poorer quality of life than those who are not HIV-positive as a result of minority stress (Meyer, 2003). Furthermore, Herek (1999) explains why HIV is so highly stigmatized and suggests that PLH are often blamed for acquiring the disease, since the primary modes of transmission are considered avoidable and voluntary. Additionally, HIV is often considered fatal and contagious, and conditions that are visible to others, such as during the advanced stages of AIDS, are more stigmatized. Lastly, PLH are often members of another minority group (e.g., sexual minorities, ethnic minorities, and/or intravenous drug users).

Results of our quantitative analyses also provide support for our second hypothesis: stigma is negatively associated with spirituality. Interviews with PLH further elaborate on the experience of stigma and spirituality in PLH. Interestingly, while our quantitative analyses suggest stigma is associated with a decrease in spirituality, few PLH actually reported that stigma negatively impacts their spiritual beliefs or practices in the qualitative portion of our study. In fact, the negative impact of stigma on spiritual beliefs was so infrequently discussed that it was not a code in the codebook. This may be a result of differences in how spirituality was conceptualized in the quantitative and

qualitative portions of our study. For example, spirituality was defined as sense of peace, fulfillment and forgiveness of self in the quantitative portion of study. However, many participants defined their spirituality as relating to God or their religion when interviewed in the qualitative portion of our study. For example, 33% of participants interviewed indicated that stigma had a negative impact on their spiritual beliefs, while 67% stated stigma had no effect on their spiritual beliefs or practices. In fact, some PLH reported their spiritual beliefs helped them cope with stigma. Others share that stigma has increased their sense of resiliency and ability to handle problems and difficulties, especially relating to their experiences of stigma within their religious group.

Similarly, Chaudoir and colleagues (2011) suggest spirituality is a general coping mechanism that helps reduce the negative effects of stress on psychological well-being. Specifically, they suggest spiritual peace (e.g., the degree to which spiritual peace provides a sense of meaning and peace) is effective when coping with HIV stigma. In the face of stressors, including HIV, spiritual beliefs can help people to view themselves and their experiences as more meaningful. Alternatively, when people experience spiritual struggle such as questioning or doubting one's spiritual beliefs can be detrimental and ultimately lead to feelings of abandonment (Chaudoir et al., 2011).

Finally, results of our quantitative analysis provide support for our third hypothesis: spirituality is positively associated with PQOL (Hypothesis 3). As with our other two hypotheses, interviews with PLH elaborate on these two constructs and provide insight into the relationship between these two variables. Again, it is important to note the differences between how spirituality was conceptualized in the quantitative portion of our study (sense of peace, fulfillment and forgiveness of self) versus how it

was conceptualized in the qualitative portion of our study (related to religion/God). However, results of our quantitative analyses suggest that no matter how spirituality is conceptualized, it can have a positive impact on mental health. Most PLH describe experiences of spirituality which positively impact their PQOL. For example, 53% of PLH interviewed attributed a decrease in depression, suicidality and stress to their spiritual beliefs and practices. PLH also note the impact spirituality has on their overall positivity and outlook on life including happiness, contentment, self-esteem, confidence, etc.

These findings are consistent with previous research which suggest PLH often reflect on the meaning and purpose of their lives after a diagnosis of HIV. In fact, Ironson and colleagues (2006) found that 45% of PLH report an increase in spirituality after receiving their diagnosis. Furthermore, Chaudoir and colleagues (2012) found spiritual peace may help counteract the negative effect of HIV stigma on depression. Similarly, Plattner and Meiring (2006) found in a sample of PLH from Namibia, religious beliefs made their HIV-status more meaningful and also brought purpose to their HIV status and hope for a positive outcome in the future.

To further understand how religion (an aspect of spirituality) can be related to PQOL, Maton and Pargament (1987), in their seminal article, provide a framework for understanding the positive relationship between religion and PQOL. They describe religion as a response to the human need for understanding the ultimate nature, purpose and meaning in life. Different beliefs and understanding of religion can positively impact cognitive appraisal of a stressful event, whereas others can facilitate hope. Another important aspect of religious worldviews relates to God's/higher power's

personal relationship with an individual. The belief that God loves and supports a person despite personal weaknesses or shortcomings, can enhance self-esteem and psychological well-being (Maton & Pargament, 1987).

Spirituality as a Mediator (Hypothesis 4)

In order to test our fourth hypothesis, we used a PLS approach. Again, in describing the results related to structural equation modeling, it is important to note that causality cannot be assumed through SEM-based approaches. We found spirituality to be a partial mediator in the relationship between stigma and PQOL. This suggests that stigma is associated with a decrease in spirituality, which is associated with a decrease in PQOL. Interestingly, PLH in the qualitative portion of our study described a positive relationship between spirituality and PQOL, but did not note a negative relationship between stigma and spirituality. In fact, some PLH report utilizing their spiritual beliefs and practices as a way to manage and cope with stigma. This may be due to the way in which many PLH conceptualize spirituality in our study. Therefore, when spirituality is viewed as a broad construct composed of sense of peace, fulfillment and forgiveness of self, spirituality is a mediator in the relationship between HIV stigma and PQOL.

Alternatively, when spirituality is conceptualized as religion or relationship with God (a subset of spirituality), spirituality may no longer be a mediator.

These results show the importance of stigma and spirituality in the lives of PLH. Furthermore, results of this study suggest that the reduction in spirituality, found in the quantitative portion of our study, may explain why stigma is associated with a reduction in PQOL. Similarly, Chaudoir and colleagues (2011) found that spiritual peace moderates the relationship between HIV stigma and depression, such that spiritual

peace buffered the negative effect of HIV stigma on depression among PLH experience high (but not low) level of HIV stigma.

These results are especially important in the light of the way many PLH experience religion (a subset of spirituality). Religious organizations have the potential to increase stigma in PLH. For example, many religious PLH may continuously experience prejudice and discrimination from their religious organizations which can ultimately lead to internalized stigma. PLH may also feel marginalized due to the HIV-status and may decide not to disclose their status. However, the results of our study suggest PLH in general rely on their spiritual beliefs as a way to cope with stigma. Additionally, they frequently report HIV-stigma has no impact on their spirituality.

Limitations

Our results may be limited due to several factors. First, the design of our study was cross-sectional and correlational. Therefore, we cannot infer causality. Second, several of our measures demonstrated a restriction in range. As such, the effect of our overall model may have been stronger if the variability in our measures was greater. Also, our participants were obtained through convenience sampling through local community-based organizations and HIV service providers, such as UT Southwestern Medical Center and AIDS Services of North Texas (for the quantitative participants), as well as the Resource Center Dallas and AIDS Outreach Center (for the qualitative participants). This limits the extent to which we can generalize our findings since certain characteristics may be met by participants who are willing to participate in a study of PLH. For example, our participants may have a greater acceptance of their HIV-status than those who are not willing to participate and disclose their status. Furthermore,

since participants were obtained from community based organizations, they may have greater access to mental health services, whereas many PLH either do not have access to or do not utilize this type of care and may experience higher levels of mental health problems or lower levels of PQOL. Additionally, the qualitative data was collected 13 years after the quantitative data. Experiences of HIV-stigma and prejudice may be significantly different in 2002 than 2015. Nonetheless, all participants in the qualitative portion of our study endorsed experiences of stigma. Lastly, our sample was obtained in one geographic location. Therefore, our findings may not generalize to areas outside of Texas or the southern United States or be representative of stigma, spirituality PQOL in PLH people across the nation.

Our findings may also not generalize to areas outside of Texas or the southern United States or be representative of spirituality, minority stress and psychological QOL in people living with HIV across the nation. The Dallas Fort Worth (DFW) metroplex is situated in what is commonly known as the Bible Belt, an area of the United States that consists of many socially conservative evangelical Protestant churches. These churches are historically intolerant of sexual minorities, which are often incorrectly associated with an HIV-diagnosis. However, Dallas is also home to the world's largest LGBT Protestant church. These factors suggest that LGBT people living in Dallas may have vastly different levels of stigma/discrimination, spirituality and psychological quality of life than PLH living in other areas.

A PLS approach to SEM also comes with some limitations. For example, the parameter consistency and accuracy of our study may be less than if we utilized a covariance-based SEM (CB-SEM) approach. Reinartz, Haenlein and Henseler (2009)

suggest parameter consistency and accuracy is poor when compared with CB-SEM approaches. Additionally, the term “PLS-SEM bias” refers to the fact that PLS-SEM parameter estimates are not optimal when it comes to bias and consistency (Hair, Ringle and Sarstedt, 2011). However, PLS-SEM develops more precise estimates of factor scores than CB-SEM. PLS-SEM is also preferred when sample sizes are small, such as in this study (Hair, Ringle and Sarstedt, 2011). Therefore, the benefits of using PLS-SEM likely outweigh the consequences of reduced parameter consistency, accuracy and bias.

Clinical Implications

People with minority identities continue to experience minority stress due to the discrepancy between society’s ideals and values and the values of the minority person. For PLH people, minority stress may come in the form of stigma. This study suggests minority stress is associated with lower psychological QOL. This study also suggests spirituality may act as a mediator in this relationship.

Quantitative results demonstrate a strong relationship between HIV-stigma and PQOL. These findings reinforce the need for practitioners and service providers to be diligent in assessing depression in PLH. This may be especially important for ethnic minorities and women, as Other Ethnicity (not European American, Asian American, African American, Latinoa/) participants endorsed significantly greater depression and anxiety and women reported experiencing significantly greater stress than men. Through the identification of the types of stigma and personal experiences, appropriate interventions can be tailored to the individual. Weiss and Roamakrishna suggest that interventions designed to reduce stigma must vary with the conditions being considered.

For example, if stigma is primarily intrapersonal, including negative self-image and personalized stigma, supportive and insight oriented counseling may be most appropriate (Weiss & Ramkrishna, 2006). Should the primary experience of stigma be discrimination, advocacy and challenging of discriminatory practices of society may be most appropriate.

These results also provide support for the important role that spirituality plays in the lives of some PLH, especially in the context of stigma and PQOL. This study has implications for therapeutic interventions for clinicians who work with PLH with low PQOL. For example, clinicians may want to inquire about PLH's spirituality (e.g., sense of peace, life fulfillment and forgiveness of self) as well as their level of stigma. Clinicians may also want to implement interventions aimed at increasing these components of spirituality. For example, spiritually modified cognitive-behavioral therapy (CBT) might be used for clients whom spirituality is a central life dimension (Hodge, 2006). The difference between traditional CBT and spiritually modified CBT is that schema from client's spiritual narrative is used to replace unproductive thought patterns. Clinicians may also elect to direct clients who wish to express their spirituality through religion to affirming faiths and organizations.

Future Research

Additional research should be conducted to assess other types of quality of life to determine the effects of stigma and spirituality. For example, researchers should examine physiological aspects of quality of life to determine the role of stigma and spirituality in reducing physical symptoms. Researchers may also want to assess sociological aspects of quality of life and its relationship with stigma and spirituality. A

longitudinal study would also be valuable to assess PQOL in PLH over time, as the relationships with stigma and spirituality may depend on participant factors such as age, level of acceptance, etc. Researchers may also want to replicate this method with a larger sample size with a covariance-based SEM approach in order to address the limitations of PLS. Lastly, this study could be replicated outside of the South to determine if definitions of spirituality vary outside of the South.

APPENDIX A
INTERVIEW PROTOCOL

Demographic Questions:

1. What is your age? ____ Years
2. How many years of education do you have? ____ Years
3. What is your annual income? \$_____
4. What is your race/ethnicity?
5. What is your sexual orientation?
6. What is your gender?
7. Do you consider yourself to be a spiritual person?
 - a. If yes, do you ascribe to a certain spirituality/religion?
Please identify: _____

Interview Questions:

Priming/Experience:

1. What is it like for you to be HIV-positive/to live with an HIV diagnosis?

HIV-related Stigma/Negative Beliefs Concerning HIV:

1. What do you think of when you hear “HIV/AIDS”?
2. What kind of beliefs or attitudes do you feel that the community has about HIV-positive people?
3. What kinds of beliefs or attitudes do you feel that the community has about HIV in general?
4. What kinds of consequences are there to other people knowing that you are HIV-positive?
5. Tell us about experiences you have had with HIV-stigma.
6. How do you typically think people will react when disclosing your HIV status?
7. How do you feel about other people knowing your HIV status?
8. What are your concerns in disclosing or telling others that you have HIV?
9. What do you do to make sure that others do not know you are HIV-positive?
10. How has an HIV diagnosis changed how you view yourself?

Spirituality:

1. How do you describe/define your spirituality?
2. How do you practice your spirituality? (church/synagogue attendance, meditation, awareness, etc.)
3. How has your spirituality affected your mental health/emotional well-being?
4. How does your HIV-status affect your spiritual beliefs?
5. How does HIV stigma affect your spiritual beliefs and vice versa?
6. How does spirituality affect your overall quality of life?

Psychological Distress:

1. How would you describe your emotions since being diagnosed with HIV?
2. How often have you felt stressed/depressed/anxious because of HIV?
3. What makes you feel stressed/depressed/anxious?

APPENDIX B
CODE SHEET

100 HIV-STIGMA

- 110 – Personalized Stigma** – experiences or fears of rejection for having HIV; for ex: perceived consequences of other people knowing they're HIV+, losing friends, people avoiding them, regrets of telling people
- 120 – Disclosure Concerns** – controlling info, keeping HIV status secret, worrying others know of HIV status or they would tell
- 130 – Negative Self-Image** – shame, guilt, feeling unclean, like a bad person
- 140 – Concern w/Public Attitudes about People w/HIV** – OTHER people's concerns and beliefs of HIV/PLWH

400 SPIRITUALITY

- 410 – Personal definition/description** – how people define their own spirituality, including how they practice (e.g., church attendance, meditation)
- 420 – Spirituality & mental health** – talk about how spirituality affects emotional health, coping with stress...
- 430 – Negative Impact of Spirituality on experience of living with HIV**
- 440 – Positive Impact of Spirituality on experience of living with HIV**

500 PSYCHOLOGICAL DISTRESS

- 510 – Stress/depression/anxiety due to HIV** – mood, emotional response directly due to HIV (e.g., negative emotions following diagnosis, stress over medical bills, medication regimen, poor health, poor psych adjustment to HIV)
- 520 – Other Sources of Psychological Distress** – other factors that cause distress, indirectly/not associated with HIV (e.g., pre-existing psych problems, social problems, financial issues, other...)

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