UNDERSTANDING HOW PEOPLE LIVING WITH HIV/AIDS (PLWHA) EXPERIENCE SOCIAL SUPPORT IN EVANGELICAL CONGREGATIONS

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ABSTRACT

The HIV epidemic continues to be a global health crisis with an estimated 38 million people living with HIV worldwide. It is increasingly important to examine the psychosocial and spiritual issues that are present among people living with HIV/AIDS (PLWHA) to help decrease at-risk behavior and stigma associated with HIV. Faith can be an empowering social support system for PLWHA. Evangelical congregations have the potential to be HIV-comportment communities. This qualitative study utilizes hermeneutic phenomenology to analyze and interpret the lived experiences of 12 PLWHA who have a connection to an evangelical congregation. Anti-Oppression Theory and the intersectionality of faith and HIV, as it relates to oppression and empowerment, provide the conceptual framework for this study. Six major themes emerged from the data: Multifaceted Stigma, Power and Oppression, Patients as Educators, Our Voices Matter: What Works and What Doesn't, Where Do We Fit In, and Mortality with Eternity in Mind. The most prominent theme, Multifaceted Stigma, identified congregational discrimination, lack of knowledge, and negative attitudes about HIV towards participants in this study. Findings highlighted a variety of psycho-social stressors exhibited by PLWHA, the importance of perceived and received support in congregations, and the intersection between spirituality and Anti-Oppressive Practice. The implications of these findings indicate the importance of PLWHA's individual and collective voices; provide suggestions for evangelical congregations to become HIV-competent communities; and discuss the role of congregational social work with PLWHA.

Keywords: PLWHA, HIV/AIDS, HIV/AIDS stigma, evangelical congregations, social support, Anti Oppressive Practice, HIV-competent communities

GENERAL SUMMARY

This study aimed to analyze and identify ways in which People Living with HIV/AIDS (PLWHA) experienced social support in evangelical congregations. An in-depth literature review examined the importance of psychosocial support for PLWHA, the role of faith-based systems, quality of life for PLWHA, and competent HIV faith-based communities. The intersection of faith communities and HIV as it relates to oppression and empowerment are discussed. An overview of hermeneutic phenomenological research, design, and analysis served as a guide to the study. A synopsis of participant findings and themes included: Multifaceted Stigma, Power and Oppression, Patients as Educators, Our Voices Matter: What Works and What Doesn’t, Where Do We Fit In, and Mortality with Eternity in Mind. Based on these themes, implications for social work practice and the profession, limitations of the study, and areas for further research are considered.

DEDICATION

To my parents, Janos Fürj and Susanna Thellmann Blair, who taught me to never give up.

To my husband, Perry Kuhn, who is the ever-encouraging, constant, love of my life.

To my children, Eliana Grace and Mira Elizabeth, may your sense of wonder and love of learning never cease.

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A*ll I can do when the road bends*
Is lean into the curve
And all I can do when the tanks run dry
Is see what's in reserve
And all I can do when the plans break down
Is stay on my feet
And all I can do at the end of the day is play on
Play on and keep the beat. - lyrics by Lin-Manuel Miranda

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IMPORTANT DEFINITIONS

PLWHA - People Living with HIV, People Living with AIDS. Infants, children, adolescents, and adults who have HIV/AIDS.

Evangelical - One who holds to a more theologically conservative position, particularly related to the authority of the Bible and the person of Jesus. (Rah, 2009, p.42).

Religious Congregation- As defined by Cnaan (2006), a group of persons who voluntarily band together for religious purposes and who share an identity with one another (p. 28).

Anti-Oppressive Practice- A social justice-oriented practice that draws on a number of approaches analyzing how power works to oppress and/or empower individuals, groups, and communities (Baines, 2011, p. 26).

HIV- Human Immunodeficiency Virus**.** This lifelong chronic virus can lead to acquired immunodeficiency syndrome, or AIDS (CDC, 2021).

AIDS- Acquired Immunodeficiency Deficiency Syndrome. The final stage of the HIV virus, which causes severe life-threatening T-Cell defects (CDC, 2021).

CD 4 - A type of T-Cell that is made up of glycoprotein (CD4) which helps to initiate the body's response to infection. CD4 cells can act as a host to HIV, allowing the virus to invade the cell and replicate itself. The more functioning CD4 cells, the stronger the PLWH's immune system will be (CDC, 2021).

Psycho-Social-Spiritual- A multi-dimensional model that provides assessment for emotional, behavioral, cognitive, social, and spiritual variables (Green et al., 2002).

LGBTQIA+- lesbians, gays, bisexuals, transgenders, queers and/or those questioning their identity or sexual orientation.

CHAPTER 1

INTRODUCTION

Research shows the duality that evangelical congregations face as they seek to understand HIV/AIDS within their communities. On the one hand, there is a body of research suggesting that evangelicals can be a barrier to HIV care. On the other, there are suggestions that evangelicals can be helpful and are uniquely positioned to respond to the HIV crisis (Berkely-Patton et al., 2013; Bluthenthal et al., 2012; Clarke et al., 2006; Francis & Liverpool, 2009; Griffith et al., 2010; Kuman & McMillam, 2013; Pichon & Powell, 2015; Pryor et al., 2015; Roura et al., 2010). Evangelical congregations continue to grow throughout the world and are known to provide broad health education and prevention services such as recovery programs for those who struggle with addiction, prevention and education efforts pertaining to chronic illness such as diabetes and cancer, and outreach to unhoused populations (Hodge, 2008; Laudet et al., 2006). These congregations are uniquely positioned to create a positive impact in the HIV epidemic.

Purpose Statement and Research Questions

As the HIV epidemic continues to be a health crisis worldwide, it is increasingly important to examine the psychosocial issues present among people living with HIV-AIDS (PLWHA). Chronic stress, depression, suicidal ideation, and the struggle for acceptance and belonging are all factors that contribute to negative health outcomes for PLWHA. Psychosocial support systems are central in helping PLWHA manage quality of life and learn coping skills as well as help establish positive health outcomes (Bosworth, 2006). These psychosocial support systems are also imperative for helping to decrease at-risk behavior and stigma associated with HIV. Although faith communities can be an effective avenue for providing psycho-social and spiritual support to PLWHA, they can also have a negative impact (Casale & Wild, 2013; Liu et al., 2013; Qiao et al., 2014).

This qualitative study uses a phenomenology research approach and aims to address four fundamental questions as it pertains to PLWHA who are associated with evangelical congregations. These questions were asked based on the assumption that faith congregations do provide support. First, do evangelical congregations provide social support services and interventions to their members who identify as evangelical and are also diagnosed with HIV or AIDS? Second, what are the lived experiences of PLWHA who interface with evangelical social support systems? Third, are they empowered or oppressed? Fourth, are the voices of PLWHA represented in evangelical social support systems and congregations?

Exploring these questions will help to contribute to the currently limited research literature around the dichotomy of congregational oppression and empowerment of PLWHA and the psychosocial impact this dichotomy has in relation to HIV health. Although there is some research examining social support provided to PLWHA by congregations, it has focused primarily on the perspective of the church leaders (Derose et al., 2010; Pichon et al., 2020; Reese, 2011; Williams et al., 2011). There is a significant gap in the literature reflecting the voice of PLWHA as it pertains to the importance of social support in their congregations. To date, I would argue no articles have been written from this critical viewpoint. It is my hope the findings from this study will help create empowering, participatory, transformative change in evangelical congregations, giving voice to PLWHA, and creating HIV-competent communities. A phenomenological research approach to the four research questions I propose will afford the opportunity to explore PLWHA and their experiences with evangelical congregations.

Background of Study

According to the World Health Organization (WHO, 2023), an estimated 38 million people currently live with HIV worldwide. Considering an estimated 1.5 million people were infected in 2020 alone (WHO, 2020), HIV continues to be a major public health crisis globally. Over 1.2 million people live with HIV infection in the United States of America, with approximately 13% of these individuals undiagnosed (The Centers for Disease Control and Prevention, [CDC], 2021). The CDC reports that close to 40,000 new HIV infections in the U.S.A. occur annually (CDC, 2021). In 2021, males accounted for 80% of all diagnoses of HIV infection. People aged 13-35 accounted for more than half of all HIV diagnoses (HIV Surveillance Report, 2021). Those most disproportionately affected by HIV infection are men who have sex with men (MSM) followed by African American, Latino, and Caucasian groups (HIV Surveillance Report, 2021).

HIV is transmitted through body fluids and includes the following four main modes of transmission: unprotected vaginal or anal intercourse, perinatal infection or breastfeeding, use of infected blood or blood products, and use of contaminated drug injection equipment. Biologically, HIV can mutate rapidly. New strains of HIV can easily spread through the body as the virus quickly makes DNA (Deoxyribonucleic acid) copies of its own RNA (Ribonucleic acid), attacking CD 4 cells that help produce a normal immune response. When the lowered immune response is seen in individuals diagnosed with HIV and CD 4 counts are below 200, severe, opportunistic infections can develop, and a diagnosis of AIDS can be determined. Without treatment, AIDS-related death can occur (CDC, 2021; Doyal & Doyal, 2014; Rowan, 2013). HIV is deemed one of the most intelligent diseases due to its complex replication process. Therefore, it is crucial for those diagnosed with HIV to seek treatment, adhere to treatment, and decrease at-risk behavior.

In the past decade, major advances in research and treatment have enhanced the quality of life for people living with HIV (PLWHA), particularly in the U.S.A., Canada, and Europe. Advances in Highly Active Antiretroviral Therapy (HAART), Antiretroviral Therapy (ART), or Combinational Antiretroviral Therapy (cART) have made it possible for PLWHA to live much longer lives than 10-20 years ago (Eggelton & Nagalli, 2022; National Institutes of Health, [NIH], 2023). Many claim that HIV is not the death sentence it once was. However, even with improvements in health, HIV rates are still rising. Conversations about HIV stigma, prevention, and support are crucial to a sustained quality of life both in diagnosing HIV and in reversing the trend of HIV transmission.

Although HIV manifests itself by attacking the immune system specifically, researchers do not view it only through an immunological lens. HIV/AIDS is a multifaceted problem: physical, medical, emotional, social, and for some, spiritual supports are found to be critical elements to successfully living with HIV/AIDS (Cadell, 2007; Grieb et al., 2020; Grill et al., 2020; Jacobson et al., 2006; Lyon et al., 2020; Nunn et al., 2019; Vigliotti et al., 2020). The use of HIV- related medication and its adverse effects, disclosure of HIV status, stages of HIV, and the continual development of symptoms impinge on the overall health of PLWHA (Vosvick et al., 2010).

Studies conducted by Zachariae et al. (2009, 2013) examined the connection between HIV and well-being and provide one example of HIV's far-reaching impact on holistic health. These studies discuss the correlation between brain interaction and the immune system, describing this phenomenon as psychoneuroimmunology. These researchers found that chronic stressors like depression are highly correlated to immune suppression. Additional studies show that psychiatric co-morbidity issues are present in people living with HIV/AIDS (PLWHA), affirming depression as the most common psychological diagnosis (Brown et al., 2021; Blank & Eisenberg, 2007; Blank et al., 2014). In addition, a study examining suicide among older adults revealed that those diagnosed with HIV have higher levels of depression and suicidal ideation (Vance et al., 2009). Furthermore, literature shows that suicide attempts are higher for PLWHA who have no regular social support systems (Préau et al., 2008).

To state the obvious, HIV is a life stressor. The period following HIV diagnosis is critical and can contribute to continued chronic stress on PLWHA. The psychosocial response to the diagnosis of HIV can either help or hinder a person's quality of life (Laurenzi et al., 2021; Ma et al., 2023; Valle & Levy, 2008). DeSantis and Barroso (2011) predict that "[HIV] stressors could be managed if psychosocial support systems were available to mitigate the stress of living with HIV" (p.350). If stressors are not managed well, PLWHA’s physical, psychological, and social well-being are at risk. In addition, stress related to HIV could lead to maladaptive coping skills that include continuing to engage in harmful, risky behavior.

It is well documented in the literature that psychosocial support systems and interventions are vital components to the quality of life of an individual living with a terminal disease such as HIV/AIDS (German & Latkin, 2012; Jenkin et al., 2006; Marks, 2005; Onuoha & Munakata et al., 2010; Rokach, 2000; Valle & Levy, 2008). According to the research these systems and interventions not only reduce anxiety, stress, and negative mood patterns but also increase coping mechanisms and social support as well as decrease stigma associated with chronic illness (Charles et al., 2005; Chesney, 2003; Ironside et al., 2005). When psychosocial support systems are not available, fear, rejection, isolation, and discrimination of PLWH are likely to occur (DeSantis & Barroso, 2011). Psychosocial support systems are an evident factor for health and well-being and are needed to help with the psychological distress that accompanies HIV. Interestingly, a significant amount of literature also suggests that faith-based support systems such as mental health and substance use peer support groups, religious coping strategies, and community health initiatives, can be a source of encouragement or, in situations where strict religious beliefs about sexuality or sexual behavior towards PLWHA occur, a source of stigma (Bigger, 1999; Courtenay et al., 2008; Jacobsen et al., 2006; Marks, 2005; Messer, 2011; Miller, 2009; Muturi, 2010; Payne-Foster, 2018).

Faith as an Empowering Social Support System for PLWHA

Upon receiving news of an HIV diagnosis, most individuals can experience significant changes physically, mentally, psychologically, socially, and *spiritually* (Courtenay, 1999; DeSantis & Barroso, 2011; Pargament et al., 2004; Peltzer, 2011; Tesoriero et al., 2000). In the past decade, an abundance of research has shown the central role that spirituality or religion play in the quality of life of many living with HIV. For example, a study conducted among intravenous drug users (IDU) and their interpretations of testing positive for HIV, revealed that they had found meaning in response to their diagnosis in three prominent ways: First, PLWHA saw their diagnosis as a "wake-up call" and a blessing, and identified more with spirituality and/or religion by increasing attendance in congregational activity. Second, PLWHA took on an active HIV advocacy role, becoming more involved in community treatment and prevention efforts. Third, PLWHA, at one point, thought of their diagnosis as a death sentence, a punishment from God due to their "past sins." This mentality at times resulted in self-destructive and minimizing behavior of the illness (Valle & Levy, 2008). Authors of this same study argue there is a link between health and faith-based support and that "twelve-step" recovery groups, HIV advocacy groups, and churches may be effective vehicles for delivering social services designed to encourage and facilitate healthier living" (p. 136).

Marks' (2005) model of *Religion and Bio-Psycho-Social Health* also suggests that faith communities can foster psychological coping through emotional, moral, and social support systems. The model identifies a relationship between HIV practices and faith philosophies. For example, it revealed that low-risk behavior correlates with religious beliefs. Some authors suggest that faith is a strong predictor in HIV risk behavior (Folkman, 1992; Shapiro et al., 1999). One study that examined the role religiosity played in women's HIV risk behavior discovered that those who were at greatest risk for HIV were also the least religious (Elifson et al., 2003, p.47). "Religiosity" can often be a disparaging term. In this article, it was defined as a strong religious feeling or belief. Another study that investigated the relationship between HIV/AIDS and spirituality found that spirituality contributed to longer survival rates as well as positive health behaviors, less distress, and lower cortisol levels for PLWHA (Ironside et al., 2002). Other factors related to longer survival rates of PLWHA included the following: a sense of peace, faith in God, religious behavior, and a compassionate view of others (Biswas, 2007, p. 224). Additionally, several studies indicate that a traumatic life crisis similar to that associated with the advancement of death, such as cancer or HIV, stimulated a reassessment of one's faith development (Courtenay et al., 1999; Jacobsen et al., 2012; Morse et al., 2013).

HIV and Stigma in the Faith Community

While some literature points to faith communities as an avenue to reduce risky behavior, increase health, and exhibit positive coping strategies for those diagnosed with HIV/AIDS, other literature reveals that these communities can act in ways detrimental to PLWHA (Marks, 2005; Messer, 2011; Miller, 2009; Muturi, 2010). Studies show that many faith communities associate HIV with behavior that can be considered "deviant," "shameful," and "illegal" (Muturi, 2010). These associations make it difficult for PLWHA not to be or feel blamed for contracting HIV and transmitting the disease to others. Literature reveals that behavior associated with stigma is more evident in rural communities, particularly with those in Black Indigenous (and) People of Color (BIPOC) communities who identify as Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, or Asexual (LGBTQIA+) (Lapinski et al., 2010; Shehan et al., 2005, p. 186). Stigma sometimes exerted by those in the faith community often leads PLWHA to fear disclosing their status. Stigma can prevent PLWHA from reaching out to potential critical support systems within their community. Aspects of vulnerability in PLWHA associated with stigma contribute negatively to positive health outcomes (DeSantis & Barroso, 2011). Researchers and PLWHA alike, see spirituality as an important psycho-social component necessary to build support systems. Yet, because of stigmatization, many feel embarrassed or hesitant to share their HIV status with their faith community. At times, PLWHA have disengaged from their congregations altogether, resulting in spiritual distance. Some faith communities have deep social stigma associated with HIV and AIDS, which can lead to the social rejection of PLWHA. In essence, religion and spirituality can contribute to positive psychological states for some but may exacerbate feelings of guilt, shame, and psychological harm for others (Yi et al., 2006).

Evangelical Communities and HIV

Religious congregations and faith-based organizations have been uniquely identified as playing an influential role in the HIV/AIDS epidemic (Derose et. al., 2011; Green & Ruark, 2008; Somlai, 1997; Sutton & Parks, 2013; Szaflarski et al., 2013). As researchers examine the severity of HIV health statistics in the U.S. A., it is evident that religious congregations are undeniably impacted (Cnaan, 2006; Derose et al., 2010;

Tesoriero, 2000). Many congregants themselves are living with HIV/AIDS. Some take active roles within their church to combat stigma and create congregational HIV/AIDS-related programs, while others are afraid to disclose for fear of rejection or ostracization.

Historically, evangelical congregations have adhered to a set of ideologies that promote a strict set of beliefs and values (Bebbington, 1989). Evangelical denominations fall on a spectrum of varying views (see Chapter 2 for a full description). On one end of the spectrum, liberal evangelicals tend to emphasize personal responsibility to care for the poor and marginalized. They have set the social agenda for congregational support, care, advocacy, and commitment to various global social issues and see this as their main mission as a church (Rauschenbusch, 1917). Fundamentalist evangelicals (sometimes known as “ultra-conservatives”) can be found at the other end of the spectrum. Fundamentalists place almost all their emphasis on biblical doctrine, law, and a salvation message (Rossinow, 2005). They would disagree that the mission of the church is *only* to solve social ills of society and have remained quite hesitant to place much effort into doing so. At times, in fact, fundamentalist evangelicals have undermined social activism or social support within the congregation (Fulton, 2011, p. 618). In the middle of the spectrum, lies the centrist evangelical, those who strive to bring about social change while adhering to the importance of sound doctrine, attempting to bring the ideological and the pragmatic together (Clarke et al., 2006).

Overall, evangelical congregations have been criticized for their slow response to the HIV epidemic in the U.S.A. (Falk, 2001; Lapinski et. al., 2010). Interestingly, evangelicals have responded more favorably to the global HIV/AIDS epidemic in contrast to the local epidemic. Research indicates that this slow response is due to the attitudes and behaviors displayed within congregations where members indicate a disparity in education about the importance of HIV prevention, treatment, and psycho-social support programs (Muturi & Soontae, 2010). Because of this disparity, some members are simply ignorant of these programs and efforts. Evangelical congregations have, at times, associated social issues like HIV/AIDS with immoral behavior, and some conservative congregations were hesitant to have a dialogue about sex, harm reduction, and sexual orientation, all issues pertaining to the epidemic and critical to prevention and education efforts (Mantell et. al., 2011).

Ultra-conservative religious traditions can justify discrimination against sexual minorities diagnosed with HIV. Some evangelical beliefs may lead to hatred, hostile attitudes, and discrimination against gay PLWHA due to views in relation to queer identities, a double stigma, (Bauer, 2013; Rodriguez, 2010). For example, one study revealed that some Christian congregations used sacred texts to depict PLWHA who also identified as LGBTQIA+, as an “abomination” or “sickening” (Genrich & Brathwaite, 2005). Researchers who interviewed evangelical leaders about their perception of HIV/AIDS found that many evangelical leaders were able to divide PLWHA into two separate groups, “guilty” and “innocent” of contracting HIV based on the mode of transmission (Green & Rademan, 1997). The LGBTQIA+ population was overwhelmingly placed into the “guilty” category. Ultra-conservative theological interpretations can have negative impacts on how PLWHA are viewed within their congregations or how PLWHA view themselves in light of acceptance, repentance, and belonging (Kuman & McMillan, 2013).

Research Approach

With the approval of Memorial University's Interdisciplinary Committee on Ethics in Human Research, I examined the phenomena of social support for PLWHA who, at some point, have been a part of an evangelical congregation. Issues pertaining to oppression and empowerment were examined. Semi-structured interviews conducted with 12 participants were the primary method of data collection. The research method of Interpretative Phenomenological Analysis was applied in this study. In addition, the tradition of hermeneutic phenomenology was utilized to best interpret these experiences.

Contribution of the Study

Data from this research could benefit social workers, lay leaders, and congregants to understand the lived experiences of PLWHA and assist them in advocating for and brokering with members living with HIV to help meet their biopsychosocial and spiritual needs. Religious congregations can provide an HIV support network to its members. Social workers have the unique opportunity to establish a significant relationship with the evangelical community to advocate for HIV-competent communities which include social support systems, prevention, outreach, ministries, and policies. Information from this study could also provide a starting point for important and relevant conversations about HIV/AIDS within the evangelical community. This study has the potential to add the ***local*** impact of HIV/AIDS to the evangelical social agenda given many evangelicals are more inclined to financially and politically support HIV/AIDS efforts internationally rather than locally (Agadjanian & Menjivar, 2008; Haile & Chambers, 2007; Miller, 2009; Trinitapoli, 2006). Finally, this study could help evangelical congregations confront the stigma associated with a "Not in My Backyard" mentality that can be associated with HIV/AIDS.

Organization of Chapters

The first chapter provided a brief overview of HIV/AIDS, the importance of psychosocial support for PLWHA, and the role of faith-based systems in their lives. The second provides an in-depth literature review of psycho-social-spiritual support systems, quality of life for PLWHA, and competent HIV faith-based communities. The third discusses the history of Anti-Oppression Theory and the intersection of faith communities and HIV as it relates to oppression and empowerment. The fourth chapter provides an overview of the epistemological underpinnings that guide the study. I apply a discourse on the position to create transparency and convey assumptions and biases that shape the conceptual framework of the study. Methodological position of phenomenological research, design, and analysis that guide the study are also reviewed. The fifth presents a synopsis of participant findings and themes based on their experience of social support within evangelical congregational settings. The sixth and final chapter analyzes and compares participant themes to the literature on social support and PLWHA. It includes the significance of the study, implications for social work practice and the profession, limitations of the study, and areas for further research.

CHAPTER 2

LITERATURE REVIEW

Literature reveals that religious congregations are uniquely positioned to provide psycho-social support systems that help to establish positive health outcomes for their congregants and community. Religious congregations can affect the overall health of someone diagnosed with HIV as psycho-social support systems are central in helping PLWHA manage quality of life, learn coping skills, and establish positive health outcomes. There is, however, a duality that congregations face as they seek to understand HIV in their communities. They can either be a barrier to care or be well-equipped to handle the HIV crisis (Clarke et al., 2006; Kuman & McMillam, 2013; Roura et al., 2010). Although there is some research examining social support provided to PLWHA by congregations, there is a significant gap in the literature reflecting the voice of PLWHA, especially as it pertains to their experience within evangelical congregations (Derose et al., 2010, 2011; Reese, 2011; Williams et al., 2011). To date, no articles have been written from this critical viewpoint. I hope that the findings from this study will help create empowering, participatory, transformative change in evangelical congregations, articulating the views of PLWHA, and creating HIV-competent communities. Whether evangelical congregations provide these support systems can leave PLWHA feeling empowered or oppressed.

This chapter presents a review of the literature concerning the key concepts associated with this study. First, I provide definitions of social support and an overview of its relevance to those with chronic or terminal illnesses. I explore a critical analysis of psycho-social response concerning the quality of life for PLWHA. Furthermore, I discuss concepts that impact the overall health of PLWHA, such as well-being, stress, discrimination, fear, and stigma.

Second, this review provides a discourse on the intersection of HIV, faith communities, and social support systems. Also included in this section is the current literature on HIV/AIDS with an emphasis on the role of the Black Church, a discussion on HIV/AIDS policies created by faith-based communities, and faith-based ministries that provide psycho-social-spiritual support to PLWHA.

The Importance of Social Support

Social Support Defined

Social support is comprised of one's social system, which includes, but is not limited to, individuals, families, groups, and communities whom all emulate valuable resources for those struggling with a particular physical, psychological, or social issue. The etymological root of the phrase "social support" finds its lineage in the words "social" and "support". "Social", derived from the Latin word *socialis,* means companion, allies, or companionship. The term "support" is defined as the "act or provision of assistance by means of services which enable something to fulfill its function" (Barker, 2014; Etymological Dictionary, n.d.). The most widely used definition of "social support" is described by Cohen (2004) as "a social network's provision of psychological and material resources intended to benefit an individual's ability to cope with stress" (p. 676). Social support is the sharing of resources between individuals to enhance the well-being of the recipient as well as provide people with a sense of belonging, love, acceptance, and self-esteem (Müller, et al, 2012, 2015). Nuclear family, extended family, friends, work groups, cultural groups, religious groups, and significant others are key dimensions within this support system.

Chronic illness is defined as “long-term or permanent medical conditions that have recurring effects on everyday life” (Shaw et al., 2010, p. 12). “Long-term” or “permanent” is conceptualized as a recurring pattern of illness lasting for more than six months or one year. Chronic illness produces long-term physical, social, emotional, psychological, and spiritual limitations, which also significantly alter day-to-day activities and lifestyle (Ironside et al. 2003; Nabors & Lehmkuhl, 2004; Stein et al., 1997). What follows is an examination of the underpinnings of social support systems and the impact they have on those living with chronic illness.

Social Support and Chronic Illness

Individuals who struggle with chronic or terminal illness often experience negative feelings in relation to their health (Applebaum et al., 2014; Boyer & Poindexter, 2005; Hatzmann et al., 2009; Hurt et al., 2014; Remien et al., 2019; Sharpe et al., 2013; Turner & Kelly, 2000). The onset of chronic illness can have a significant impact on social relationships, inside and outside of the family (Sharpe et al., 2013). Adaptation to new roles and new ways of living with illness, in addition to dealing with the loss of identity or sense of self, can lead to stress, worry, depression, and anxiety (Arestedt et al., 2014). It is critical for patients to comprehend the severity of their illness upon receipt of diagnosis and to utilize pertinent support systems. People living with chronic illnesses need more than just medical treatment; they need systems in place to help make sense of being diagnosed with their health conditions. Social support systems can assist with positive health and well-being for those living with an acute illness and can help patients to positively respond to chronic issues (Hurt et al., 2014; Verhoof et al., 2014; Wong et al., 2014). Family, friends, and community entities, which have an important impact on quality of life, form such support systems (Arestedt et al., 2012; Lim & Zebrak, 2004; Noronha & Mekoth, 2013; Theeke & Mallow, 2013).

When measuring quality of life employing social support, several things are taken into consideration: the timing of the chronic stressor, whether the stressor is controllable, the effectiveness of received support, and perceived support. Received support can be defined as social exchanges that take place when one is not only experiencing a life stressor but equally experiencing the response from others in demonstrating their support. Examples of received support include support groups provided by professionals or peers in the form of individual, group, or community contact, referral systems, or an engagement of social interaction with others who share a common problem (Cobb, 1976; Cohen, 2004; Reilly & Woo, 2004, p. 97). On the other hand, perceived support is the perception or belief of being socially supported, people's positive assessment of connecting to others (Alsubaie et al., 2019; Li et al., 2021; Reilly & Woo, 2004; Szkody & McKinney, 2019). Perceived support measures the extent to which one believes their network would be supportive in nature, whereas received support measures the type of support that took place to help combat the stressor (Helgeson, 2003). In short, perceived support encompasses the future potential of social support systems, and received support is about the past actuality of these systems (Siegel & Schrimshaw, 2002).

Both primary and secondary sources attest to social support's effects (Thoits, 2011). Primary sources consist of family or significant others who, for the most part, have not had experience with a chronic stressor. Secondary sources are "similar others or peers" (p. 52) who live with or have a personal understanding of chronic illness. Secondary support systems thrive on similarities exhibited between themselves and the distressed person. They come to know that these ties exist between and within their social networks. Primary and secondary sources can demonstrate social support by exhibiting others' self-worth, conveying to individuals that their life matters to others, and indicating acceptance and belonging within a network of others who care. Research shows these sources are critical to physiological and psychological well-being (Cobb, 1976; Helgeson, 2003; Thoits, 2011, 2020; Szkody & McKinney, 2019). The more extensive social networks are within primary and secondary support systems, the more probable it is for the distressed person to display increased overall well-being.

Stressors associated with chronic illness can diminish social support or enhance it. Lack of social support can depend on barriers associated with the stressor such as negative primary or secondary support relationships and stigma connected to the stressor. The provision of social support can help to further educate the individual on ways to overcome the stressor. Thoits (2011, 2020) conveys that the most beneficial form of social support exists when the primary and secondary support systems partner together for the good of those who have experienced the stressor.

Two prominent models indicate a reduction in stressors related to chronic illness employing social support: The Stress Buffering Model and Direct Effect Model. The

Stress Buffering Model, developed from significant health behavior outcome studies, proposes the more social support individuals have during times of high stress, the more they can buffer or eliminate the adverse effects of that stressor (DeGarmo et al., 2008, Ditzen & Heinrichs, 2014; Schwarzer & Knoll, 2007; Szkody et al., 2021; Thoits, 2011, 2020). Stress buffering, displayed by consistent emotional, physical, and spiritual support, is highly effective when utilized by family members, friends, and other support ties (Ditzen & Heinrichs, 2014; Thoits, 2011, 2020). Research shows social support buffers the effects of stressors of chronic health significantly. Unfortunately, however, studies reveal that this buffering may not occur with more marginalized groups who live in areas with high poverty levels (Moskowitz et al., 2013). Like received support, stress buffering provides an avenue in which social support takes on a more visible and deliberate role.

The Direct Effects Model (DEM) goes further than the Stress Buffering Model (SBM), revealing that patients perceive social support as valuable, regardless of the stress one is experiencing. This model proposes that even when stress levels are low, individuals enjoy being part of a social support network. Like the SBM, the DEM shows that when stress levels are high, social support systems enhance one's health. In addition, much like perceived support, the DEM claims the more social support perceived to be in place, the better the perception of quality of life (Cohen, 2004; Helgeson, 2003). These two models are not competing; in fact, they work well together to establish the integral influence social support has in relation to patients' stress management.

House & Kahn (1985) divide social support into three main categories: emotional, informational, and instrumental assistance. Emotional support can be characterized by displays of love, encouragement, empathy, and sympathy. Validation of feelings and acceptance of those struggling with chronic illness are key components of healthy social support systems. The literature argues that a healthy social support approach emphasizes hope and positive coping strategies relating to chronic illness. Emotional assistance can help maintain emotional balance and cope with negative feelings associated with one's condition (Antonucci & Bayer, 2017; Killian & Turner, 2014).

Informational support is the distribution of facts or statistics about the stressor. One example of informational support is the resource databank available to those who experience chronic illness (Arora et al., 2007). Stressors related to chronic illness include difficulty with daily activity, potential unemployment due to physical and psychological limitations, financial issues, major depression, decreased quality of life, and difficulty in finding others who relate to their illness (Lindholm et al., 2001; Piazza et al., 2013; Porter, 2009; Schnittker, 2005). Informational assistance includes support services and problem-solving techniques exhibited by healthcare professionals or community leaders who can deliver expert knowledge to the patient. Informational support is a helpful tool for treatment plans and medication compliance (Cagle, 2004).

Finally, instrumental support is defined as tangible assistance which aids an individual to help live with the stressor in healthy, beneficial ways. Instrumental support is comprised of concrete, palpable services seeking to diminish additional burdens that can potentially impact overall health. Examples of instrumental support are helping with a task such as grocery shopping, accompanying the individual to a doctor’s appointment, or paying one’s bills for a month. Instrumental support sends a symbolic message that declares one is cared for, belongs, and is accepted.

While social support networks can be sources of encouragement, they also can be sources of pain (Arestedt et al., 2014; Boyer & Poindexter, 2005). For instance, Bonsaken et al. (2012) report that sometimes a typically consistent source of social support, such as a family member or spouse, can withdraw and become unresponsive after the onset of a loved one’s chronic illness. This type of response can occur when the network member perceives the ill individual as blameworthy and responsible for the stressor. Rosland et al. (2012) reveal that some social networks adhere to beliefs about healthy lifestyles or behaviors that can be exerted through social influence. When a network member strictly adheres to such beliefs the patient can be caused great pain, leading to negative health consequences. Examples of these beliefs include blame, shame, and judgment for one’s illness. Moreover, social networks can exhibit social control, trying to restrict or control behavior to correct people who are unwilling, unable, or unsuccessful in making healthy changes that potentially lead to the onset of chronic illness. Consequently, social networks can also consist of people who engage in drug use or risky sexual behavior which also contributes to negative health outcomes.

In addition, well-intentioned support systems can be construed as offensive or off-putting to those experiencing negative stressors. Some individuals living with chronic pain may not have positive relationships with their allotted support systems (Cohen et al., 2021; Detweiler-Bedell et al., 2008; Friedman et al., 2009), so they find it difficult to seek assistance from critical social support systems, like close friends or family. While the family unit is an important aspect of social support, the literature reveals that family criticism, non-cohesion of the family unit, and family over-involvement all predict negative health outcomes related to chronic illness (Rosland et al., 2012).

A significant amount of research, however, has examined the correlation between chronic illness and social support as it relates positively to quality of life (Applebaum et al., 2014; Matthias et al., 2014; Panayiotou & Karekla, 2012; Wang et al., 2014; Wicke et al., 2014; Williams et al., 2015). The literature points to healthcare professionals, family, friends, and community support systems as predictors in determining improved well-being. These support systems also show an increase in positive self-management relating to chronic illness (Bonsaksen et al., 2012; Chang et al., 2014; Christensen et al., 1992; DiIorio et al., 1996; Erdtmann, 2015; Gallant, 2003; Glasgow et al., 2005; Hurt et al., 2013; Lindsay et al., 2014; Newman et al., 2004). Gallant (2003) states, “Being in a supportive social network may have beneficial effects on motivation, coping and psychological well-being, and individuals who are more motivated, have greater morale, or who are less depressed, may be better self-managers” (p. 172). Extant research indicates social support for those who experience chronic illness can improve their quality of life. Several studies show that social support systems for people living with chronic illness were paramount in the following areas: dealing with mental health issues, maintaining quality of life, gaining access to health care, maintaining their health, developing self-efficacy, finding hope and coping with their disease, growing personally, increasing peer relationships and social functioning, and accepting their illness (Froland et al., 2000; Müller et al., 2012; Roehrle & Strouse, 2008).

Singer et al. (2014) examined the effects of a psycho-oncological screening and treatment model that assessed mental health in cancer patients. This psycho-social care model was utilized as a form of intervention to measure emotional well-being in one thousand cancer patients. The results reveal that patients experienced high levels of psychological and emotional distress related to their chronic illnesses. The study notes the role of the health care professional as a critical social support system, which functioned as a conduit to various types of psycho-social treatment. The study also determines that chronically ill cancer patients, who struggled with depression and did not seek mental health treatment, often did not adhere well to cancer treatment. Singer et al. study is relevant to this research in that it highlights the reality of the psychological, physical, and emotional toll experienced by chronic health conditions. These stressors can significantly impact medication adherence and ultimately quality of life.

Friends and family support are also seen as positive contributors to quality of life. Some studies found that those who struggled with chronic illness looked to family, friends, and peers as beneficial forms of social support (Hlebec et al., 2009; Gilliss et al., 2019; Rayland & Andrews, 2023). The most encouraging and effective roles of social support occurred directly after an acute negative event was disclosed, such as a devastating medical diagnosis. Support systems like family and friends were best utilized as an immediate response to the revelation of the illness and to help cushion the stressors that accompanied it (Arestedt et al., 2012; Houman & Stapley, 2013; Dinenberg et al., 2014; Theeke & Mallow, 2013).

Not only do individuals who struggle with chronic or terminal pain benefit from social support, their families equally benefit. Some studies show that 75% of family caregivers of chronically ill patients have an unmet psycho-social support need (Corrigan et al., 2013; Ducharme et al., 2014). Caring for family members with a chronic illness is stressful and requires knowledge of a multitude of resources. These caregivers stated that a reduction of stress, more free time, and more time spent with family and friends were necessary for their well-being and quality of life (Ducharme et al., 2014).

In addition to social support from health care providers, family, and friends; social support from community also shows improvement in people's mental health and self-esteem. Community support often creates an environment for those living with chronic illness to feel included and accepted by their community (Corrigan et al., 2013). Community social support includes individual or group exchange with others who experience similar difficulties, illness, or problems (Yuan-Huang et al., 2014). Sometimes referred to as network support (Harel et al., 2012), community support provides empathy, a sense of belonging, encouragement, and companionship for those living with chronic illness. Such support also acts as a platform for the exchange of ideas, advice, information, activities, and prayer (Yuan-Huang et al., 2014).

Research shows "when people do not feel as if they are part of their social environment, they feel separate and in no manner integral to the fabric of the community" (Stumbo et al., 2015, p. 37). Living with a chronic illness can be isolating and lonely

(Corrigan et al., 2013; Theeke & Mallow, 2013). These researchers suggest that when persons living with chronic illness utilize community support their self-esteem, self-efficacy, self-management, and overall quality of life improves. Additionally, community support can be effective in terms of self-care. Such support helps to normalize chronic illnesses by offering emotional and practical support (Blickem et al., 2013; Dadich et al., 2013; Dieleman, 2014; Gilmour, 2015; Killian, 2014; Shum et al., 2014; Tiernan et al., 2013). Studies reveal that community resources, such as community learning; connectivity; linkage between community resources, patients, and healthcare communities; and social support enhance health research, prevention, and treatment efforts for those experiencing chronic health issues (Bayliss et al., 2014; Chillag et al., 2002; Findlay & Sunderland, 2014).

One important example of effective community social support is the Chronic Care Model (CCM). CCM empowers chronically ill patients to utilize community social support systems. The model was developed by Wagner in 1998 and shows an important correlation between the community and the healthcare system (Findlay & Sunderland, 2014). It is proactive and patient-centered using an integrated community approach to healthcare (Spoorenberg et al., 2015). An essential aspect of CCM is its emphasis on the need for community linkages to facilitate better care for chronic illness. Findlay & Sunderland (2014) suggest that CCM is important because when personal and/or community resources are used it encourages freedom of choice and a reduction in relying on more formal healthcare resources. Critical community social support requires health and non-health communities to collaborate and work together in finding suitable prevention and treatment options for people living with chronic illnesses (Erdtmann, 2015).

Healthcare professionals, family, friends, and the community are necessary support systems for individuals living with chronic illnesses. Evidence suggests that these systems enhance quality of life and well-being (Arestedt et al., 2012; Dinenberg et al., 2014; Houman & Stapley, 2013; Theeke & Mallow, 2013).

Social Support and HIV

PLWHA are living longer given medication advancements such as HAART, ART, and cART. As a result, new challenges related to psycho-social coping have arisen (Bogart et al., 2012). Illness-related depression and anxiety, access to social support, stigma, and illness acceptance are among the highest psycho-social variables to influence HIV health-related quality of life (Andrinopoulos et al., 2011; Bogart et al., 2012; Hand et al., 2006).

As with chronic illness, professionals, family, friends, and community support systems are critical in the psychological and physiological health and well-being of PLWHA. These supports positively relate to beneficial coping strategies, medication adherence, and a decrease in psychological distress associated with an HIV diagnosis. (Edwards et al., 2012; Hand et al., 2006). The literature suggests that high levels of social support reduce depressive symptoms, anxiety, and stigma related to HIV (Armoon et al., 2022; Bogart et al, 2012; Letteney et al., 2012; Meno et al., 2006; Solorzano & Glassgold, 2010; Stutterheim et al., 2011; Wood, 2007), whereas low levels increase risk behaviors associated with HIV (Airhihenbuwa et al., 2009; Allen et al., 2009; Armoon et al., 2022).

PLWHA who experience positive forms of social support from family, friends, peers, and community have reportedly higher levels of self-satisfaction and well-being (Andrinopoulos et al., 2011; Armoon et al., 2022). Such supports provide important coping mechanisms that augment self-esteem, reduce HIV risk factors, increase safer sex practices, and help to break down barriers of stigma and discrimination (Auerbach & Beckerman, 2010; Chutuape et al., 2010; Fair et al., 2014; Liu et al., 2013; Stokes, 2014).

Liu (2013) emphasizes psycho-social well-being as a multi-faceted, complex, and stigmatizing issue for PLWHA. Cree et al. (2010) conclude that HIV/AIDS is a highly stigmatized disease, so much so that it falls into a different category from any other chronic illness. Stigma can appear in many different facets: community stigma toward the PLWHA and/or their families; stigma received via the family to the loved one diagnosed with HIV; self-stigma; and stigma perceived by PLWHA from the community at large (Liu, et al, 2013, p. 40). In addition, there is a high correlation between HIV stigma and HIV status disclosure. Studies show that status disclosure not only leaves PLWHA feeling stigmatized, but also impacts HIV discrimination, psycho-social well-being, stress, and social support systems (Stutterheim et al., 2011). PLWHA experience negative and positive social support, mostly concerning HIV status disclosure. Some family, friends, and community members display positive social support that helps PLWHA deal with their illness. In contrast, PLWHA who experience discrimination or negative social support upon initial disclosure, refrain from any further disclosure.

According to some researchers, if PLWHA fear that disclosure will be detrimental to their quality of life (i.e., social support systems will diminish and social relationships will be strained), they may deem it more beneficial to keep their status a secret. Those keeping their status secret admitted to experiencing social isolation, enhanced stress, and limited access to social support systems (Stutterheim et al., 2011). There seems to be a risk associated with disclosure one way or the other. Full disclosure could lead to enhanced stigma. Limited or no disclosure could lead to the development of psychological issues. Either way, impacts on quality of life and well-being are significant. Other studies have shown, however, that with adequate and effective social support, disclosure can have positive outcomes **(**Letteney et al., 2012).

Like chronic illness, the two types of social support most identified in the literature for decreasing stigma and discrimination for PLWHA are perceived support and received support (Bigger et al., 1999; Hand et al., 2006; Liu et al., 2013; Reilly & Woo, 2004). The importance of received support utilizing family, friends, or community is widely discussed in the literature. A great deal of the literature suggests that community-based interventions are critical (Kumakech et al., 2009; Lee et al., 2007; Meno et al., 2006; Müller et al., 2012; Munoz et al., 2010). A meta-synthesis of HIV intervention literature has suggested that community-based psychological interventions promote a sense of togetherness that includes holistic care and support efforts proven to increase acceptance, belonging, self-esteem, and overall well-being (Knowlton et al., 2004). Community interventions are proven to decrease stigma, loneliness, depression, and anxiety for PLWHA (Emlet, 2006; Operario et al., 2010; Ramirez-Johnson et al., 2013;

Sacks et al., 2011; Weiss et al., 2011). Most community-based psychological interventions focus on HIV-related coping skills, prevention, treatment, community and cultural involvement, risk reduction and HIV counseling, and peer support groups (Ellis, 2012; Marino et al., 2007).

In addition, there is a body of literature that suggests social support in faith-based communities and/or organizations allows for social connectedness and engagement, both of which have the potential to positively affect health outcomes for PLWHA (Ellis, 2012; Lorenz et al., 2005; Ownes, 2012; Reilly & Woo, 2004).

Religious Congregations as Competent HIV/AIDS Communities

Research suggests that competent HIV/AIDS communities are a significant social support resource (Reed & Miller, 2013). Six psycho-social resources characterize these communities:

- people with knowledge and skills related to HIV
- dialogue among relevant sectors of the community
- local ownership of issues pertaining to HIV
- confidence in local strengths
- social capital
- community partnerships. (Reed & Miller, 2013, p. 256)

Social support systems with these six resources are not only well-positioned to improve health and social outcomes for PLWHA but can also help to decrease HIV-related illnesses (Chutuape et al., 2010).

Religious congregations have the potential to be competent HIV/AIDS communities. This potential is recognized in the 2010 United States of America's Affordable Care Act (ACA). According to this Act, congregations are key players in addressing the HIV epidemic. It specifically addresses disparities in HIV treatment by providing better avenues for accessing treatment and providing health education through faith-based organizations and churches (Owens, 2012). The ACA expanded the quality of treatment for those diagnosed with HIV and created community-based healthcare treatment teams to holistically deal with issues about HIV. The potential of religious affiliation as a significant social support for PLWHA is borne out of research. For example, Lorenz et al. (2005) used data from the HIV Cost and Services Utilization Study (HCSUS), which represented a national sample of HIV-infected adults who had made at least one visit to a medical provider other than for emergency-related issues. From these data, of the nearly 3,000 participants, 80% of HIV-infected patients identified with an affiliation to a religious group. Seventy percent of those who identified as "religious" confirmed that religion was "very" or "somewhat" important to them. Close to 50% of those who identified as "religious" identified with Mainline Protestantism and 23% with Catholic Christian denominations (p. 776). Lorenz et al. (2005) state, "This study reports that religiosity and spirituality are more important to patients with HIV than the general population" (p. 778). The results of this study further revealed that women, non-whites, and older HIV patients were determined as most religious or spiritual.

The research of Suzuki-Crumly et al. (2010) also concluded the significance of religious involvement for PLWHA. They suggest religion is important for both

LGBTQIA+ groups as well as heterosexual groups. In addition, Reilly and Woo (2004) note that religion is seen as a supportive coping mechanism, predominately in Latino and Black or African American cultures.

There is also a body of research to suggest that for individuals who identify with the LGBTQIA+ community, religious, and/or spiritual support are not necessarily viewed as helpful. For example, according to Reilly & Woo (2004), "Identifying and linking religious or spiritual networks that are supportive of HIV positive individuals and do not conflict with the values and norms of specific HIV people groups is an important intervention that religious or spiritual organizations should make available" (p. 102). Suzuki-Crumly et al. (2010) are quick to emphasize that those who identified as LGBTQIA+ and benefited from religious activity also found it important to find faith communities open to diversity and tolerant of issues related to HIV.

With close to 350,000 religious congregations across the United States of America, the potential for the development of HIV-competent communities is great (Paiva et al., 2010; Rajabiun et al., 2021; Rosenthal et al., 2023; Werber et al., 2012). These congregations have the potential to collaborate with such initiatives as the Treatment Advocacy (TA) program and social support groups. TA acts as a conduit to community support systems for those who might not feel comfortable receiving information about HIV in a traditional medical setting. TA helps PLWHA set up individualized treatment plans and create short and long-term goals. Bogart et al. (2012) found that communities accessing TA had higher HIV medication adherence rates as well as enhanced self-efficacy and self-esteem development. TA could help pinpoint unmet social support needs for those living with HIV.

Studies revealed that PLWHA, who were part of a social support group, did not feel judged or stigmatized but rather accepted and understood (Armoon et al., 2022; Auerbach & Beckerman, 2010; Simoni et al., 2007). HIV-specific support groups can help PLWHA adhere to medication, gain knowledge of HIV-related information, and reduce sexual risk behavior (Kelly, 2009; Marino et al., 2007; Martin, 1993). They contribute to lowering psychological distress associated with HIV, enhance one's self-esteem, and are successful in the engagement and retention of PLWHA in care (Pomeroy et al., 2000; Vance et al., 2009; Wood, 2008).

Congregations provide a multitude of services and ministries to the community (Cnaan, 2001, 2006, 2013). Cnaan (2006) researched nearly 2,000 urban congregations and found that approximately "93% of congregations engage in at least one form of social service delivery" (p. 101). In addition, Williams (2010) states that congregations are well-positioned to provide "access to social networks and social support; encourage the development of coping strategies; and improve emotional health" (p. 73). Religious congregations can be collaborative partners in creating community resources to address unmet health, socialization, and service needs in their communities (Castro et al., 1996; Quinn & Thomas, 1994; Rajabiun et al., 2021; Rosenthal et al., 2023; Todd & Allen, 2011). PLWHA can experience social engagement, interaction, acceptance, or belonging in such congregations and communities (Francis et al., 2009; Francis & Liverpool, 2009).

The following are benefits of congregations providing HIV support to their congregants: collaboration with other local congregations, congregational attitudes of acceptance regarding gender identity, social connectedness, engagement for PLWHA, and HIV health education and advocacy (Aholou et al., 2016). These congregations provide tangible, emotional, informational, esteem, and appraisal support to PLWHA (Adedoyin, 2013; Bauer, 2013; Brennan et al., 2010; Derose et al, 2010, 2011; Frenk & Chaves, 2012; Frenk & Trinitapoli, 2013; Leong, 2005, 2006). Williams (2011) described two essential elements of successful HIV congregational support programs: collaborating with community agencies and tailoring HIV programs to meet the cultural, environmental, social, and psychological needs of congregation and community. Williams (2011) stated that providing HIV support in congregational settings contributes to decreased risky HIV behavior, increased compassion for PLWHA, implemented HIV testing, and increased knowledge of HIV/AIDS prevention, transmission, and support for PLWHA within their respective communities (p. 528).

Externally focused congregations are intricately aware of their communities' needs and provide a plethora of social support programs (Cnaan, 2006; Fulton, 2011). They provide critical community-based support to PLWHA in collaboration with other congregations, community faith-based organizations' alliances, and community secular healthcare entities (Werber et al., 2012).

Some studies depict urban congregations as better equipped to provide social support to PLWHA than rural congregations. The literature implies that urban congregations that provide social support services to PLWHA, particularly those in the

Black or African American community, do so in tangible ways like provision of food, housing, transportation, and harm-reduction components (e.g., bleach kits). These congregations are also more likely to provide intangible services such as counseling, HIV Testing, HIV referral for employment and health support, HIV-affirming sermons, HIV advocacy, and health information programs (Adedoyin, 2013, Derose et al., 2010; Cunningham et al., 2011; Florez et al., 2017; Pichon et al. 2023; Szaflarski et al., 2014; Williams et al., 2011, 2015).

Despite such congregations' successful history of promoting health, well-being, and social support, challenges exist in providing support services to PLWHA in these congregations. Primary transmission of HIV/AIDS entails risky behavior. This behavior can be stigmatizing, especially within conservative congregations. Addressing HIV/AIDS in religious congregations has been significantly difficult (Ayers, 1995; Jeffries & Henny, 2019). Many faith communities avoid addressing sexuality at all and instead promote a disposition of "don't ask, don't tell," especially with those who identify as LGBTQIA+. Some congregations are unclear on how to respond to the HIV epidemic. They may preach messages that inadvertently, overtly, or consciously portray PLWHA as blame-worthy, leaving PLWHA further alienated and compelled to conceal their HIV status from the congregation (Carr & Gramling, 2004; Woodyard et al., 2000). This phenomenon coincides with Serovich's consequence theory of HIV disclosure, which states that people disclose HIV based on the perceived risks the disclosure may bring (Serovich et al., 2008). When congregations are intolerant to discussing issues pertaining to HIV/AIDS, PLWHA probably will not feel safe disclosing their status, further perpetuating alienation and stigma (Aholou et al., 2016). Some PLWHA may even change their place of religious worship or avoid attending any congregation at all after being subjected to judgment or silence on the topic of HIV/AIDS (Green & Ruark, 2008).

Tesoriero (2000) stressed that while religious congregations have the potential to function as an empowering conduit for PLWHA, they can also be a barrier to HIV services. He cited a lack of education about HIV/AIDS and the presumed “low to moderate need” for HIV services in congregations as significant reasons why they do not provide HIV services. Tesoriero (2000) also noted religious congregations that do not discuss issues related to gender identity and sexual orientation were not likely to discuss HIV. Additional barriers to creating competent congregational communities included victim blame, stigma, shame, discrimination, absence of social support networks, and congregational financial constraints for creating HIV programming (Adedoyin, 2013; Bauer, 2013; Brennan et al., 2010; Derose et al, 2010, 2011; Frenk & Chaves, 2012; Frenk & Trinitapoli, 2013; Leong, 2005, 2006). Data from the 2006-2007 National Congregations Study highlighted the importance of having increased HIV-competent congregations. This study indicated that 58% of congregations were involved in health-related programming, yet only 6% have programs specifically serving PLWHA (Mendel et al., 2014). These statistics indicate a large disparity in the provision of social support to PLWHA in religious congregations.

Evangelical Congregations as HIV-Competent Communities

Historically, significant theological and doctrinal differences within congregational settings can potentially deter or ignite the provision of HIV-competent communities. Balkin et al. (2014) provided a discussion on the intersection of faith, sexual orientation, and gender identity from varying faith perspectives, including Evangelical. These authors draw attention to Christians who embrace highly conservative theological perspectives on particular scriptures. Specifically, fundamentally conservative Christians view same-sex marriage and same-sex activity as inconsistent with literal scriptural teachings regarding human sexuality found in the following books of the Bible: Genesis, Leviticus, Romans, 1 Timothy, and 1 Corinthians (Dessel & Bolen, 2014). However, they also alluded to faith perspectives which are more affirming and supportive of sexual orientation and gender identity. Less theologically conservative Christians affirm same-sex orientation, relationships, and clergy (Balkin,et al., 2014, p. 189). Regardless, research indicates that both conservative and non-conservative evangelical congregations are lacking in the provision of social services to PLWHA (Fulton, 2011, p. 623).

Dessel and Bolen (2014) allude to the difficulty in defining “evangelical” in the 21st century. Varying religious views, values, and denominations fall along the spectrum of Christianity and they do not technically adhere to one governing body. Some evangelical congregations exhibit barriers to support PLWHA, while others have seen the urgency to raise awareness about HIV and AIDS. For example, according to the research BIPOC have been disproportionally affected by HIV/AIDS. In 2020, Latinos accounted for 27% of new HIV cases. In addition, 42% of estimated new diagnoses in the United States of America were among Black or African American people (CDC, 2021). Given these high rates of HIV some Black or African American and Latino lay leaders saw the urgency for HIV education and prevention. One Black or African American evangelical pastor states:

> As persons of faith, we must be concerned with the sexual health of all our members, making sure they know how HIV is and is not transmitted. Unlike other genetic and communicable diseases, one does not easily get infected. HIV is a preventable disease, and it is a sin to deny life-saving information to persons on how they might avoid infection (as cited in Messer, 2011, p. 390).

Of concern for Black or African American populations, in addition to being the highest risk group for new HIV infections, other racial disparities affect their health. These disparities include socioeconomic status, access to healthcare, and stigma related to HIV (Bazant & Booulay, 2007; Derose et. al, 2010; Frenk & Chaves, 2012; Frenk & Trinitapoli, 2013). Since 2000, the CDC has partnered with faith-based entities, the Black or African American Church (most often referred to as The Black Church in the U.S.A.) specifically, to combat HIV (CDC, 2021). Levin (1984) states, “Black ministers have not only functioned as teachers, preachers, and politicians but also as promoters of health and wellness” (as cited in Eke et al., 2010 p. 57). A recent study conducted qualitative interviews with ten Black or African American pastors in the rural south regarding the types of HIV prevention services being offered in their respective congregations. The results of this study show that HIV stigma was prevalent among the congregation and community members toward PLWHA. This same study revealed that the Black Church can “foster holistic ministry, maximize, reach and influence communities and provide education and prevention of HIV” (Aholou et al., 2016, p. 5; Douglas & Hopson, 2001).

By examining ways the Black Church has approached the HIV epidemic, one can discuss both the effectiveness and the futility of HIV prevention and social support in evangelical congregations (Beadle-Holder, 2011; Berkley-Patton et al., 2010; Wooster et al., 2011).

The Black Church and HIV/AIDS

The Black Church in the United States of America combats oppression and remains at the forefront of social issues. Often, the Black Church contests the various “isms” in American society: racism, sexism, and classism. Tackling these injustices has helped Black Church members to thrive against the odds that society has stacked against their culture. The Black Church promotes a strong sense of community, family ties, and celebrating their cultural and ethnic heritage. Perceived as a place for individuals to talk about life issues impacting their community, black congregations feel free to address issues like poverty, gender, race, mental health, and substance abuse.

Despite the Black Church being at the forefront of social change within American society, some black congregations have at times been very hesitant to tackle issues of sexuality, risky behavior, and sexual orientation. Eke et al. (2010) maintain that the Black Church faces contradictions: on the one hand, it is a leader in eradicating oppression within the Black community; on the other hand, the church does not often discuss oppressive issues like HIV/AIDS.

A 2012 study conducted in New York City surveyed religious congregations to document the extent to which they offered HIV social support services. The results showed a vast majority of Black or African American congregations reported only a *moderate* need for HIV prevention, a shocking revelation considering the large percentage of HIV cases within this population group (Chaney & Patrick, 2011; Tesoriero et al., 2000).

McNeal and Perkins (2007) questioned Black or African American evangelical lay leaders in Jackson, Mississippi about the need for HIV programs within their community. Their study revealed both the urgency for and the benefit of HIV faith-based prevention programs and HIV health care for the community. None of the congregations surveyed offered any type of HIV prevention or healthcare programming, although several offered HIV activities for their members. The study also indicated that congregational community involvement was minimal and the level of trust between the community the congregation served and the congregation itself was significantly low.

Adedoyin (2013) identified several systemic issues when providing support to church-going Black or African American people living with HIV. These include homophobia, economic inequality, discrimination in healthcare settings, and distrust of the healthcare system. These congregations are more apt to provide prevention interventions for Black or African American people living with HIV rather than direct support. Also, of significance, according to Adedoyin (2013), is the lack of HIV knowledge on the part of congregations concerning risky behaviors associated with HIV and the absence of any denominational commitment to HIV policies.

The Black Church can act as a catalyst in prevention efforts for those at risk for HIV and can provide an environment to exemplify the love and support of those affected. However, there are some black evangelical congregations, clergy, and communities still at odds with how to transform faith values into action (Aholou et al., 2016; Coleman et al., 2012; Fisher et al., 2014; Giger et al., 2008; Harris, 2010; Hatcher et al., 2008).

Despite being viewed as slow to respond to the HIV crisis, the Black Church has progressed further than other religious congregations. This is due in part to their commitment to social service supports being mostly independent of a liberal or conservative theological orientation. According to Fulton (2011), the "relationship between liberal-conservative ideology and its social service activity might only be salient for white churches" (p. 627). By mobilizing efforts for discussions on HIV, the Black Church has set precedence for how religious congregations can obtain knowledge and insight into the epidemic. For example, in 2007, hundreds of Black clergy convened together for a National Black Clergy Conclave on HIV/AIDS Policy. Clergy from Baptist, Methodist, Protestant, African Methodist Episcopal (AME), and Pentecostal congregations attended the event to discuss the implications of HIV within their communities. This event spurred The National Black Clergy for the Elimination of HIV/AIDS Act of 2009, 2011(H.R. 1462; S. 3011) aimed to tackle HIV and AIDS in Black or African American communities, with Black clergy acting as the front runners in declaring HIV/AIDS a "public health emergency." Black clergy, in conjunction with medical providers, HIV/AIDS service organizations, and American legislators, advocated for all Black congregational leaders to provide education, prevention, and HIV testing to their congregations. Included in this legislation is the ABCD (abstain, be faithful, use condoms, and don't engage in risky behavior) model. Black congregational leaders decided to use this model to educate their communities on the risk factors associated with HIV/AIDS.

Sections of the Act include HIV/AIDS education and prevention efforts with at-risk youth as well as at-risk Black or African American communities. Also included was a media outreach campaign, research efforts to examine HIV/AIDS within the black community, and HIV/AIDS risk reduction training designed specifically for faith leaders and faith-based non-profits. The Act also called for a National Black Clergy HIV/AIDS Awareness Sunday in every state. Such an initiative paved the way for the President of The United States of America and other federal officials to ask Black Clergy around the nation to address the topic of HIV in their congregations as well as hold HIV awareness activities within their communities (National Black Clergy for the Elimination of HIV/AIDS Act, 2009).

The original bill was introduced to the House of Representatives, with 46 co-sponsors, in 2009 and again in 2011. No action has been taken since. The proposed Act seeks to authorize the Director of the Office of Minority Health and the Department of Health and Human Services to create grants for public health agencies and faith-based organizations to conduct HIV testing and prevention and outreach activities specific to the Black or African American community (National Black Clergy for the Elimination of HIV/AIDS Act, 2011). In addition, the Act sought to reduce transmission of HIV in black women, youth, and MSM groups. It also included efforts to decrease the rate of HIV transmission to Black or African American people within the federal prison system and to create comfort care centers as well as culturally relevant and sensitive treatment for PLWHA (National Black Clergy for the Elimination of HIV/AIDS Act, 2009, 2011).

Another example is The Balm in Gilead. It is a “non-profit, non-government organization (NGO) network of interfaith providers striving to support and provide congregations with information to create, implement, evaluate and *sustain* HIV/AIDS programs within the confines of the faith community”.

> “The Balm in Gilead was the U.S.A.’s first mobilization campaign to focus solely on HIV/AIDS. It has had tremendous success in helping Black congregational leaders address issues of HIV/AIDS in their faith communities and has provided HIV/AIDS information to over 5 million Black or African American people through the engagement of Black congregations throughout The United States of America”. (Balm in Gilead, 2023, March 7. Retrieved from http://balmingilead.org)

Based in Richmond, Virginia (USA) and Dar es Salaam (Tanzania), The Balm in Gilead programs and services include seminars and training in the following areas:

> [F]aith-based HIV capacity development, HIV pastoral care, HIV program design and development, organizational development (forming an HIV faith-based non-profit), evaluation (community mapping, community assessment), advocacy (faith-based advocacy and policy), cultural competence, communication, and mobilization in HIV testing and other service. (Balm in Gilead, 2023, March 7. Retrieved from http://balmingilead.org; Ellison et al., 2008)

This faith-based initiative has also established a National Week of Prayer to bring all people of faith together to pray for HIV/AIDS healing on a national and global level. The National Week of Prayer for the Healing of HIV/AIDS sponsors educational and prevention events throughout the week, emphasizing prayer for those in the Black or African American communities impacted by HIV and AIDS.

Gospel Against AIDS (GAA) is another example. It began when the HIV/AIDS epidemic started and was initially developed to train Black or African American faith leaders and their congregations on strategies to combat AIDS. Currently, GAA promotes HIV rapid testing within the congregational setting, participates in HIV prevention efforts, and builds community to produce HIV-competent communities. The curriculum created by GAA has been utilized by the University of Michigan’s School of Social Work, the Ecumenical Theological Seminary, and the NAACP of Michigan. In addition, GAA assists in the implementation of HIV-relevant social support services for congregations.

Project FAITHH (Faith-Based Anti-Stigma Intervention to Heal HIV) is yet another example of Black Church initiatives. It created an HIV prevention and educational manual designed specifically for Black or African American pastors in the rural South. Since HIV rates continue to increase in the South, especially in Alabama, Black Churches must obtain critical training to help combat the epidemic in their communities (Alohou et al., 2016; Hill & McNeely, 2013; Jeffries et al., 2017; Lewis, 2015; Lumpkins et al., 2013; Payne-Foster, 2018). Project FAITHH was funded by the

CDC in the USA to initiate this training (Lindley et al., 2010). To date, the project has served ten Black Churches in the deep South.

Conclusion- Gaps in the Literature

The onset of a chronic illness like HIV can bring about a variety of psycho-social pain and stigma. Received and perceived social support systems are critical to a positive quality of life and overall health and well-being for PLWHA. Primary and secondary sources of social support help PLWHA cope with pertinent stressors associated with their illness. Research and the literature show a decrease in physical and psychological distress when community social support systems are present.

An important means of social support for PLWHA lies within HIV-competent communities. Faith-based congregations have the potential to be HIV-competent communities. This potential is recognized by The United States of America's Affordable Care Act, the National Institutes of Health, and the Centers for Disease and Control Prevention. All have determined the necessity for faith-based congregations to become involved in providing social support and other services such as education and prevention initiatives for PLWHA. (Aholou et al., 2016).

Historically, faith-based congregations have either provided social support that helps the quality of life for PLWHA or they have created barriers. They are positioned to either empower or oppress PLWHA. Some congregations in the U.S.A. such as The Black Church have taken initiatives that are aligned with empowerment. This is critical given that HIV disproportionality affects this population. Other faith-based congregations can learn from the Black Church’s initiatives. These initiatives align with an Anti-oppressive framework.

CHAPTER 3

THEORETICAL FRAMEWORK

The following section contains an in-depth review of the literature on Anti-Oppressive Practice (AOP) and its significance as a theoretical framework for this research. The history of HIV and Evangelicalism is highlighted as it relates to empowerment and oppression.

Anti- Oppressive Practice (AOP)

AOP is a social justice-oriented approach to social work with its historical roots grounded in “feminist,” “anti-racist,” “anti-colonial,” “Marxist” “poststructuralist,” “postmodernist,” “Indigenous,” and “critical constructionist” theories (Baines, 2011, p. 4; Millar, 2008).

To characterize AOP, it is important to consider how oppression has historically been demarcated and what is meant by “anti-oppression.” Oppression has been described in various ways as it relates to oppression theories. According to Mullaly (2010), it is most broadly described as the internal or external use of power to marginalize, by either exploiting or excluding difference. Freire (1970) suggests oppression is displayed when those in positions of power benefit from the exertion of their power over others. Baines (2011) on the other hand defines oppression as “any act or policy enacted unjustly against an individual or group because of their affiliation to a specific group” (p. 2). She goes on to describe forms of oppression that are blatant, such as denying individuals basic human rights, as well as those that are covert, like the imposition of one’s belief system, values, and laws on others, thus limiting access to social resources. Oppression can be both purposeful and intentional in a well-intentioned society. (Foucault, 1977; Mullaly, 2010) It can include exploitation, marginalization, powerlessness, cultural imperialism, and violence (Mullaly, 2010).

Oppression is ultimately about power and control involving an oppressor (dominant) and one who is being oppressed (subordinate) (Marsigha & Kulis, 2009, p. 33). Canda (2008) designated oppression as the power to control collective actions, which in turn emulate issues of injustice, self-identity, and efficacy experienced by marginalized groups. Oppression is multi-dimensional, sometimes capturing a fluidity between the oppressor and the oppressed, demonstrating that one can be both/and within various subgroups who experience systematic subjugation.

Dominelli (2002) notes that oppression is not just limited to individualism but can also encompass structural domains. According to her, “Oppression is socially constructed through people’s actions and behaviors toward others” (p. 9). Mullaly (2010) adds, “The basis of oppression is difference--not the fact or reality of difference--but how we respond or do not respond to it” (p. 34). He emphasizes that difference must be viewed through the lens of oppression to see and unmask power structures that divide.

To truly grasp elements of AOP, one must understand the dynamics of individual, cultural, and structural oppression. Individual oppression consists of thoughts, behaviors, and actions by dominant group members that “depict negative prejudgments of subordinate groups” (Mullaly, 2010, p. 68). Oppression at the personal level impacts one’s identity negatively when subordinate group members internalize oppressive actions by the dominant group. For example, subordinate group members may display feelings of inferiority and insecurity when the privilege of one group is valued over the other, leading to an "us" vs. "them" mentality. They can also act in ways that reinforce these prejudgments to cope with the painful experiences that accompany oppressive acts. Subordinate groups can also respond to acts of individual oppression by way of resistance, promoting change by challenging negative stereotypes and focusing on positive self-identity (Mullaly, 2010).

Cultural oppression maintains negative stereotypes of subordinate groups. Culture, in this sense, evolves and expands over time, plays a part in every group in society, and includes in its broadest sense the following: "ideologies, religious faith, and texts and representations of social communication that we (as a society) produce" (Mullaly, 2010, p. 97). It occurs when negative cultural structures and stereotypes become the norm in everyday society for those who are a part of the dominant group. Mullaly (2010) emphasizes the importance of using non-oppressive language and discourse to break down negative cultural stereotypes within personal and political relationships.

Structural oppression contains these stereotypes on a much broader level through social, economic, and political systems. Structural systems work together to benefit dominant groups in society, according to Mullaly (2010).

> [S]ocial institutions, laws, policies, and practices disproportionately allocate goods and services with positive social value (e.g., good health care, decent housing, high social status) to dominant group members and disproportionately

> allocate goods and services with negative social value (e.g., inadequate housing, low social status, incarceration) to members of subordinate groups. (p.150)

He provides an informative example of the social determinants of health as they relate to structural oppression by stating there are various factors outside the healthcare system that negatively or positively affect one's health. Included in those determinants is the importance of social support networks.

To combat oppression, one must be honest about privilege and power on individual, cultural, and structural levels. In doing so, it is important to listen to subordinate groups' experiences and strive to change the status quo.

While oppression occurs at one end of the continuum, at the other end is empowerment. The modern use of the term empowerment in the United States of America emanated from the field of community psychology in the late 1970s and early 1980s during the heightened practice of political activism of the Civil Rights and Women's Movements (Rappaport, 2010, 2011). Empowerment entails elements of community activism, equality, and the ability to influence social and political systems (Bolton & Bookings, 1996). It has become a rich part of social work theory and practice, seeking to challenge and combat injustice and oppression (Bolton & Brookings, 1996; Malloy, 2014; Ward & Mullender, 1991).

The ontological definition of empowerment is "the *granting* [italics added] of political, social, or economic power to an individual or group" and "the process of supporting another person or persons to discover and claim their personal power" (Tucker, 1976). Psychoanalytically, Karpetis (2015) defines empowerment as "a reduction in self-reproach; a development of self-confidence" (p. 432). Turner and Maschi (2015) allude to empowerment as both a theory and a personal process. Empowerment is deemed as a framework that seeks to increase individual, cultural, and structural power within oppressed populations, for individual and collective awareness, action, and transformation (p. 152). They credit Friere and Gutierrez's concept of personal and political empowerment for helping pave the way for effective AOP.

Empowerment is the "process by which those who have been denied the ability to make choices (disempowered) acquire such ability" (Beattie et al., 2014, p. 1516). Beattie et.al (2014) emphasize the important interplay between "gaining internal skills and overcoming external barriers, often drawing upon the conceptual frameworks of 'power within' (self-confidence), 'power to' (individual decision making that effects positive change), and 'power with' (corporate decision making that effects positive change)" (p. 1516).

AOP examines how power can oppress and marginalize yet also liberate and empower. It strives to help society understand its ability to empower and oppress by seeking to confront displays of systematic and individual oppression. Core themes of AOP focus on oppression, access to power and resources, social structures, and the impact on individuals and society. It gives voice to those who are found in oppressed and marginalized situations. Baines (2011) labels AOP as a "heterodox approach, involving and incorporating the strengths of a variety of critical approaches . . . providing ongoing development and refinement of theory and practice" (pp. 7-8).

AOP vacillates between old and new theoretical paradigms in becoming its own approach to social work practice. Theoretical underpinnings challenge systems that exhibit oppression such as sexism, heterosexism, racism, ableism, and classism (Danso, 2009). It reveals that these oppressions can be exhibited independently but will most likely intersect with each other in various forms and fashions. Although AOP encompasses a variety of approaches, these approaches are not all cohesive. For example, some modernist proponents of AOP emphasize-that human relationships, and how we morally relate to one another, can be avenues for oppression. They also claim that as much as humans can oppress, they also can cease oppression and move toward empowerment (Baines, 2011).

A post-modernist approach to AOP would seek to understand the use of knowledge and language as it relates to how humans exercise power in harmful ways. Those who adhere to this approach question whether humans can truly be non-oppressive, perhaps making a kyriarchal claim that all humans are oppressors, and all humans are oppressed; depicting the intersectional structural positions of simultaneous oppression and privilege (Baines, 2011; Caufield, 2015). AOP is not without its limitations as its framework does have some criticisms. Wilson and Beresford (2000) portray this intersectionality well. They critique AOP, claiming that oppressed groups in need of liberation are rarely asked how their liberation should take place. They go on to discuss the contradictory “client” vs. “expert” relationship in social work practice which can leave one wondering if some AOP practitioners could be oppressing the very clients they are striving to liberate.

There is a plethora of examples that elucidate the varied intersections of AOP. Danso (2009, 2015, 2018), Sakamoto (2005, 2007), and Falcone (2023), in their work with devalued skilled immigrants, believe AOP can help to dismantle racist ideology on individual, social, institutional, and political levels often accompanying immigrants during and after cultural assimilation to developed countries. Strier and Binyaman (2010), when exploring theories of poverty, found that social services utilized by vulnerable populations are potential avenues for oppression. They state these services when practiced from a neo-liberal perspective, adhere to a "concept of individual responsibility as a supreme social value and the foundation upon which the social contract [service] is based." (p. 1911). They resolve that by utilizing AOP, social service agencies and workers can change oppressive organizational and institutional culture by partnering with vulnerable populations to create more empowering, ethical, thriving, and critically conscious communities as opposed to hierarchal, oppressive ones. Researchers allude to the importance of gaining perspective from vulnerable populations' lived experiences and moving away from the "expert" model so frequently utilized by social service agencies (Ali & Lees, 2012; Langley, 2001; Pollack, 2004, Windsor et al., 2014).

Most notable to this research is the limited literature on AOP as it relates to HIV and faith. Jones, LePeau, and Robbins (2013) discuss the importance of deconstructing college students' narratives as they pertain to HIV. The article discusses students returning from a service-learning project with PLWHA in New York City, recognizing personal power and privilege constructs that led to the creation of their stereotypical narratives about HIV. They then compared these stereotypes with issues of societal power, privilege, and oppressive forces that are daily present in the realm of HIV.

Greene et al. (2010) examine the intersection of housing instability and HIV/AIDS in Canada. They found that parents living with HIV, who had unstable housing, experienced problems such as stigma and discrimination, unsafe living conditions, inaccessibility to medication, and lack of social support-leading to stress, anxiety, and depression (p. 228). The authors call for "anti-racist, anti-oppressive education and training with the community regarding the multiple layers of oppression experienced by HIV-positive parents" (p. 231).

Sharma (2008) examined issues of empowerment and oppression with women's sexuality when they were part of a Protestant faith community. Drawing on the work of Foucault, she suggests how "accountability to the church community and its gendered construction of sexuality can shape and limit behaviors and experiences" (p. 350). Her findings revealed that while women experienced a sense of empowering community within the church, these same relationships exhibit a potentially oppressive Christian femininity that can "hinder sexual exploitation and development" (p. 350).

Sharma and Arbuckle (2010) discuss the intersectionality of spirituality and social work education. They maintain that AOP plays a significant role in bridging spirituality and social work education by including "spiritually based inclusiveness into the anti-oppressive, anti-racist practice lens" (p. 455). They contend by doing so, one could move from a view of practice and spirituality at opposite ends of the spectrum to a more inclusive, accepting, collaborative view that promotes appreciation of "other."

Todd and Coholic (2007) argue that viewing spirituality in an all-inclusive light somehow disconnects it from its history of oppression. However, the authors did examine the dichotomy between Christian fundamentalist beliefs and professional social work practice, particularly as it pertained to the issue of sexual and gender diversity. While they questioned if some social workers can set aside their personal fundamentalist values and convictions to help a client self-determine, they also questioned whether more AOP pedagogical practices should be created that "expand the notion of inclusivity to include those with competing and exclusionary worldviews" (p. 9). This article brought attention to the paradox of inclusivity in AOP. Is there a limit on inclusivity if it contradicts what one may deem as acceptable or unacceptable beliefs and values (p.14)? A significant tension exists in this theory and within social work practice.

In summary, oppression and empowerment play a significant role in AOP. Proponents of AOP seek to deconstruct socio-economic, racial, and gender marginalization and draw attention to the oppressive power dynamics within the context of social work practice on micro, mezzo, and macro levels. This includes work in therapeutic, academic, research, and global settings (Bransford, 2011; Calvo et al., 2014; Campbell et al., 2008; Chand et al., 2002; Chatterjee, 2015; Clifford & Burke, 2005; Dustin & Montgomery, 2010; Rogers, 2012; Yee et al., 2013). Literature contends that a blended-intersected approach to AOP is most effective, pulling together the various perspectives of social work that enable empowering, participatory, transformative change to occur on every level (Baines, 2011; Sastry & Dutta, 2011). Reflecting on paradoxical tensions held within AOP can help do the least harm to those who experience oppression on various levels. To date, there is limited research on AOP practice specific to HIV or evangelical faith. The following sections seek to present a brief history of the HIV/AIDS epidemic, as well as Evangelicalism. These sections highlight issues of oppression and empowerment found within each of these areas.

A Brief History of HIV/AIDS --Through the Lens of Oppression and Empowerment

The literature is extensive when it comes to describing oppressive issues regarding HIV/AIDS. Stigma (Bluthenthal et al., 2012), homophobia (Lemille, 2004; Miller, 2007), limited access to health care, and the financial burden of treatment (Schuster et al., 2005; Whetten et al., 2006) are among some of the most pertinent problems for people living with HIV/AIDS (PLWHA). In the early years of the U.S.A. AIDS epidemic, discrimination was widespread. For example, mandatory state HIV/AIDS testing policies were introduced. The state of Massachusetts went so far as to introduce additional legislation authorizing anyone diagnosed with AIDS to be quarantined (Albert & Stryker, 1993).

AIDS was first discovered in 1981 after Pneumocystis carinii pneumonia and Kaposi sarcoma were diagnosed in gay men living in large urban areas. Shortly after, the U.S.A. Center for Disease Control (CDC) named the infection gay-related immune deficiency (GRID), or the “gay disease.” GRID added to the fear and stigma that was (and still is) associated with the epidemic. One year later, the virus was renamed Acquired Immunodeficiency Syndrome (AIDS) when it was discovered outside the gay community (McLaughlin, 1998). The AIDS outbreak was significant. In the U.S.A. alone, after just three years, close to 2,000 people were diagnosed and 800 individuals died before the CDC acquired adequate funding to begin research on the disease (Gronfors & Stalstrom, 1987). Although the U.S.A. government initially failed to disseminate accurate information about AIDS and its transmission, the Reagan Administration bears the most blame for the lack of attention given to the initial crisis. California Representative Henry Waxman (1987) described the Reagan Administration's response by stating,

> I am convinced that had the first victims of AIDS been members of the Chamber of Commerce, the Reagan Administration would have responded immediately and forthrightly…I think when people look back historically at the Regan Administration, they will comment on its failure to deal with the AIDS crisis, which unfortunately will have gotten out of hand and maybe affected millions of people (p. 43).

Representative Waxman's sentiments reflect the structural oppression that PLWHA were (and *still* are) facing. Although medically it was proven in the early stages of the epidemic that the AIDS virus was transmitted through sex, needle sharing, blood transfusions, and childbirth, all PLWHA were depicted as being responsible for their infection due to immoral and irresponsible choices. Among those most marginalized were the LGBTQIA+ community, sex workers, and intravenous drug users. Many fundamentally conservative circles believed AIDS only affected gay men. They believed it was a curse brought on by God to "homosexual deviants" (Harris, 2010; Gillett, 2011; McLaughlin, 1998). Political, financial, and medical neglect of the AIDS epidemic continued until it emerged in other populations such as women, children, and BIPOC.

For PLWHA, the late 80s and the 90s were not only filled with isolation, stigmatization, and exclusion but also a time for empowerment and mobilization (Simon, 1990; Staples, 1984). From an Anti-Oppressive perspective, “The [re]actions of people who have been oppressed revolve around three possible choices of action: acceptance, accommodation, and rejection” (Dominelli, 2002, p. 11). Some who experienced AIDS-related oppression began to reject and deconstruct how society viewed the disease and countered oppressive acts by critical conscious-raising in their communities to stop the spread (Baines, 2011). Paulo Freire (2002), known as the originator of critical conscious-raising, described this concept as a shared process between the oppressor and the oppressed. He emphasized critical reflection of each other’s world views and their political and social contradictions. PLWHA wanted to share their realities of living with a chronic disease with all who would listen, to take social action against the political and social forces keeping them in an oppressed state, and to further educate the medical and research communities. Those most impacted became the experts on their disease and set the stage for future education and prevention efforts to combat the virus. According to Epstein (1995):

> The AIDS movement is indeed the first social movement in the United States to accomplish the mass conversion of disease ‘victims’ into activist experts, and in that sense, the AIDS movement stands alone, even as it begins to serve as a model for others (p. 414).

With little help from the U.S.A. government, AIDS grassroots endeavors were put into place demanding the need for PLWHA to be active participants in any treatment, research, and policy discussions (Gillett, 2011). AIDS activist groups and agencies such as ACT UP, AIDS ACTION NOW, and the National Association of People with AIDS (NAPWA), initially established in San Francisco and New York, soon emerged in most major urban cities. These groups would be among the first to change a medical issue into a social and political one. They challenged medical professionals to care for their patients physically, psychologically, emotionally, and spiritually. They deemed this holistic approach as most critical for PLWHA.

As Americans navigate through the 21st century, the face of HIV/AIDS has changed quite dramatically. Advances in disease monitoring, HIV/AIDS education, confidential voluntary testing, and the introduction of antiretroviral medication to treat asymptomatic patients enable people to live much longer. The shift in demand toward outpatient care helped propel the passage of the Ryan White Comprehensive AIDS Resource Emergency (CARE) Act which created the opportunity for more comprehensive acute and long-term community-based services (Health and Human Services, 2013).

With the introduction of HAART, ART, cART, and Pre-Exposure Prophylaxis (PrEP) the United States witnessed a significant reduction in HIV-related morbidity and mortality (Fleishman et al. 1990; Hamilton et al., 2023). AIDS Service Agencies (ASO) developed a variety of service-based agencies that were attuned to the needs of PLWHA. However, not all segments of the population living with HIV benefited equally. A national cohort study taken by the HIV Cost and Services Utilization Consortium surveying 2,466 adults with HIV discovered that BIPOC, women, uninsured people, and low socioeconomic status populations were less likely than others to receive optimal health care utilization, outpatient care, and access to the latest antiretroviral drugs (Agrahari et al., 2022; Shapiro et al., 1999, Tseng, 2015). Another survey documented that out of 163 men and 78 women living with HIV/AIDS, 33% received no form of HIV antiretroviral treatment (Kalichman et al., 2002).

Over forty-one years have passed since the first recorded diagnosis of AIDS. Communities have come to recognize that people living with HIV/AIDS need a variety of medical and social services, including primary medical care, dental care, home health and hospice care, mental health services, meal delivery, emergency financial assistance, and spiritual or religious engagement.

A Brief History of Evangelicalism--A Dichotomy of Oppression and Empowerment

> Historically, Christian awakenings have been associated with progressive politics, not conservative politics. Indeed, it’s hard to think of periods of egalitarian or progressive social change in the United States that have not been preceded by a period of Evangelical fervor (Putnam, 2010).

Evangelical congregations are the most prevalent form of religious organization within the United States of America. Such congregations often act as an American all-purpose association. Putnam and Campbell (2010) likened congregational life to a civic, patriotic duty or a unifying community event, a “civic religion” (p. 80). This civic religion is woven throughout American history as its imprints are marked on American founding documents, patriotic pledges, and its currency. In addition, religious Americans are more prone to take part in political and civic life and advocate for political or social change (Putnam & Campbell, 2010). The following are examples of the intersection of evangelicalism and politics within the U.S.A.

The 1980s was a significant historical period for evangelical congregations. The nation's first openly Evangelical president, Democrat Jimmy Carter, contributed his faith to a commitment to progressive policies reflecting "peacemaking, conflict resolution, and justice" (Smith, 2011, p.67). Carter, however, came under scrutiny from conservative evangelicals for his support of equal rights, such as feminism and LGBTQIA+ rights (Freedman, 2005) As a result, he coined the terms "Religious Right" or "Christian Right," showing the growing connection between politics and conservative evangelicalism in the U.S.A.

The Religious Right movement gained momentum by helping to overturn Carter's chance of a second term in the White House. Made up of mostly white evangelical men, the Religious Right determined Carter responsible for holding predominately white conservative evangelical universities accountable to U.S.A. desegregation laws. As a result, several evangelical universities lost their tax-exempt status as a violation of section VI of the Civil Right Act. The Religious Right felt threatened by the U.S.A.'s government interference in religious freedom yet understood that defending racial segregation would not be a viable platform to grow their movement. They mobilized their voter base by helping to elect Republican candidate Ronald Reagan and shifted their focus from desegregation to anti-abortion efforts. To date, the Religious Right continues to expand, and these terms still are frequently used in conservative political environments (Freedman, 2005; Smith, 2011).

In 2001, George W. Bush instituted the United States of America Office of Faith-Based Initiatives and Community Partnership (the Barak Obama administration renamed it the Office of Faith-Based and Neighborhood Partnerships) and through Charitable Choice gave congregations who provide social services to the community the opportunity to be funded with federal dollars while also imposing certain restrictions for faith-based groups receiving Federal funds (Cnaan & Boddie, 2001; NARA, 2002).

In 2018, Donald J. Trump signed an executive order that established the Faith and Opportunity Initiative intended to empower faith-based organizations *and* protect religious freedom. The Initiative amended the previous U.S.A. President's Executive Orders to grant faith-based organizations equal access to government funding *and* the equal right to exercise deeply held conservative religious beliefs. Opponents of the executive order cited concerns over the Trump administrations growing number of federal policies aimed at discriminating against the equal rights of the LGBTQIA+ community, women in need of reproductive health, diversity, equity, and inclusion initiatives.

Sexuality and family issues became the platform for policy debate throughout the 20th and 21st centuries. Conservative religious entities boldly voiced their opinions on topics such as same-sex marriage and abortion. According to Putnam and Campbell (2010) "abortion and same-sex marriage are the glue for holding the coalition of the religious right together" (p. 387).

The United States of America is a highly religious nation, yet there is a large amount of diversity found in its religiosity (Putnam & Campbell, 2010). One of the most prevalent, yet diverse religious groups in the U.S.A. are Evangelicals. Evangelicals identify with several denominations that generally adhere to the tenets of Evangelicalism (Putnam & Campbell, 2010, p. 14). Evangelicalism has been defined in various ways throughout history. However, the essential elements include:

1. God’s word is the Bible. It is inspired by God, has no error, and is literally true.
2. Humans are both sinful and good.
3. Salvation is only found by faith in Jesus Christ alone.
4. There is high importance in having a personal relationship with Jesus.
5. Absolute moral standards exist (Smith, 1998).

Evangelicalism is rooted in first-century Christianity in the transformation of Paul the Apostle and the New Testament books he authored. In U.S.A. history the Puritans worked for the establishment of church and state relations and strived to incorporate biblical principles into every aspect of American life. The establishment of the first church can be seen in the biblical book of Acts (ESV, Collins, 2005). American Evangelicalism emerged at the beginning of the 19th century as Protestants, highly active in civic associations, secured leadership in most areas of American society. For almost a century, Protestants were engaged socially, culturally, politically, and intellectually and became leaders in some of the most prestigious academic institutions. By the end of the 19th century, however, the emanation of modernism and liberal theology threatened the Protestant landscape.

The beginning of the 20th century gave way to a significant split in the evangelical community. A group of Protestants, known as Modernists (today known as Mainline Protestants), began to adhere to a social gospel that emphasized Christian priority as one that should reform social institutions by bringing to light "social evils" created by oppression and extortion (Putnam & Campbell, 2010; Rauschenbusch, 1917). Other Protestants fought back. They created a new theological perspective called fundamentalism, which would come to be known for its legalistic and separatist attitude. Fundamentalism took its name from a twelve-volume book series named *The Fundamentals* which was written to combat liberal theology (Rossinow, 2005). Those who were a part of this branch incorporated rigid rules and disengaged with secular society, which they deemed was consuming the religious landscape in the U.S.A.

As Modernists were aligning themselves with liberal theology and Fundamentalists were consumed in ultra-conservatism, a group of neo-evangelicals led by Billy Graham, Charles Fuller, and Carl Henry emerged as sort of a middle ground between the two. Neo-evangelicals (today known as conservative evangelicals) had a mission to advance the world for the kingdom of God by becoming a part of secular society and actively engaging in political and social arenas. Smith (1998) says of evangelicals, "They are both distinct and engaging with pluralistic modernity" (p.147). Evangelicals are quite aware of who they are and who they are not. They draw boundaries between themselves and non-Christians, and at times, other Christians. This type of dualism is necessary for Evangelicals as they feel called biblically to "be in the world but not of it" (Romans 12:2, ESV); however, it can at times, seem oppressive to

Christians and non-Christians alike. Evangelicals have the power to unite people, embrace them, and provide social support, acceptance, and love; they also can appear insensitive and judgmental, undermining attempts at social influence, activism, and social action. Most evangelicals often fluctuate between fundamentalist and neo-evangelist worldviews, sometimes leaving them paralyzed to act on issues related to injustice. Finding the balance between the two positions is critical to the success of congregations in providing holistic ministry to individuals and communities most in need.

To stick closely to the basic tenets of evangelicalism, while exhibiting a clear balance between the two positions, David Bebbington's and The National Association of Evangelical's definition of "Evangelical" is used for the purpose of this study. It is defined as:

1. The Bible is the highest authority for what one believes.
2. It is very important for one to encourage non-Christians to trust Jesus Christ as their Savior.
3. Jesus Christ's death on the cross is the only sacrifice that could remove the penalty of one's sin.
4. Only those who trust in Jesus Christ alone as their Savior receive God's free gift of eternal salvation.

In 1917 Walter Rauschenbusch led a series of lectures at Yale University that later would become the impetus for a Social Gospel that shattered much of the Evangelical Movement for years to come. The Social Gospel (Rauschenbusch, 1917) challenged the historical church on the importance and weight it placed on individualistic sin. This forthcoming theology faulted evangelicals for not considering societal sin as one of the most prevalent factors for oppression. Rauschenbusch and his contemporaries, Henry Proctor, Reverly Ransom, and Nannie Burroughs sought to “bring men under repentance for their collective sins and create a more sensitive and modern conscience” (p. 5). They preached from a gospel of socioeconomic injustice, promoting an end to poverty in the U.S.A. They made great strides in strengthening unions, establishing restrictions for child labor, and paving the way for women’s suffrage (Evans, 2001; Rossinow, 2005). Proponents of the Social Gospel felt that conservative evangelicals had forgotten a central theme in biblical teaching, which accentuated the prominence of being in and caring for community. They believed that the kingdom of God (the second coming of Christ) could be established by righteous life and action in the here and now and that social sin was the true form of original sin. Social Gospel proponents believed many evangelical communities stressed the importance of individualized salvation to the neglect of social justice (Bowman, 2007). The solution to social problems, Rauschenbusch (1917) proposed, is the need for churches to rise to a higher order of sacrifice, love, and service: to empower all.

Opponents of the Social Gospel movement argued that initiators of the movement were overly optimistic in thinking that they could rid the U.S.A. of poverty and felt that the Social Gospel did not accurately understand or make clear connections between all the “isms” dominant in American society (Hinson-Hasty, 2009). They argued for a realistic concept of social reform and attacked Rauschenbusch for “substituting sociology for theology” (1917, p. 97). Conservative evangelical leaders like D.L. Moody argued that Evangelicalism was incompatible with the Social Gospel since there was a distinct absence of individual spiritual regeneration as a critical component of its theology. Conservative evangelicals also argued that according to the Bible, one cannot reject the doctrine of the depravity of people and claim only the depravity of society (Bowman, 2007).

Literature reveals that as more modernists (mainline Protestants) aligned themselves with Social Gospel theology, Protestant denominations became significantly involved with social justice issues while neglecting Evangelism and church planting (Marsh & Perkins, 2009; Perkins, 2011). At the same time, conservative and fundamental evangelicals became significantly consumed with one-on-one evangelism and orthodoxy while neglecting social justice issues (Sider, 2008, p. 92). The tension felt between these two theological perspectives set the landscape for how the U.S.A. defined evangelicalism in the mid to late 20th century.

In the 1940s, an oft-forgotten theological voice emerged to advocate for *both* social action and biblical obedience. Carl Henry's (1947) book, *The Uneasy Conscience of Modern Fundamentalism* emphasized the importance of central biblical doctrine as well as concern for social problems. He urged evangelicals to adhere to an understanding of sin as "both personal and social" (Sider, 2008, p.128). For years after a small group of like-minded individuals grappled with how evangelicals could advocate for a both/and theological position on helping combat oppression and injustice, they pioneered what today many in the U.S.A. are calling the "new or next evangelicalism" (Rah, 2009). This theology emphasizes faith *and* action together; engages in economic, political, and cultural matters; is active in the struggle against classism, racism, and oppression; and views the church as the most revolutionary force from which to abolish injustice (Smith, 1998). It is not afraid to confront the damaging effects of individualism displayed for so long by white American evangelicals; it brings to light that "isms" are systemic issues rather than mere individual matters (Rah, 2009). The new evangelicals engage the culture, choosing both the social gospel and the faith gospel simultaneously (Markham, 2010). Martin & Haugen (2012) describe four truths about the role of social justice displayed by the new evangelicals. They state,

1. God is deeply and passionately concerned for victims of violent oppression in our world.
2. God hates injustice and wants it to stop.
3. God's plan for ending injustice in the world includes the church.
4. It is possible for the church to engage injustice with efficacy (p.124).

To further support these claims, there are over fifty passages in the Bible depicting justice-related issues. These issues range from human trafficking, abuse of prisoners, slavery, rape, racism, and illegal land seizure (Martin & Haugen, 2012).

Marsh & Perkins (2009) make clear that evangelicals should not think their calling is in any way superior to others, but rather eloquently articulate mercy and justice without seeking to control individuals or the community. They encourage evangelicals "to listen to others, learn from others, and link arms with others" (p. 102) to seek solutions to social problems. They also state that "a Christian community does not exclude the stranger, but rather welcomes them into the peace that God makes possible"

(p. 103). In discussing the evangelical mission to one’s neighbor, Alan Keith Lucas (1992) stated that it is important for the evangelical to adhere to both a vertical and horizontal faith position in the way we care for one another. Lucas said, “We need to respond to God’s love and to be a conduit of God’s love . . . our theology then must be both vertical, between us and God, and lateral, between us and our neighbors” (pp. 6-7). Perkins and Keith-Lucas’ approaches both resonate with Anti-Oppressive Practice.

As the new evangelical movement continues to grow, so do crucial conversations about the social and cultural realities of the 21st century. The younger generation of evangelicals is becoming more passionate about injustice and oppression in their communities. New ministries and faith-based programs deal with pertinent social issues such as human trafficking, child laundering, predatory lending, and global poverty. While these topics are reflective of 21st-century society, one wonders where the topic of HIV falls on the social agenda of evangelicals. With the development of sophisticated medication and treatment, it would seem to some that HIV is no longer a topic of relevance; however, as indicated in the literature it is very much prevalent in congregational settings today. The importance of social support for PLWHA, or lack thereof, could make a significant mark on the continued prevention and intervention of a global crisis.

Conclusion

The themes of oppression and empowerment are fluid in the history of HIV/AIDS and the history of Evangelicalism. AOP, as the theoretical framework for this research, not only captures the significance of both but equally guides the methodology for data collection in addressing the research questions. The next chapter will provide an in-depth review of the qualitative tradition of phenomenology.

CHAPTER 4

METHODOLOGY

Research and literature indicate a decrease in physical and psychological distress when community social support systems are present for PLWHA. The presence of these support systems creates HIV-competent communities. Faith-based congregations are positioned to either be these competent communities or collaborative partners in building them. These congregations can play a critical role in creating opportunities to empower PLWHA. A significant dimension in this empowerment process is the inclusion of PLWHA; having their voices heard by hearing their lived experiences (good or not so good) as members of faith-based congregations. This important voice has not been present in much of the literature and research on the intersection of social support, faith-based congregations, and PLWHA. This research is about hearing the voices of PLWHA. The findings will assist in informing faith-based congregations on how to best build HIV-competent communities that are supportive, liberating, and empowering.

The research questions guiding this study:

1.) Do evangelical congregations provide social support services and interventions to their members who identify as evangelical and are also diagnosed with HIV or AIDS?

2.) What are the lived experiences of PLWHA who interface with evangelical social support systems?

3.) Do PLWHA feel empowered or oppressed when receiving support within their congregations?

4.) Are the voices of PLWHA represented in evangelical social support systems and congregations?

Details of the study, a brief history of phenomenology, and my rationale for utilizing this approach as my research design are included in this chapter. In addition, I outline my process for participant participation, the roles of the researcher and participant, as well as data collection and analysis procedures.

Phenomenology

Phenomenology is “the philosophical approach to the study of experience” (Smith et al., 2009, p. 11, 2022). Etymologically speaking, phenomenology is defined as the metaphysical study or theory of phenomena. It is the division of any science concerned with the description and classification of phenomena, as opposed to casual or theoretical explanations (Soanes & Stevenson, 2004). Phenomenology as developed by Edmund Husserl (1931) can be understood as both a philosophy as well as a research-oriented process. Husserl emphasized the importance of one’s conscious experience through the subjective lens.

For Husserl, the highest level of community was the community of humankind, and the highest responsibility of humankind was to collectively seek to elevate its members to new understanding, new mental phenomena, and new purpose in the lived world (Embree & Drummond, 2002).

He emphasized that mental phenomena and the object (the act of consciousness itself or the object of attention for that process) completely correlated with each other, always interacting, and influencing one another. In other words, he felt that the internal world was made up of a myriad of experiences that impacted how we view the external, public world. Husserl called this binding union between subject (the mental state of the one experiencing) and object (the acts of consciousness themselves or the object of attention for that process), *intentionality* (Mohanty & McKenna, 1989).

Husserl saw the importance of reflection and introspection of presuppositions. He did not completely doubt these presuppositions but suspended them until he could make further or alternative understanding of the lived experience. This type of reasoning he referred to as *Epoche* (defined in Greek as “suspension”). It is displayed by bracketing thoughts and preconceived ideas about the lived human experience (Husserl, 1931).

In summary, Husserl desired to identify and explore the essence of mental phenomena and connect them to the experiences of the outside world, all without the interference of presuppositions. He accentuated the need for humans to deeply reflect on experiences occurring in human consciousness to grasp the full meaning of those experiences. Smith et al. (2009, 2022) emphasize Husserl’s notion of reflection as vital in suggesting that, “To be phenomenological, we need to disengage from the activity and attend to the taken-for-granted experience of it” (p. 13). Husserl’s philosophy of phenomenology can be quite perplexing. There have been various interpretations of his work and speculations about whether his concept of intentionality and methods of *Epoche* are realistic.

The phenomenologist views consciousness as intentional. The human experience is lived in, reflected upon, and mostly made up of judgments, perceptions, and emotions that give things meaning. Husserl (1931) and Smith et al. (2009, 2022) illustrate the human experience as one made up of common threads that develop the personal phenomenon being experienced. Every person comes with a story and a history that has meaning and can be shared.

Hermeneutic Phenomenology

Martin Heidegger (1995) made a significant contribution to hermeneutic phenomenology in what philosophers call the “interpretive turn.” This turn signified the end of metaphysics, the abstract, the *what is,* the questions of yes and no. This turn was crucial. It focused on the ontological view of the world as opposed to the epistemological view. Heidegger was more concerned with lived time, the “as”, and the hermeneutic untangling of the “always already” differing relationships that surround us. Out of his fascination with hermeneutics, Heidegger developed hermeneutic phenomenology. Creswell (2007) states that hermeneutic phenomenology not only “describes research as oriented towards lived experience but also in interpreting the ‘texts’ of life” (p. 59).

“Hermeneutics is a linguistic philosophy that focuses on questions of how people understand spoken language, written texts, and themselves across sociocultural environments” (Mantzavinos, 2016). Hermeneutics has no beginning or end. It is a continual experience in the phenomenological process (Darbyshire et al.,1999).

Heidegger (1995) was determined to seek what is to be known rather than how we come to know. He defined “ontological” as “what can be known.” The root of the word “ontological” is *ontic* which mainly describes demographics or events. The ontological understanding appealed to Heidegger and was the premise for his philosophy. He was committed to increased understanding as well as to revealing shared practices and common meanings (Darbyshire et al., 1999).

Hermeneutic phenomenology encompasses the way we notice things when they are interpreted in the day-to-day learning, experiencing the world as engaged openness. By “engaged openness,” Heidegger meant that humans are already engaged in the world. He felt they were thrown into being and things happen in their lives that determine how they see themselves in the world. This concept of beings-in-the-world is quite frequently referred to by Heidegger as *Dasein* (defined as experience). His thoughts on the day-to-day and the significance of its interruption were influential in connecting the substantive area of this research to the philosophical ideals of hermeneutics (Palmer, 1969). For instance, it prompts the following questions for this certain study: What happens when a person’s HIV diagnosis is revealed to individuals in their congregation? What is it like to have (or not have) a social support system in one’s respective congregation? How is one’s world forever changed by this experience, this interruption of the day-to-day?

Hermeneutics, Heidegger would argue, is absence and presence belonging together, a pathway of mutually revealing possibilities, which is not yet, but can be. Heidegger asks what we can obtain through interpreting and maintains the notion of intersecting regions that allow for practice and thinking to permeate together. Heidegger articulates these concepts by making use of the Hermeneutic circle for analysis of the lived experience.

Heidegger developed the concept of the hermeneutic circle to be a fore-structure of understanding. These fore-structures indicate that knowledge is constructed through historical, cultural, and social experiences. The hermeneutic circle emerged from Heidegger's non-adherence to Husserl's concept of bracketing. Bracketing can be defined as "a process of setting aside predilections, prejudices, predispositions, and allowing things, events, and people to enter anew into consciousness, and to look and see them again, as if for the first time" (Moustakas, 1994, p. 85). Heidegger felt that bracketing limited the role of the researcher and sensed that the researcher should, as much as possible *be in the world* of the participant (McConnell et al., 2009).

The hermeneutic circle is always at play, revealing and concealing phenomena. For everything that is revealed, something else is concealed. In the hermeneutic circle, there is never a total un-concealing (Heidegger, 1959). There are three components to the hermeneutic circle: fore-having, fore-sight, and fore-conception. Fore-having is defined as the practical familiarity with the phenomena (pertaining to this study, the researcher's understanding of HIV). Fore-sight is the perspective of the phenomena (pertaining to this study, the researcher's understanding of HIV, and social support). Fore-conception is the anticipated sense (pertaining to this study, any insight learned about PLWHA in evangelical congregations that might provide innovative understandings of the phenomena of social support). Gadamer (1982), a contemporary of Heidegger's, also conceded to the hermeneutic circle to gain a deeper understanding of the phenomena being studied. He emphasized that the hermeneutic circle is a way of putting aside one's prejudices to "hear what the text says to us" (p.10), enabling us to make new pre-judgments and pre-understandings. Smith (2009, 2022) refers to this process as balancing the research context by considering parts and whole.

The hermeneutic circle entails much reflective thought, is circular, and, at times, can seem never-ending. Some opponents of the hermeneutic method of inquiry state, “Hermeneutic studies do little more than crude, unsophisticated content analysis, or regurgitate, in an unsystematic manner, some of the words of the participants” (Cutcliffe et al., 2004, p.311). Yet others, such as Heidegger and Gadamer, would argue that the method of hermeneutic inquiry retrieves the forgotten or overlooked in most research studies, aiming to understand phenomena in a new and invigorating way.

In summary, hermeneutic phenomenology seeks to find the things right in front of us that we aren’t even recognizing. It inquires what might be on the other side of the phenomena so we might be better able to understand it and create new understandings that could potentially have positive effects on those whose stories we hear.

The Lived Experience: Interpretative Phenomenological Analysis

My research questions focus on the phenomena of social support, specifically, with PLWHA in evangelical congregations. The method of analysis used for this qualitative study is Interpretative Phenomenological Analysis (IPA). This methodology has been utilized in a myriad of human, social, and health sciences qualitative research studies to focus on the “subjective experience of individuals…as an attempt to unveil the world as experienced by their life-world stories” (Kafle, 2011, p. 181). It focuses on a significant common life experience, a shared personal meaning, and seeks to make sense of major lived experiences (Moustakas, 1994; Smith et al., 2009, 2022; van Manen, 1997).

IPA is appropriate for this current study for several reasons. First, hermeneutics is a major theoretical underpinning of IPA. As participants seek to make sense of and reflect on their lived experiences, IPA research aims to “engage with these reflections” (Smith et al. 2009, p.3, 2022). IPA highlights not only the language and rich transcription of the participant, but also seeks to help participants understand themselves from a historical, cultural, and sociocultural context; a critical factor woven throughout AOP. In addition, IPA researchers employ double hermeneutics. They construct interpretations of what the participant is trying to make sense of, playing a critical role in the analysis of their lived experience (Smith et al. 2009, 2022). IPA is most identified with giving a voice to PLWHA, *on their terms*, by understanding and gaining insight into their lived experiences of “being” and experiencing social support within evangelical congregations. Furthermore, IPA is “idiographic in its commitment to examining the detailed experience of each case in turn, prior to the move to more general claims” (Smith & Osborn, 2015, p. 42). IPA offers insight into how each participant, within a given context, makes sense of their situation (Smith & Osborn, 2015). Last, IPA was found to be the most succinct step-by-step, systemic analysis that allowed for capturing the experiential and qualitative aspects of the research (Smith et al., 2009, 2022). The research design adopts Smith et al. (2009, 2022) method of interpretive phenomenological analysis as outlined in the following steps. These steps will be further discussed later in this chapter.

1. Reading and re-reading;
2. Initial noting;
3. Developing emergent themes or experiential statements;

4. Searching for connections across emergent themes or experiential statements;
5. Moving to the next case;
6. Looking for patterns across cases.

Conducting this research from the perception of grounded theory was considered. Although there are similarities between grounded theory and phenomenology, there are also some distinct differences. Grounded theory questions a phenomenon happening over some time and is often much more traditional in what it aims to produce in terms of outcomes. The use of grounded theory usually generates the *development* of a theory from the analyzed data. It can be conducted as qualitative or quantitative research and is intended to be a specific methodology. Phenomenology, on the other hand, was never meant to be a methodology although contemporary methodologists such as Moustakas, van Manen, Smith, Flowers, and Larkin have done a tremendous job at creating ways to make this possible. IPA emphasizes searching for patterns so common within the lived experience that they cannot help but be present in every interview (Moustakas, 1994; van Manen, 1997; Smith et al., 2009, 2022). Grounded theory is based on how people make meaning. Within the realm of phenomenology, however, meaning *is*. It is often the outlier that most phenomenologist researchers want to hear from and yearn to know more about (Smith et al., 2009, 2022).

A narrative approach for this qualitative study was also examined. However, a narrative approach entails the researcher studying the lives of one person or a small group of people through the telling of stories. According to Bloomberg and Volpe (2008) “[T]he information gleaned from the story or stories is then retold or ‘restoried’ by the researcher in narrative chronology" (p. 11). Instead of a strictly narrative approach, this study used a hermeneutic interpretative phenomenological method. This is because the lived experience of a certain phenomenon (social support) is being studied in PLWHA, as well as the commonalities surrounding this experience (e.g., oppression, empowerment).

Research Design

This phenomenological study utilizes a qualitative research design with participants representing the phenomenon being studied, the absence or presence of social support services in Evangelical congregations. Purposive and snowball sampling was used to ensure the homogeneity of respondent selection (Maxwell, 2005).

Participant Selection

Research participants were recruited from both urban and rural settings. According to the 2010 Census, urban areas have a high population density with a high percentage of non-residential land use, whereas rural settings have a low population density with a high percentage of land dedicated to farm use. The criteria for inclusion included the following: a) a self-reporting diagnosis of HIV or AIDS, b) a current or past connection (within the past 10 years of the interview date) to an evangelical congregation c) a minimum age of 18.

According to the literature, the sample size of participants for a phenomenological study varies. Creswell (2000, 2007) suggests the standard number ranges from five to twenty-five. However, the number of participants acceptable for a phenomenological study is better defined as the point at which saturation is likely to occur. It is at this point when similar patterns and themes begin to consistently emerge from the data. Crist and

Tanner (2003) suggest “The size of the sample is considered adequate when interpretations are visible and clear, new information reveals no new findings, and meanings from all previous narratives become redundant” (p. 203). For the purposes of this study, twelve participants were interviewed.

A snowball sampling approach was utilized for participant recruitment. Creswell (2000, 2007) describes snowball sampling as research in which participants recruit others who have had similar experiences. I chose this avenue of recruitment to solicit individuals who shared a common experience but who also live in various places around the U.S.A. Employing this approach, I completed four face-to-face interviews, six interviews via Zoom video recording, and two interviews via Zoom audio recording. Avenues of recruitment for participants included the following:

- Informational research study letters (Appendix A and B) sent to AIDS Service Organizations and HIV-specific Health Care Centers in the Tri-State Ohio area including AIDS Resource Center, Equitas Health, and Mid Atlantic AIDS Education Training Center.
- Informational research study letters sent to the National Center for AIDS Research Community Advisory Board Coalition.
- Recruitment efforts took place by sending information about the study on HIV awareness, prevention, education, community sites, community blogs, forums, and health services directory agencies. An email address and phone number were the point of contact for individuals to discuss eligibility for the study.

As soon as an eligible participant was identified, a time and place for the interview was confirmed, and information regarding informed consent (Appendix C) was disseminated and signed. The informed consent sheet contained facts about the purpose of the study, the significance of the study, confidentiality, anonymity, dissemination of the information obtained in the study, and participants' right to refuse consent as well as their right to re-negotiate consent. It was important for the participant to have knowledge of data that was coded and stored in a secure space. Participants were informed of the use of data for Ph.D. studies, dissertation purposes, and potential future publications. An example of an informational research letter to participants and the informed consent sheet is found in the appendixes. Participants were not reimbursed for their contribution to this study.

Ethical Considerations

Institutional Ethics Requirements and Conformity

I submitted to and obtained approval from the Interdisciplinary Committee on Ethics in Human Research (ICEHR) to follow Memorial University's ethics policy (Appendix D). Ethical protection included, but was not limited to, obtaining informed consent before interviewing participants, maintaining the confidentiality of participants using pseudonyms, and obtaining permission to audio or video record all interviews (Rubin & Rubin, 2005). In addition, I stored all data related to participant interviews on a computer secured by a password. I was the only person able to access this computer.

Due to the sensitive nature of the research, I made every effort possible to maintain trusting and respectful relationships with my participants, conveying that the intent and scope of my research was for purposes of meeting the requirements for my doctoral degree in social work. In addition, I showed respect to my participants by arranging meeting times and places amenable to their convenience and privacy.

On November 8, 2019, an amendment request sent to the ICEHR was approved that allowed for the use of virtual interviewing by way of Zoom (Appendix E). These virtual interviews were conducted and recorded via audio or video Zoom conferencing. For confidentiality reasons, the Zoom recordings could only be accessed on the computer that recorded the meeting, in this case, the researcher's (my) personal computer. Zoom audio or video conference recordings were not stored on any type of server. The consent form and all recruitment material were changed to reflect this approval (Appendix F and G). The allowance for Zoom audio or video conferencing enabled me to find participants more willing to interview for longer lengths of time. Interestingly, participants voiced that they felt better interviewing in the privacy and comfort of their own homes. This was especially helpful during the COVID-19 pandemic as Zoom interviewing helped me find a safe, healthy, confidential environment where the participants felt secure enough to discuss the sensitive nature of my research topic.

Data Collection

Investigating lived experience calls for a “re-learning,” “re-telling,” and “re-living of the original experience (van Manen, 1990). “Lived experience” means “recovering somehow the living moment of the now” (van Manen, 2014, p. 216). It was important to challenge the phenomenality of the phenomenon, to challenge the everyday lived experience. van Manen (2017) states, “[W]hen we talk about lived experience, we must focus on experiential concreteness, vividness, and descriptive detail (p. 810).

Phenomenological questions seek meaning and significance in a certain phenomenon (van Manen, 1990). Therefore, creating the phenomenological question required a deep commitment to the phenomenon to provide a rich description of its experience. The following four questions were created to “help transform the lived experience into a textual expression of the hermeneutic essence” (van Manen, 1990, p.36).

1. Do evangelical congregations provide social support services and interventions to their members who identify as evangelical and are also diagnosed with HIV or AIDS?
2. What are the lived experiences of PLWHA who interface with evangelical social support systems?
3. Do PLWHA feel empowered or oppressed when receiving support within their congregations?
4. Are the voices of PLWHA represented in evangelical social support systems and congregations?

It was critical to utilize methods of conversational interviewing, personal reflection, close observation, and experiential descriptions related to the phenomenon as explained by each participant (van Manen, 1990, 1997, 2017). A vital part of the interview process was the ability to gain the trust of each participant. I became skilled in the interview process to attain the artistry needed to complete a successful interview

(Ritchie & Lewis, 2003). I explored and asked questions in a way that allowed each participant to engage in the phenomenological process. In each interview, I exhibited trust by displaying strengths-based verbal and nonverbal communication as well as active listening. (Rubin & Rubin, 2005). During the interview process, I elaborated on the phenomena by asking the following questions:

1. Describe how you became a part of an evangelical congregation.
2. Describe what it is like, for you personally, to be a PLWHA and a part of an evangelical congregation (personal reflection).
3. Describe your feelings, moods, and emotions as a PLWHA who is (or was) a part of an evangelical congregation (close observation).
4. Can you describe a specific event or vivid experience as it relates to social support (or lack thereof) in an evangelical congregation (understanding the significance of the story)?
5. Can you describe what it would look like for an evangelical congregation to provide social support services to PLWHA?
6. As you reflect on your experience of being a PLWHA, what would you like to say to those who are part of an evangelical congregation?

At times, additional questions arose and evolved during the interview. (Crist & Tanner, 2003; Seidman, 2013). I utilized the following exploratory questions that were reminiscent of the phenomenological process:

1. Can you give me an example of that?
2. Can you say more about this event?

3. What does that mean to you to have experienced this?
4. Who said what?
5. In what way?

We assume that we understand what we hear. We also assume that what we hear is congruent with our personal understanding of a phenomenon. These assumptions can be dangerous because they lead the interviewer to hear only what reinforces anticipated themes. Clarifying what I heard was an important way to keep the phenomenon under study, and understand the story as it unfolded (Benner et al., 1996; Hair & Fine, 2012). During the participant interview, I tape-recorded the conversation and took additional notes on non-verbal expressions displayed throughout the interview process. Tape recording the interview allowed me to fully engage in the dialogue of the lived experience, while simple notetaking enabled me to catch observations not visible during transcription.

Data Analysis- Interpretative Phenomenological Analysis

Reading and Re-reading and Initial Noting

I transcribed interviews as quickly as possible after each interview, utilizing voice recognition software. By listening and transcribing simultaneously, I remained engaged in the data, creating an opportunity for data to be heard repeatedly. It was beneficial to let the interviewees' words sit with me for a while, learning to be quiet and hear what stood out in each participant's account, while at the same time not risking the chance of hearing a theme too quickly. Throughout the IPA analysis, it was critical to immerse myself in the data. As I began reading and re-reading each transcript, I sought to understand the relevance of the phenomena being researched (Moustakas, 1990; Smith, 2009, 2022). In addition, I identified how my interests and presuppositions contributed to the analysis of data. This is consistent with social constructivism and the hermeneutic approach to phenomenology. While actively engaging with the data, I positioned myself in constant reflection about what I was learning regarding the phenomenon and documented initial thoughts about the interview and/or transcripts. Heidegger (1992) often explains this process as "being lost in thought" as it is derived from his concept of the hermeneutic circle.

After reading and re-reading each participant's transcript, I created a table of exploratory comments situated next to each original transcript. The table of exploratory comments contained descriptive comments (I **highlighted** those moments or experiences in the text that seemed to matter most to the participant), linguistic comments (I *italicized* the specific use of language in the text used by the participant), and conceptual comments (I <u>underlined</u> any preunderstandings and/or a newly emerging understanding in the text exhibiting reflexive engagement between researcher and participant). I aimed to "produce a comprehensive and detailed set of notes and comments on the data" (Smith et al., 2009, p.83-90, 2022). This stage of analysis provided thorough sections of the text, bringing forth contradictions, paradoxes, and newly emerging knowledge of each transcription. Creating converging conversations with the data makes it relevant and warranted. The most important element within phenomenology is to let the text speak for itself; IPA always attends to the context and the background of the situation (story) under analysis. The use of exploratory comments during the analysis of the data as well as in the presentation of the data helped me stay very close to the text.

Developing Emergent Themes or Experiential Statements

Smith (2009, 2022) inspires the researcher to ask how to make the best sense of what the participant experienced in the day-to-day, articulated in the portrait of each participant's story. Hermeneutically, this is illustrated by a constant movement between the whole and the parts, reading across interview texts to discover new paths of thinking, dialoguing, and creating converging conversations with the transcripts (van Manen, 1990; Darbyshire et al., 1999).

I used Dedoose, a secure web-based cross-platform system for analyzing qualitative research. Dedose software helped to organize themes and generate reports of emerging phenomena across all participants for further analysis.

Initially, I looked for connections and patterns, developing emergent themes or experiential statements, chronologically as they appeared in the transcript. First, by utilizing abstraction analysis, I examined the emergent themes or experiential statements that had parallel or similar understandings; the "superordinate or personal experiential" themes. Second, by utilizing polarization analysis, I examined the emergent themes or experiential statements that showed oppositional differences. Finally, by utilizing numeration analysis, I examined the frequency that emergent themes or experiential statements appeared within each transcript. For a theme to be classified as a "recurrent" theme, it would need to be present in at least half of the participant interviews (Smith, 2009, p. 96-98, 2022). After repeating and completing this process for each participant transcript, I began to compile a master table of themes, called group experiential themes, for all 12 participants (Smith et al., 2009, 2022; van Manen (1990).

In addition, I built interpretative, reflective, and anecdotal narratives of how the phenomena came to be what they are, considering the countless possibilities emerging connected to the meaning of the lived experience, and exploring the experience to understand the way others and their communities saw the experience. The organization of these themes or narratives can be found in Chapter 5.

Process for Ensuring Trustworthiness

Collecting Rich Data

A basic premise in phenomenological research is to make sense of one's experience. As researchers try to reach an understanding of life experiences, the richness of meaning within these experiences emerges. Findings of phenomenological research can develop into beautiful stories that encourage, direct, touch, and help others who may be on the same journey. The use of raw data, the emergence of themes, and the interpretation of data help the study to remain accurate and true to the researcher's and participants' original intent.

To further enrich the data, a second interview was, at times, pertinent. This helped me to deal more effectively with bias, close any gaps in the data, or clarify information discussed in my initial interviews (Cohen et al., 2000; Lincoln & Guba, 1985). To further reduce bias, I prepared an audit trail of field notes, reflective journals, and other pertinent information that enabled me to come to the conclusions I have.

Member Checking

The accuracy of information obtained in a phenomenological research study is contingent on the researcher's interpretation of the information. The researcher's perspective on the experience can be highly intrusive, making the information biased. This bias can damage the results of the data if the researcher has assumptions and beliefs about the way the questions should or would be answered before the beginning of the study.

Interpreting the data received is crucial for the phenomenological study to be effective. Therefore, to ensure my participants' voices are fully represented, I employed member-checking to improve the accuracy, credibility, validity, and transferability of the current study (Maxwell, 2013). I shared an appropriate portion of the finding of my data with each participant in the study, checking to make sure I was accurate in my summary and changing my findings when wrong or incomplete. Verifying the content of the interview data with the participant provided an authentic resource for me when I interpreted a participant's experiences, perspectives, and feelings. When I used direct quotes from participants in the findings recorded in Chapter 5, I omitted words such as "um," "like," and "you know" to make their quotes easier to read.

Triangulation

Triangulation is used to “reduce systematic bias and improve the evaluation of findings” (Carter et al., 2014; Lemon & Hayes, 2020, p.606). In addition, it seeks to demonstrate a “convergence of information from different sources” (Carter et al., 2014, p. 545). For this current study, measures of trustworthiness occurred by triangulating my interpretative narratives with interview data, diverse groups of participants, and relevant literature on the phenomena being studied.

Inner Rater- Reliability

To assess the rigor and transparency of the research I depended on my committee to provide insight into the themes and interpretations of the data I collected. While these processes increased trustworthiness within the analysis and interpretation stages of this current research study, they do not fully abolish researcher bias. The researcher must understand that the interpretation of data is still filtered through the lens of their past experiences, values, and personal predispositions (Kvale, 1996; Ryan et al., 2013). The next section is a discussion about the beliefs and biases that likely influenced this research study.

Role of the Researcher

As a twenty-three-year veteran of the social work profession, one of my most rewarding career opportunities was in the field of HIV/AIDS. After obtaining my MSW, I began a career as the Coordinator of the Community Advisory Board (CAB) at the Penn Center for AIDS Research (CFAR). In this role, I helped to mediate between the research community and the HIV community, as the CAB's mission was to foster partnerships and maintain open communication between Penn CFAR researchers and the community. My assistance ensured that any study conducted about HIV/AIDS in the Behavioral and Social Science Core, included the voice of the HIV/AIDS community in Philadelphia. The CAB was made up of PLWHA, HIV educators, legislators, researchers, faith leaders, and directors of AIDS Service Organizations (ASO). Throughout my time coordinating the CAB, I befriended several individuals who lived with HIV or AIDS and who experienced extreme stigma as it related to their diagnosis. At times, colleagues or community members would share intimate stories, many weaving the importance of faith into their narrative. Some conveyed feelings of empowerment. Others discussed examples of oppression within their congregations.

One theme emerged in these narratives: regardless of their congregational experience, whether my friends left their respective congregations or stayed, faith remained an important factor in their lives. Being a person of faith, these narratives spoke to me. They often left me wondering how congregations could better serve the HIV community. As a social worker, I wondered about the intersection of social support and faith.

I bring practical experience to the inquiry process, having partial knowledge and understanding of the environmental, and social contexts of faith and social work. I acknowledge that these experiences could provide valuable insight but could also serve as a liability. Therefore, I remained committed to the process of critical self-reflection by way of journaling before, during, and after the interview process. I conducted this research from a constructivist paradigm which helped mitigate personal biases by allowing my participants' voices and perspectives to transcend my perspective and create new meaning (Lincoln & Guba, 2013). I conducted this study as a white, middle-class female who understands privilege in a myriad of ways. I anticipated that many of my research participants would come from different cultural, social, and racial backgrounds. I also recognized that the structural system of the evangelical congregation has widely benefited dominant groups in society. I did my best to challenge oppression when necessary, striving to make positive changes within these structures. In the interview process, I asked questions and allowed participant voices to be heard and honored, being careful to not privilege one voice over the other. Likewise, I listened actively and deeply to any constructs that were different from my values, beliefs, or attitudes (Lincoln & Guba, 2013).

It's important to note that my data collection took place during the COVID-19 pandemic. There was a heighted sensitivity and awareness of what it felt to be isolated, stigmatized, and afraid of transmitting or living with a virus that had taken the lives of millions. We, as a collective society, were all impacted. Although, not the same, it gave me a small appreciation of what PLWHA experience daily. As participants voiced in their interviews, COVID-19 was an added layer of stigma and health co-morbidity encountered on their journey.

Conclusion

To summarize, in this chapter I provided a historical and philosophical overview of phenomenology, emphasizing the work contributed by Husserl and Heidegger.

Furthermore, I outlined the importance of hermeneutics as it relates to hermeneutical phenomenology as a chosen method of analysis for this study. I provided an overview of the proposed research design, data collection, and analysis as outlined by Smith's (2009, 2022) six steps of methodical structure for hermeneutic phenomenological research. Finally, I detailed my role as the researcher, discussed the ethical protection of participants, and described the process for ensuring the trustworthiness of this current study.

CHAPTER 5

FINDINGS

Twelve individuals agreed to participate in this study-four females and eight males. They were from four separate regions of the U.S.A.: the West Coast, Midwest, Southeast, and East Coast. Their races and ethnicities include one Asian, four African Americans, three Caucasians, and four Hispanic/Latinx. Eight individuals reported Male-to-Male Sexual Transmission of HIV/AIDS with four reporting Male-to-Female.

Each participant identified as having a diagnosis of HIV/AIDS and a connection to an evangelical congregation within the past 10 years. Based on the responses to the research questions and using interpretative phenomenological analysis, six master or group experiential themes emerged: Multifaceted Stigma; Power and Oppression; Patients as Educators; Our Voices Matter: What Works/What Doesn't; Where Do We Fit In; and Mortality with Eternity in Mind.

Multifaceted Stigma

Multifaceted Stigma emerged as the most prominent theme under which three superordinate or personal experiential themes became evident: mode of transmission, lack of knowledge, and shame.

Mode of Transmission

Participants were unequivocal about the correlation between stigma and the mode of transmission for HIV or AIDS. They reported their evangelical congregations tend to classify individuals inversely based on their mode of transmission. Some participants felt there was more compassion shown for PLWHA whose spouses or significant others were unfaithful or on the “down low.” Many of their congregations often labeled PLWHA as individuals that associated with “undesirable characteristics or behaviors.” Any conversations or attempted education about HIV in these congregational settings correlated to how an individual acquired HIV and whether congregational lay leaders felt those social behaviors were acceptable to discuss. One participant stated, “Well, this person acquired HIV *this* way so we can talk about that, that’s something I don’t have an issue with. But if HIV is transmitted in *this* particular way. Hmm…I’m not sure we are going to talk about that.”

Seven of the 12 participants experienced stigma based solely on the mode of HIV transmission. Each participant's personal story helps to appreciate the extent of the stigma in congregational settings related to modes of transmission. Here are their stories:

Attila, Caucasian Male

Attila lived openly gay for 13 years of his life. When he tested positive for HIV, it was a shattering and sobering experience. His HIV diagnosis caused him to evaluate if his sexual orientation was God's will. HIV was the catalyst for him to walk away from his identity as a gay man. Five people know about Attila’s HIV status, including the researcher. Attila reiterated several times that his life is filled with secrecy, fear, and shame as it relates to HIV. He has not discussed any part of his journey with anyone in his current congregation.

Bela, Caucasian Female

Bela was a 26-year-old, single female when she was diagnosed with HIV. She received a call from her previous boyfriend telling her that he had recently been diagnosed with AIDS. Bela recalls not thinking she was at risk for HIV. She was a middle-class professional. She utilized birth control pills as a form of protection from unwanted pregnancy. She did not think HIV would ever invade her world until it did. Upon receiving news of her diagnosis, she thought she had a year to live; however, she remained in very good health. She began clinical trials and became highly educated about HIV/AIDS education and prevention. Bela describes her congregation as being open to dialogue about HIV/AIDS. She has a good support system through the various ministries she is a part of.

Csaba, Asian Male

Csaba grew up in a conservative Christian home. He stated that although it was a slow process, at the age of 27, he identified his sexual orientation as Bisexual. Csaba discovered he was diagnosed with AIDS in the year 2000 when he lost 30 pounds in a month or two. He had a CD4 count of six and was given six months to live. Shortly before his AIDS diagnosis, Csaba had attended church and felt a sense of renewed faith. Therefore, after hearing of his diagnosis, he felt a sense of peace and committed to "serving God for the rest of his days." After a brutal year of pain and suffering, the doctors found the correct combination of antiretroviral medication. Csaba has been married to his wife for a decade. They have two children. Csaba admits there is a lot of stigma surrounding PLWHA who also identify as LGBTQIA +. He has been the recipient of this stigma in congregational settings. He feels that the U.S.A. is changing regarding their views on sexual orientation but feels Christians need to as well. He expressed that Christians have “no idea how to minister to the LGBTQIA+ population.” He stated that he has begun to work primarily with PLWHA who also identify as LGBTQIA+.

Dora, African American Female

Dora discovered that she was diagnosed with AIDS in the late 1980s. She stated that one night she was at a hotel drinking and partying with a friend of her fathers who took advantage of her via nonconsensual sex. He was an IV drug user. He told her that if she told anyone, he'd "hurt her family.” She didn't tell anyone until she found out that he died, several years later, from AIDS. This prompted her to get tested. She recalls her life changing drastically after her diagnosis. She felt like giving up. She stated she used to be the "light in the room" but soon moved to a very dark place. During the next several years she experimented with drugs and alcohol and experienced various forms of domestic violence. She had one child during this time, who died of AIDS at the age of two. Dora stated that “through all the trauma she experienced in her life, she never left God.” After being in recovery for years, and maintaining a healthy medication regimen, she was hired as an HIV care coordinator for the state government. Dora has advocated for HIV prevention and education in her congregation with pushback from lay leaders. Sometimes Dora feels like she is treated the same as everyone else in her congregation, and sometimes she is made to feel very different, mainly when sensitive topics surrounding HIV/AIDS are discussed. She says congregants don’t know how or what to say to her. Dora indicated that in the church she attends, the community leaders are focused on stopping crime and violence in the inner city. She understands the importance of promoting nonviolence, but also stated "We [the African American community] still haven't got to the point where we focus on being healthy. We still need to strive to be better people. How can you be better people when you are not healthy?" She continues to advocate for those living with HIV/AIDS in her community.

Emanuel, Latinx Male

Emmanuel described that before his faith conversion, he identified as Bisexual. Emmanuel had various causal sexual encounters with both men and women throughout his adolescence and adulthood; however, in his mid-twenties, he was introduced to his current wife by a good friend through a bible study at church. He kept his sexual orientation a secret from his wife and the church for years. He continued having casual sexual encounters with men only, while married, for fear of getting a woman pregnant. He was adamant about getting tested for HIV every year. After receiving news of his HIV diagnosis in 2016, Emmanuel revealed his sexual encounters to his wife, children, and the pastoral staff at his current church. Emmanuel felt very supported by his lay leaders as a PLWH. They arranged for his family to obtain therapy, accompanied his family to appointments with his medical specialists, and paid all his expenses for a year so that he could focus on his health and family. Emmanuel stated that he "wants people who struggle with sexual identity to be restored."

Felicia, Caucasian Female

Felicia recalls her mother providing written consent for her to marry an older gentleman when she was just 16 years old. Felicia states that after two or three years into her marriage she was unfaithful. She shortly divorced her first husband and married her lover. Two years into her second marriage, her husband became very ill. After his prolonged illness, his doctor suggested getting tested for HIV. This was the early 1980s when little was known about HIV. Shortly after her husband’s diagnosis, Felicia was also diagnosed with HIV. Due to the drastic decline in her husband’s health, Felicia immediately became the caretaker for her husband, who soon needed hospice care. Six months after his initial diagnosis, Felicia’s second husband died from AIDS. Felicia remarried her first husband. They had one child together, who is HIV positive. After divorcing a second time, Felicia met her current husband, who is also diagnosed with HIV. Felicia has six children altogether, with one child testing positive for HIV. Both Felicia and her husband work to educate their respective communities about HIV/AIDS. Felicia discussed stigma at church related to her diagnosis but also the diagnosis of her child and a presumed diagnosis of her other children. Felicia also discussed the stigma she felt within her medical community regarding her advocacy against aborting her child due to her HIV diagnosis. She also advocated for vaginal birth instead of C–section for all six of her children. Felicia describes her congregation as growing in their knowledge of HIV but still feels there are barriers placed on what she can and cannot discuss as it pertains to HIV prevention and education. Felicia and her daughter are currently undetectable.

Gabriella, African American Female

Gabriella discussed feeling sick for quite some time before diagnosis. After much research of her own, she inquired about the possibility of being diagnosed with HIV. The doctor replied, "You're not in the population group for that!" as she was married for several years, with two children, living the “American dream.” She delayed testing based on the provider's suggestion. When she was diagnosed with HIV several years later, due to her husband’s infidelity, she repeated that exact phrase back to a nurse who had administered her HIV test. She looks back and laughs but realizes how uneducated both she and her doctor were when she first inquired about testing. Gabriella is currently directing an ASO where she can incorporate aspects of spirituality and faith into support groups for women living with HIV. She acknowledges she had a very positive support system. Social support is “everything to her,” and something her current clients do not have. She feels that evangelical congregations have a long way to go in terms of creating safe and supportive spaces for PLWHA; however, she has advocated holding HIV support groups at her local church. She feels her congregational lay leaders have been supportive throughout her journey with HIV.

Harold, Latinx Male

Harold identifies as a "homosexual male due to unwanted same-sex attractions while in a marriage with a mixed racial wife to whom who he is attracted." Harold grew up in a conservative Christian home and stated his same-sex attractions felt shameful, so he kept them secret for much of his life. Yet, he eventually disclosed them to a former roommate who showed incredible grace. Harold engaged in high-risk sexual behavior and during his years in medical school was diagnosed with HIV. Harold was, at one point, arrested for non-disclosure of HIV to three of his partners. This was a time he felt that his faith was all he could cling to. In prison, he decided to pursue sexual purity. After prison, he joined several faith-based ministries where he met community and friends that walked the journey with him. While at one point Harold fully embraced a gay lifestyle, he now has been married to his wife for four years. Harold provides social support services to

PLWHA through a faith based ASO. Harold and his wife currently attend a church where individuals who identify as gay are welcome, although sexual purity is promoted. They have found great acceptance in this congregational setting; however, there is little discussion, ministry, or social support specifically for PLWHA.

Ivan, African American Male

Ivan developed significant health issues before his HIV diagnosis. These health issues warranted surgery, which in turn mandated bloodwork. Ivan found out he was HIV + because of pre-surgery bloodwork. He was diagnosed in 2015. His surgery was postponed. Ivan was referred to a social worker who provided “incredible social support, and the infectious disease doctor took very good care of him.” Ivan began his daily HIV regime immediately, and within six months was undetectable. He was able to regain his health and strength and had successful surgery for his prior health condition. Ivan stated that he only told one person at his church--a social worker who works with HIV-infected patients. He stated that he had a ***small set*** of people to whom he "spilled his guts.” He also has a mentor at church who knows almost everything about him, including his sexual orientation, except that he is a PLWHA. Ivan stated “I don’t want to deal with telling folks I have HIV. I don’t want to have to ‘myth bust’ with everyone.” Thus, he doesn’t talk about his HIV diagnosis. Ivan stated there is *still* ignorance and social stigma associated with HIV. He has heard people in his congregation and the healthcare market make ignorant comments about HIV.

Jakob, Latinx Male

Jakob grew up and was a part of one of the largest evangelical congregations in his state, the Christian Coalition, and worked with key conservative leaders in his community. Jakob is currently a part of the LGBTQIA + population. Jakob stated that he was infected by two casual sexual encounters. He became ill and ended up in the emergency room when his HIV status was confirmed. At the hospital, there were 50 people in the waiting room, concerned about his recent illness. He stated, "I have no words to describe the kind of pressure that was. I was not out at the time and the social pressures were immense. My world was being turned upside down. My CD4 count was 64 at the time." During the time of his HIV diagnosis, he was also living with the senior pastor's family at his church. Jakob recalls knowing that hundreds of people were praying for him at the time of his diagnosis. He could sense peace and the presence of God in that room and he "just knew that it was going to be okay." Jakob's HIV is currently under control; however, he is in stage four kidney failure. Jakob stated that he is not currently in a place in his life where attending church is beneficial. He stated that "part of the problem of returning to his home church is their response to the LGBTQIA+ population group." He feels that he has no support from his former congregation and that the evangelical church, in general, does not understand "what it means to be gay and a Christian."

Kristof, African American Male

Kristof grew up in a conservative evangelical church and identified as a gay man. Throughout his adolescence, he experienced significant religious trauma related to his sexual orientation. He stated, "I was fed, as an openly gay person growing up in a heavily religious family, going to church and what have you, you're told that God doesn't love you, doesn't love your life. You are an abomination. All of this was told and preached to me growing up.” Kristof eventually was “pushed out” of his childhood church. Kristof did not begin going back to church until after he was diagnosed with HIV and was fully open as a gay man. He found a congregation that affirmed sexual orientation and encouraged him to begin what would eventually become one of the biggest HIV/AIDS ministries in a large urban city. Kristof stated that he felt loved and valued by leaders and congregants in his affirming church. Kristof did note, however, that from 2018-2020, he and his partner moved to a different state where they attended a more conservative church. He did not reveal his HIV status to anyone in the congregation. He stated that a reason for moving back to his former state of residence and former congregation was due to the congregational response to the LGBTQIA + population group.

Liam, Caucasian Male

Throughout adolescence and into adulthood, Liam questioned his sexual orientation *and* his faith. Liam struggled with substance use and abuse for several years. Liam tested positive for HIV in 1995, and in 2001, his HIV transitioned into AIDS. He lost his career, his medical insurance, and his private disability. Liam stated, "It was at this point in my journey that I had a significant encounter with the Lord." He has not touched alcohol or drugs since 2001. Liam had always felt marginalized within the evangelical church due to his sexual orientation. Although he had held several positions of leadership within the church, he did not reveal his sexual orientation to anyone, for years. His early experiences with the church, as a closeted gay man and a person living with HIV, led him to create a curriculum for evangelical congregations, nationally and internationally. He has advocated for churches to have honest and open conversations about HIV and sexuality. He has mostly been met with opposition. After 20 years of advocating for PLWHA and the LGBTQIA + population, Liam recently decided to leave the church. He stated, “There is no open door for me in the church. This topic will split the body of Christ. I would rather be in the trenches where I can interact with people who are gay, trans, whatever. Earn a place of trust and try to bridge the gap between these two worlds.”

Lack of knowledge

Lack of knowledge, the second subordinate/personal theme emerging from Multifaceted Stigma, was identified by most participants. They emphasized that a lack of knowledge about HIV/AIDS exists within their respective communities, their congregations, and even within the U.S.A. generally. Even after 40 + years into the HIV/AIDS epidemic, there is still a great deal of stigma and fear rooted in ignorance.

In sharing their HIV status, participants discussed responses from friends, family, church, and community about HIV transmission. In their experiences, they have found this lack of knowledge about HIV transmission existed with both congregational lay leaders and congregants. For example, Bela expressed experiencing ignorance in the church regarding the difference between HIV and AIDS. She recalled a time when a congregant commented about her “AIDS diagnosis,” to which she proceeded to explain that, for her, HIV transmission never transitioned into an AIDS diagnosis. In addition, many participants recall instances when lay leaders of their churches were “preparing for them to die" or "not expecting that they would live." Gabriella recalled working with a young woman in her church who was diagnosed with HIV in 2020. After the woman used the restroom, Gabriella said, her grandmother would follow her around with a bleach bottle. In addition, Gabriella described an interaction with a new congregant. She stated, "When I introduce myself, I say Hello, my name is ____ and I have HIV. And the woman said to me "Wow, you don't have any marks on your face!" I thought, 'What year is this?! We are living in the year 2020!'"

There was little comprehension that HIV is no longer fatal, but chronic, meaning participants can live full lives. Participants reiterated that although the stigma has changed, a variety of mistruths about HIV remain throughout the evangelical church.

Misinformation about HIV transmission was also experienced by participants' medical community. Harold described his encounter with a cohort of third-year medical students in graduate school. Likewise, Gabriella discussed her experiences with various medical professionals upon experiencing symptoms related to HIV:

> In medical school, I faced some obstacles because of my HIV status. Some medical students surprised me and were like "Hey, are you OK if you drink after him? Is she OK if she drinks after you?" I'm like, you're a third-year medical student! I think (HIV) is still not talked about enough. And in evangelical circles…it's just *not* talked about. I don't know anyone else in my evangelical circles with HIV…at my church. I'm sure there is someone, but we've not been connected. (Herold)

> In 2001 and 2003 I went for an annual mammogram. Both times, the results showed that my lymph nodes were swollen. I asked the OB what that could be from. He said it could be my body fighting an infection. I went home and began researching on the internet. HIV was one of the illnesses that came up. I didn't say anything to my primary care physician after the first exam. I was recently divorced. Things were running through my head. But I was like "Nah." I'm a black woman. I knew this existed, but I didn't see a lot of it. After the second exam, I said to my doctor, "HIV was something that came up in my research."' This was a hospital in [her state]. A *really good* hospital. The doctor said "No, you don't have to worry about that-you're not in the population for HIV." So, I didn't worry about it. In 2005, I went to donate blood. The blood bank called me and asked me to come in. When I walked into the room, there was a nurse, psychologist, and doctor. The nurse said, "We tested your donation twice. We need to tell you, you have HIV." I said very plainly, "No, I'm not in the population for that. My doctor told me I wasn't in the population for that so you must have gotten my donation mixed up with someone else!" (Gabriella)

Another example of a lack of knowledge expressed by the participants was the fear of HIV transmission to congregants when PLWHA interacted with children and youth in Sunday school or large church gatherings. Participants described fears of having healthy conversations surrounding sexuality and more specifically, HIV. They emphasized to their congregational lay leaders that "talking about sex is okay." However, in so doing they were often met with responses such as, "If we discuss sex, then we are going to have to discuss sexual orientation." In addition, some participants emphasized that if lay leaders are focused on talking about abstinence, then they must also talk about what abstinence is *not.* According to some of the participants, creating clear definitions of what constitutes sex can help educate and prevent the spread of not only HIV but also other STIs.

Lack of knowledge about HIV contributes to fears within congregations according to the participants. For example, Emmanuel described fear, exclusion, and ignorance from congregants upon disclosing his HIV status. He stated:

> People were afraid to serve me food, etc. My pastor was clear you know, "____ can serve food, eat and be at peace with people". People have been afraid that I might do something to their children, but I don't have any interest in ministry with children. My passion is about sharing the gospel with other men, adult men, especially married people. (Emmanuel)

Felicia and Gabriella expand on the importance of having open and honest conversations about sexuality with church leaders and congregants to combat fears surrounding HIV.

> I was devastated because I, you know, church was my safe spot and you're taught you can let your guard down-- you can be, you can be transparent, and no one will judge you. Really? Okay. I was told that to my face. And I still wonder… I love my church. It's full of sinners, just like myself. But many times, if [HIV] comes

> up, you can see it. You can see it on people's faces, or they don't want to talk about it, which I think is worse because you've got to talk about this stuff. Several times I’ve tried to talk about HIV prevention and education in my church, but it had to be abstinence only. You can’t bury your head in the sand, it's here. (Felicia)

> So, when I joined the church, I said to the pastor, "I need to tell you--I want to start an HIV ministry." He said, “Welllll, Okay.” And I said, "But I need to tell my testimony to the church because I don't want to stigmatize myself. I'm not just starting this group if they don't know about me and what I'm doing.” I said, "So I need to give my testimony to the church.” And he said, "Well, what service”. I said, “The largest.” They had two services. And he said, “Well, let me pray about it. Because I'm really worried about your protection.” I said, “I’m fine!” You know, and I talked to my family. My kids were fine with it. And so, in the 11 o'clock service, I gave my testimony. My father had been his mentor. So, he was kind of well-known in the church. I started with you know, "God takes us through stuff”! Everyone was saying, “Amen! Amen!” Then, I said, "I'm living with HIV.” You could hear crickets. I said, “Now, If I said I had cancer you'd be asking me how you could pray for me, but said 'I had HIV', and now all you're wondering is ‘How did I get it?' " (Gabriella)

Congregants’ beliefs about HIV transmission within certain cultures were also expressed by the participants as a contributor to disinformation about HIV/AIDS. In some congregations, based on the experiences of some participants, HIV was viewed as a form of cultural genocide. In other congregations, belief in existing theological ideologies perpetuated judgment and harmful behavior towards PLWHA who identified as LGBTQIA +. Dora described her congregation's perception of HIV in African American communities. Likewise, Liam discussed his congregational experience with sexual orientation and the LGBTQIA+ community:

> Sometimes when congregations are not educated, and they are set in their ways--that cultural relationship--their values don't change. It's instilled in them. They think about other things that were placed upon them as African Americans. Tuskegee. Experiments. You know, a lot of people [African Americans] believe this disease was invented to wipe out an entire race. African Americans have the highest rate of transmission. We are a minority, with the *highest* rates. (Dora)

> There's an existing theology that allows people to treat someone who identifies as gay as entirely inhumane. Like, you have no value as a person, if you're gay until you "repent of what you do," Those core ideologies express themselves in very judgmental ways. Some of that "angry gay" community that people see out in the world… Evangelicals think the behavior is demonic and that the gay community is our enemy. No! That's behavior that part of the church has to repent and take responsibility for. Humble themselves. I think it's in that place that there could be a release of forgiveness and even grace to allow people to grow, to be more attentive to areas that are different from their comfort zone. God hasn't called us

> to be comfortable. He's called us to be in and amongst the world. Christianity in the U.SA. has become like a private club. We want people that look and act like us. It’s an entire subculture. I can tell you, *that* expression of Christianity is way off! (Liam)

Shame

Shame, the third subordinate/personal theme emerging from Multifaceted Stigma, was also noted by the participants. In some cases, this shame contributed to PLWHA leaving the church. Participants discussed fear of being “turned away” from their churches after disclosure of their diagnosis. They, in turn, chose not to disclose their status, fearful of uncontrolled consequences and rejection from the evangelical community. Participants voiced that congregations were vital avenues for building community and social support, yet they experienced isolation within their congregations due to non-disclosure of their HIV status. Many participants described experiencing judgment via traditional views on sexuality. They explained that evangelical churches not only forgo opportunities to discuss sexuality but also place “sexual sin” in respective categories or levels that are shame-based. For instance, Emmanuel described how LGBTQIA + identities were ridiculed in his congregation. He explained the response of the congregation when an invited speaker shared a pivotal moment in his journey related to sexual orientation:

> We brought a guy here (to the church) to talk about his journey with substance use and back then, nobody knew about my sexual orientation or HIV status. So,

> he was teaching/speaking and recalled the time in his life when he began to be involved with other men. People began to laugh in the congregation.
>
> So, I felt, "How am I gonna share my story? To be seeking help?" Even pastors, not intentionally, will address [sexual orientation] in a funny way. Yeah, but for me, it wasn't funny. At that time, I was like "I hate my life because of this." (Emanuel)

Some participants expressed the notion of shame and self-condemnation by "identifying as their virus." This led to PLWHA internalizing the stigma they experienced, sometimes developing a negative self-image. For example, Gabriella explained the following:

> You know, there's a mark. Sometimes, you even put a mark on yourself… a lot of the women in my group say that "I'm damaged, I'm dirty. I'm sick, or I'm HIV." Not, I have HIV, but I'm HIV. So, you're saying you're a virus?! After my testimony, about three women came up to me and whispered in my ear, "Me too." To this day, I know. You know, people in the church don't know that, but I individually…I talk with them. Even in a group, they're scared to come to the group because they're scared that someone in the church will see them.
>
> So, at first, we changed the name from HIV Ministry to HIV and Chronic Disease Ministry. And then people come because then it's like you could have any chronic disease, and you won't give it away, but *everyone* in the group is living with HIV. It's just the stigma and shame that comes along with HIV.

Other participants reiterated the importance and need to encounter dignity, acceptance, and love within their congregations. Harold indicated that the church should be the most comfortable place to have conversations about HIV, although more times than not, it isn’t. He added,

> There is a lot of influence (in our evangelical churches) from a lot of people that were part of the church pre the AIDS crisis that just don’t want to approach it or make it comfortable to be in a relationship with someone who is HIV positive, even though the disease has changed. They are still holding on to the trauma of crisis and all the other things that came along with it. (Harold)

Moreover, Kristof elaborated on the need to eradicate shame-based HIV perspectives in congregational settings by engaging PLWHA with non-stigmatizing attitudes, providing social support, and treating PLWHA with dignity.

> We spend too much time judging everybody, you know. We (evangelicals) are not good at lifting one another up. That’s the whole purpose of the Bible. The whole purpose of the Christian movement is to show love, lift one another up, and give folks hope. You can’t do that while you’re tearing people down. (Kristof)
>
> Dora added:
>
> If you say you love the people; you love the Lord. Lay down the people before the Lord. Because the Bible says, "If my people will humble themselves and pray and turn away from their wicked ways--they will hear from heaven.” And what do I

> mean by that? “Wicked thoughts” or preconceived notions about people who are HIV +, LGBTQIA +, those who struggle with mental health issues, those imprisoned (wrongfully or rightfully), and people who live in domestic violence situations. They have dignity! Give them their dignity. Don't be their God. Let God be their God. Love above all else. Do not judge. The Bible says, "If you judge, I'll have judgment for you! Allow God to minister to you--BEFORE you open your big ‘ol mouth and say some stupid shit to somebody that you might hurt and devastate for the rest of their life. Tongues bring down nations. Guns and weapons only happen when that tongue says, “Let's do it!” Cease your tongue. Listen to your heart! (Dora)

Power and Oppression

Power and Oppression, the second most prominent theme, focuses on forms of power, oppression, and empowerment participants experienced as PLWHA in their respective evangelical communities. Many participants alluded to feelings of exclusion or exploitation due to their HIV status. Some discussed examples of covert and overt institutional power and privilege found within the evangelical system. They described being silenced from discussing sexuality, excluded from positions of leadership, and targeted due to their sexual orientation by those in positions of power and authority who treated them unjustly. They also indicated avenues in which they regained power by challenging certain ideologies of evangelicalism. By striving to dismantle the oppression that exists in their respective congregations, some participants were empowered not only to experience autonomy from ideologies that limited their freedom but also to use their voices for others in similar situations.

Many participants noted that they are “Jesus followers” who respect the church, but they also know how to maneuver around it because it’s “broken”. In sharing their stories, participants discussed feelings of being excluded and categorized in certain ways due to their HIV status, gender identity, and sexuality. For example, Liam held positions in church leadership but battled internally with his identity and what it meant to follow God. When he was diagnosed with HIV, Liam focused all his efforts on doing what was needed to maintain his health. At first, he chose not to deal with core issues related to his identity since, he explained, “My identity issues pressed into my core battles with the church and what I had experienced. And so, it was a painful area.” In his darkest days of living with HIV, Liam received support through the Gay Men’s Health Crisis Center as opposed to the evangelical church, which only offered him a “five-minute prayer and a closed door.” As a result, Liam began to challenge highly conservative theological positions on sexual orientation in the evangelical church.

Dora belonged to a conservative evangelical church in a large urban city. When asked if she felt her voice was heard in the church she replied, “When they [lay leaders] want it to be heard,” Dora explained that she’s been given a position of leadership within the church to help educate the community on HIV/AIDS, but she admits that her voice is limited. Dora described how such a limitation feels:

> So, you made me a leader…well, actually God made me a leader, you didn’t. So, now you gonna’ shut that leader up? Didn’t you tell me you wanted me to be better than you, the teacher? To rise above? Well, sit back and watch me rise above! No longer will I come under religion or man. God looks all the way down on us and He doesn’t see nobody above anyone else. (Dora, female)

In addition, Dora has experienced a lot of resistance and control from church leadership regarding congregational HIV prevention and education. She described how her church committed in theory to provide outreach to sex workers but in reality, refused to hand out condoms and allow for HIV testing.

Although Attila did not share his HIV status with anyone in his current congregation, he discussed a time when he chose to share his HIV status with members of the Ex-Gay movement. He was asked to contribute to a documentary that sought to convince others that “same-sex orientation is a sin, and that those who are part of the LGBTQIA + community can change.” Attila recalled there being "a lot of pressure to put forward people in their ministry that were great examples of coming out of the gay lifestyle." Attila explained that the Ex-Gay movement was hopeful these narratives would counter the liberal political public policy of the time. His story unknowingly ended up on the internet years later, without his consent. Attila recalled, “That haunted me for probably 10 years. It was stressful and painful. I felt helpless, trapped, exposed, and vulnerable. It was humiliating and shameful and had so many ramifications.”. Attila’s example reflects how evangelical churches can exploit LGBTQIA+ populations and PLWHA, causing harm to them.

Many participants struggled with congregational lay leaders’ dominant theological ideologies of the LGBTQIA + population. Liam explained that some evangelical churches “see no value in you if you’re gay. There’s nothing about you that’s redeemable. That’s what lives in Christian theology. It’s not what you’re doing that’s wrong; it’s *who* you are.” Kristof also described his struggle with lay leaders’ acceptance of his sexual orientation. He was the youth choir director of a highly conservative church for several years. He described a time when the lead pastor of the church suddenly asked him to step down from directing the choir. He described the experience like this:

> When [my partner and I] first joined the church, the pastor that was there, a black minister from the south, had his views, but he let me direct the choir. He didn't make a big deal out of it openly until some of his other ministers were like, "Oh, how can a gay person be up there directing the choir, blah, blah, blah, blah." I stopped going to church for like, a couple of months or whatever, and just praying or whatever. And then I decided to go back, and I stood up in front of the church and said you know, you can't drive me away from God because of your beliefs, you know, so I'm going to direct the choir, and sing in the choir, regardless of what some of the people say.” At the time, he didn't stop me. However, he soon made this declaration that he didn't want no men directing the youth choir. He didn't say he didn't want gay people. He said he didn't want no men, directing the

> youth choir. He only wanted a female director for the youth. So, he tries to get around it and not openly and publicly say, "Hey, I don't want a gay man to direct the kids." He said he didn't want a man, period. You know, I accept me for who I am. I let God do the rest. I love God. The problem is that you’re saying I can’t love God here. I’ve come to the point where I don’t need any walls to love God. (Kristof)

Likewise, Jakob, who identifies as gay and Christian, stated that he still hears church leaders "trashing gay people and gay marriage.” He feels that the church's response to the LGBTQIA+ population has ruined it for an entire generation of people who now hate God. He also mentioned that the only response from the church over the past 35 years is to keep preaching heteronormative interpretations of Scripture. He feels that such teaching is not the answer in moving forward.

Some participants also discussed the prominence of such attributes as “white, straight, and Republican” being evident within the culture of their evangelical congregations. Such attributes, according to them, often made it difficult for their congregations and communities to provide effective HIV care and support services. Other participants identified the privileged position of some evangelical churches. Such a position, according to them, could easily provide support to PLWHA within their congregations. Yet, say the participants, these congregations chose not to because “*they* [PLWHA] got what they deserved.” Csaba, Gabriella, Harold, Kristof, and Jakob agree that those in positions of power within evangelical systems exercise this power when they shut down conversations about HIV and AIDS. Yet, according to these participants, these same individuals want to be perceived as if they are addressing issues about HIV and AIDS, even though they invest little effort in doing so. Gabriella described feelings of exclusion in her congregation as some lay leaders attempted to silence important conversations about sexual health and HIV/AIDS. In so doing, she likens PLWHA, including herself, to the Samaritan woman at the well Jesus ministered to in John 4:

> Evangelical congregations need to understand that it's okay to talk about sex and that HIV is not a death sentence. That we [PLWHA] are NOT lepers. We're not going to be the lepers! Some of us have been standing at the well and are wondering WHY you have not stopped to talk to us. (Gabriella)

In short, the participants in this study are keenly aware that privilege and power exist in evangelicalism. They experienced both overt and covert oppression from their respective congregations as well as the larger evangelical movement. Many participants experienced moments of liberation on individual, community, and systemic levels. These moments of liberation included choosing to leave their congregations. Other times, participants stayed in their congregations to support and empower PLWHA and to help others find their voices within their spheres of influence. Most participants stated that the evangelical church had (and still has) not only the opportunity to look at its behavior toward the LGBTQIA + community, PLWHA, and the HIV/AIDS epidemic but also the responsibility to improve its actions.

Patients as Educators

Due to a lack of knowledge, prevention, and education about HIV in their respective congregations, most participants stated they quickly transitioned from patient to educator to help better equip their faith communities. Upon first receiving news of their diagnosis, most participants recalled yearning for peer and emotional support to help them cope with feelings of denial, anger, fear, and isolation. In addition, some participants grieved not having appropriate resources about HIV/AIDS within their church community. They voiced feeling “alone” as they processed having a chronic illness that is often silenced. They longed for open and honest conversations. Many stated that instrumental support such as practical assistance with the cost of medication and/or medical bills, cooking, cleaning, etc. would have indicated they were a valued part of their congregation. Since many participants lacked congregational support for HIV/AIDS, they were left to navigate becoming the experts of their illness while simultaneously sensing the need to become educators within their faith-based communities. Dora illustrated this need when she stated, “I took care of people with HIV inside the church. My church never talked about HIV until I started going there.”

As participants discussed their desire to promote health and wellness in their congregations, two superordinate or personal experiential themes emerged under From Patient to Educator: the need for congregations to a.) create safe spaces for PLWHA and b.) create HIV-competent communities.

Creating Safe Spaces

Creating safe spaces is critical for PLWHA, according to the participants. Safe spaces, they say, provide an environment of acceptance and belonging, help PLWHA find appropriate treatment, enhance one's quality of life, and assist in addressing vulnerabilities, fear, and stigma surrounding HIV.

Dora and Csaba both discussed the importance of knowing how and when to talk to someone about HIV. After first being diagnosed, Csaba recalled that he sensed empathy from his congregation, yet he also experienced how difficult it was for the church to "know how to deal with me or talk to me." Dora explained the significance of normalizing the conversation around HIV/AIDS:

> I try to sit down and have an open and honest conversation. You can question me; I can question you. We can teach each other and find out how to help one another. I try to educate people in a language they understand. How can we help one another eradicate this virus together? I show them a level of support and assure them they can live good, healthy lives. If I have any hope for the future, I need to give somebody else hope. Until I die, I will educate, or until it's eradicated. I'll either die or [HIV] will be eradicated. That's just keeping it real. (Dora)

Normalizing the conversation and knowing when and how to approach PLWHA can lead to tearing down walls of stigma and shame instead of building them.

Bela created safe spaces in her congregation by advocating for a confidential hotline for congregants or community members to access counseling on issues related to HIV/AIDS. In addition, she worked with lay leaders to establish an HIV/AIDS policy within her church. This policy, she stated, was beneficial for two reasons: “It needed to be present so that people knew we were not afraid to deal with HIV/AIDS and it showed that we were wise in our approach to HIV/AIDS.”

Several participants explained that creating safe spaces involved a delicate balance of transparency, confidentiality, and privacy. Csaba stated, “I don’t give every detail of my journey, but I’m honest about being HIV positive. And now, after 11 years, I’m being open to how and why I acquired HIV.” Csaba’s response indicated that disclosing one’s HIV status comes with benefits and challenges. However, many of the participants felt benefits, such as feeling empowered and combating shame and stigma within their congregations, outweighed the perceived risks.

Creating HIV- Competent Communities

Participants collectively agreed that creating HIV-competent communities within their congregations was critical to improving health and social outcomes for PLWHA as well as decreasing HIV transmission. As HIV transmission rates slowly decrease in the U.S.A., participants emphasized the importance of remembering that each statistic reflects a person and that some of these people are found within the walls of evangelical congregations. Gabriella described it like this:

> We have non-conforming and reconciliation churches but most people living with HIV, whether gay or heterosexual are in traditional churches. So, the church must have programs that accommodate those people. You know, in my opinion, just in the black community, we have one out of nine women living with HIV who don’t

> even know it. So, you can say "I don't know anybody with HIV," but most likely you do. (Gabriella)

Many participants alluded to the importance of not only providing HIV education to congregations but also protection. Some participants explained that it is possible to encourage abstinence, but in the chance that people don't practice abstinence, the provision of protection is critical in reducing the spread of HIV and creating HIV-competent communities. Gabriella gave an example of how to respond to lay leaders who are in opposition to providing protection. She explained, "I sometimes say, well, it's like where I grew up in ____, my father said don't cross the street *but* in case you do, look both ways!" In addition, many participants stated that congregations must understand the risk factors of HIV/AIDS. For example, in one congregation youth were not having vaginal sex, but they were having anal sex and considered themselves virgins. They were in the highest-risk category for HIV transmission, yet when lay leaders inquired about practicing abstinence, these youth were convinced they were.

Each participant reiterated that their congregations are seeking to do good work, but they aren't fully prepared and overlook core issues within their communities. Liam encouraged congregations to seek ways to engage the community. He urged congregations to

> [d]o some introspection in terms of the history of what's happened with many churches, and you know, the HIV/AIDS community. There's no way that you are going to change behavior without addressing core issues. Much of the church is

> insular and program driven. They want people to come and participate in a physical building when God has called us to be out amongst the people. (Liam)

Likewise, participants alluded to going out into the community and sharing their stories, putting a new face to HIV as people of faith, and breaking the stigma that exists in evangelical communities.

For these 12 participants, their determination to become patient educators was important to help to create safe spaces and competent HIV communities within their congregations. They emphasized normalizing conversations about HIV education, care, and prevention. In addition, participants mentioned that creating avenues to show PLWHA they belong is essential. Most participants stressed meeting the person where they are in their health journey. As Bela stated, “To be a competent HIV congregation, it shouldn’t matter how HIV was transmitted.” Remaining approachable for PLWHA to seek support was highlighted. Participants also noted the importance of allowing PLWHA to self-determine what supports are most beneficial. They also emphasized the need for churches to create authentic community connections in places that might feel “out of their comfort zone,” showing communities that they are willing to be an “ally and an advocate.”

Our Voices Matter: What Works and What Doesn’t

Listening to the voices of PLWHA in evangelical congregations reveals what approaches work effectively to support PLWHA. Participants stressed that PLWHA must have a seat at the table in creating social support systems for PLWHA in churches. In sharing their successes and challenges as people of faith who are living with HIV/AIDS, participants described the most effective social support systems within their respective communities. They stressed that HIV/AIDS does not exist in a vacuum and described the various psycho-social stressors that accompany a positive diagnosis. Including the perspectives of PLWHA creates awareness of these psycho-social stressors, in turn helping to establish HIV support systems that are holistic, relevant, successful, and knowledgeable. In short, three personal experiential themes emerged here: a.) HIV's continuing relevance, b.) psycho-social stressors, and c.) effective congregational social support.

HIV's continuing relevance

All participants wanted their faith communities to know that HIV is *still* relevant. Participants stated that over the years, rates of HIV infection have not gone down significantly. For example, according to Bela, "We have the same number of infections year after year. We may not see the epidemic of death that we saw when I was first diagnosed, but HIV is still among us; it needs to be dealt with." Likewise, Gabriella agreed that HIV is currently viewed as irrelevant and expressed concern that youth are missing from the solution:

> People that came before me. ACT UP! They paved the way. They said, "Come On!" So, I was able to be a part of the health council for ___, for getting ___ zero between 2020-2030. We have some fabulous people on the council. City Councilmen, Deputy Mayors, Commissioners, Public Health doctors, etc. They chose me to be a part of the council. When I sit on the council, I see all these

> brilliant men and women. A lot of educated people, BUT only TWO youths! On the whole council. TWO YOUTH! (Gabriella)

Kristof acknowledged that there is a generation of people who can live chronically with HIV as opposed to living with a death sentence. Yet, he yearned for individuals to comprehend what it took for that medical advancement to come to fruition:

> We have a generation of folks who think they can pop a pill and look cute. We watched people die. We watched people DIE! The church says education on HIV 'isn't needed' anymore. Oh yeah, it's needed because now you have people sayin' "I'm not using a condom because I have PreP," dancing around and havin' a blast. That wasn't the life we lived. People died. It's a slap in the face of the people who fought this fight. (Kristof)

Other participants acknowledged similar feelings to Bela, Gabriella, and Kristof. They expressed that some people are less concerned with utilizing protection if their viral load is undetected and CD4 counts are good. There is a perception that people can successfully live with HIV, take medication, and continue to participate in risky behavior.

Participants emphasized the importance of bringing together different generations of PLWHA to learn from one another and grow together. Gabriella described what it might look like if older and younger generations come to the table and empower one another. She stated, "It might be like this, here are some of my greens, give me some of your greens. Let's mix it up and see what we can learn from one another." Bridging the generational divide can bring about transformative and empowering education and prevention interventions for people of all ages.

Psycho-Social Stressors

In addition to the relevance of HIV/AIDS, participants voiced that understanding psycho-social stressors is important in providing holistic care to PLWHA. Most participants discussed their experience with the following co-morbidities: mental health, complex trauma, lack of housing, and lack of access to medication.

Participants unanimously agreed that they struggled with anxiety and depression as it related to their diagnosis. They often expressed facing feelings of "loneliness, anger, stress, shame, and blame." Some participants described having difficulty forgiving others or themselves for how they acquired or transmitted HIV/AIDS. Bela stated, "There are many PLWHA who can't let go of people that have hurt them or people that they've hurt. Many issues related to depression and anxiety are present when I'm helping folks process their pain." Anxiety and depression seemed to be most evident in the initial diagnosis of HIV/AIDS, as Dora explained, "When people are first diagnosed, they are not sure what HIV means. They don't have any hope." In addition, Emanuel recalled his first years of living with HIV, saying, "I was a mess, living day to day, hour to hour, depressed and not knowing what to do." Attila also shared the story of a dear friend who was diagnosed with both HIV and a mental health disorder. He remembered that his friend would often stop taking his bipolar disorder medication, leading him to go off his HIV medication for six to nine months at a time. His health would deteriorate, the virus would mutate, and doctors would put him on another regimen. Attila stated, “Eventually, he ran out of regimens and passed away. But it didn’t need to be that way.” Many participants expressed that the church is often concerned with a congregant's spiritual health but emphasized that physical and mental health are equally important in providing holistic care for PLWHA.

Half of the participants interviewed also discussed the complex trauma that came to light after their HIV/AIDS diagnosis. Some shared stories of childhood sexual abuse as well as trauma related to abuse by the church. For example, Felicia shared that growing up in an alcoholic home where she was also sexually abused by her stepfather attributed to some of her risky behavior as an adult, something she had not processed until she was living with HIV for several years. Like Felicia, Emanual experienced childhood sexual abuse not only by his father but also other male adults in his life. He described that for years he blocked out these memories as a way of coping with trauma. It was not until years after his HIV diagnosis, that he began restoring and processing lost memories due to his dissociative amnesia. Furthermore, Attila, Dora, Jakob, Kristof, and Liam alluded to experiencing “church hurt” or “church trauma” attributed to the non-acceptance of their sexual orientation or engagement in risky behaviors. Some participants left the church, because they felt oppressed, only to return after their HIV diagnosis. Returning to church called for intense counseling to tackle the pain and suffering the church had caused. Participants reiterated that it’s important for

PLWHA to have a safe place where they can process their past hurt and seek restoration. Congregants who populate such a place need to be understanding and sympathetic. Then PLWHA can move forward instead of remaining “stuck” in their trauma or experiencing re-traumatization.

Grief and loss were also evident in participant stories. Several participants were diagnosed in the early 1990s at the height of the epidemic. Some lost a significant number of friends and family to HIV/AIDS, like Emanuel, whose parents both died due to AIDS-related complications. Others had to process survivor’s guilt. Dora, whose two-year-old daughter died from AIDS stated, “At first, I thought that God took my baby because I was a bad mom. But, God said, ‘You ain’t bad, you’ve just been through a lot of stressful things in your life.’” Dora expressed that after receiving intense therapy, she began to understand her complex trauma. She noted, “I fell in love with God again. I fell in love with myself. I began to use my life story to help others who were grieving.” On the other hand, Felicia expressed grief about her choice to be unfaithful to her husband, which led to her and her daughter’s diagnosis with HIV. She stated, “I can't change that one stupid mistake in my life. I would give my life today if I could [sobbing], but I can’t.” Despite her regrets, Felicia does find healing through her ministry, sharing HIV education and prevention.

Lack of housing and access to medication were also psycho-social stressors prevalent in participants' lives. Gabriella stressed that psycho-social stressors are fluid. In her city, she sees an immediate need for housing for those living with HIV but expressed that various psycho-social stressors impact one another. Focusing on the most pressing psycho-social need can then open the door to work on other needs. She explained, “Once you get your mind together, you can then have a house where you can put your meds up, go to doctor appointments, get nutritious meals, etc.” Support for psycho-social stressors is critical for PLWHA to experience holistic health. Access to mental health treatment, trauma-informed care, and grief counseling were prominent themes shared by participants. In addition, access to housing, health care, and medication are challenging social issues that impact PLWHA. Participants reiterated that it’s important for congregations to stay abreast of current social issues impacting their community, learn what best practices relate to psycho-social issues, and learn to love people without an agenda.

Effective Social Support in Congregations

All 12 participants agreed that relationships matter when providing effective social support to PLWHA. Relational support included an emphatic ear, compassion, acceptance, and understanding. Harold illustrated how relationships gave him a sense of belonging when he was at his lowest when he stated, “I was saturated with relationships and people that were for me…people who pursued me…people that desired to have me around.” Likewise, Gabriella recalled a pivotal moment of relational care after revealing her HIV diagnosis to a good friend, who was a pastor:

> His response: I'll never forget it till this day. He said: “Okay, we are coming to dinner on Sunday.’’ And that was his way of telling me ,“I'm not scared of you, I’m coming to your house, you can't say no.’’ He and his whole family came next Sunday. And I'm not really a cook, so it was like, “Okay, well what are we going to eat?!!” It was just, um, that was the most real response. He didn't know what to say, which was fine. But he knew what to do. He said, “I’m not scared of you. I'm not scared of the disease you have. I'm gonna be your friend.” He immediately gave me all the support I needed. (Gabriella)

Many participants stressed that individuals who are knowledgeable about HIV were critical to enhancing their quality of life. In addition, allies who stood beside them, fought stigma on their behalf, and embraced them indicated their value and worth. Dora agreed, “It was important to keep positive people around me who believed in something greater than themselves.”

Participants described support groups and one-on-one counseling as key components of relational support. They shared that when others were vulnerable about their HIV journey, they felt relatable and invited into the conversation. Felicia emphasized, “When you start sharing your heart with people and making it real. They sit up and listen every time.” Some participants voiced that had they not had a place to voice their struggles, they might have given up. Emanuel explained it like this:

> My therapist is not a Christian. He said, “You are doing better than a lot of my other clients with HIV. The reason is not just your adherence to medication, it’s

> your support group." He called it my "support group" but I call it "family and church." Having that kind of support has been so incredibly good for my health. I would not have survived without it. You know, in Spanish, we have two words for "present". One, "in a conversation" and two, "into the life of the matter." We need to be more present [second definition] in one another's lives. (Emanuel)

Bela, on the other hand, sought peer support in her congregation and found none. She noted the lack of Christian resources about HIV. She decided to attend a local, state-funded support group where she met other HIV + women. There, she found women whose faith was also important to them as they lived with HIV. They soon thereafter formed their own faith-based HIV support group.

It's important to note that although many participants had been open about their HIV status within their respective congregations, a few were not. Ivan, for example, indicated that support outside of the church was instrumental in maintaining an undetectable level. He shared, "My social worker called me regularly, at least a couple of times a week, and stayed with me for over a year to make sure I was making doctor appointments and taking my medication." In addition, Jakob expressed that although he held positions of leadership in his congregation, he never felt comfortable revealing his status because "there was no support in the church for anybody who was diagnosed with HIV." Jakob's comment conveys the importance of normalizing the conversation around HIV/AIDS, creating HIV-competent communities in evangelical congregations, and understanding that HIV education and prevention begin with the leaders of the church.

Participant responses showed that in addition to peer support, support groups, and individual counseling, informational support was key to providing PLWHA effective social support. Informational support included relevant HIV resources that are culturally competent, reflecting the demographics of their congregations. Harold described informational support like this: “The church has the opportunity to put information out there to educate not only the congregation at large but also the individuals with HIV to help them know what they need to know in order to care for themselves.” Kristof, in fact, described his role as the “informational gatekeeper” of his congregation. Every month, he would have a table outside of the chapel with information about free HIV/STD testing, case management services, medication, etc. Kristof would briefly converse about health-related or HIV/ AIDS-related issues during the service so that there was constant information conveyed to his congregation. Additional ways of providing informational support in congregations included inviting expert speakers to discuss current trends in HIV/AIDS and providing monetary funds to family members who care for PLWHA. Gabriella discussed an interment initiative that her senior support group created to provide support to families of PLWHA. She stated, “We set up a fund, not a lot, sometimes $2,000, $15,000, or $20,000, but enough to help people be buried with dignity.” In addition, funds established to cover medical costs or the cost of medication proved beneficial since, as Harold stated, his current medication is “$3,000 a month for one pill, one day.” Almost all participants conveyed that staying on their medication regime was one of the most important aspects of maintaining a low viral load, so churches providing financial assistance for such needs can play a vital role not only for such individuals but also for the community.

Participants conveyed that congregations have the potential to be successful at providing social support to PLWHA if they acknowledge that HIV still has relevance, comprehend the multiple psycho-social stressors that accompany HIV/AIDS, and advocate for relational and informational care via support groups, one-on-one counseling, provision of relevant HIV information, medication, and treatment.

Where Do We Fit In?

Identifying (or having identified) as both LGBTQIA+ and evangelical presents complex and unique challenges. Eight of the 12 participants identified as LGBTQIA+. At the time of their interviews, five participants stated they were either “ex-gay,” “practicing sexual purity,” or “married and living with unwanted same-sex attraction.” Three of the eight participants still self-identified as LGBTQIA+.

After Attila made the difficult decision to no longer identify as gay, he joined an interdenominational “ex-gay” evangelical organization. There he found a strong support network that included a significant number of PLWHA. Attila was involved with small-group leadership, attended large conferences, and became a spokesperson for the movement. He recalled the organization being a place where he “felt fully accepted,” saying he “even shared his HIV diagnosis with a small number of individuals he trusted." Attila stated that the network of friends in this organization was its greatest strength because he felt a common bond and a sense of belonging with them. However, Attila also voiced challenges within the movement:

> Ministry leaders were always eager to put forward people that were great examples of people coming out of the [gay] lifestyle. They sort of wanted to hold us up as examples that change is possible and take someone that is articulate and willing to share their story. And they kind of put people out way too soon into the public eye. In the ex-gay world, well, really in the broader evangelical community, we see all sorts of people falling away from the faith in various leadership positions that were just put out way too soon in leadership positions. And then they stumble, and they fall or start to question or waiver. There was just a level of desperation. Desperation isn't the right word, but there was a real desire to put forth people that sort of countered the public… the spirit of the age which said change isn't possible and that people were born gay. You know that whole nature/nurture argument. Are people really born gay? And you have people saying, "Hey I, by the power of Jesus, have walked away from this and have changed"; then that really undercuts the whole nature/nurture argument and the whole born gay conversation. So, a lot of people were really interested in pushing us out there. (Attila)

Attila further explained that sharing his story to benefit the organization and its mission led to some unexpected traumatic moments, not only for him but also for others.

Eventually, in 2013, the organization closed its doors when its president made a public apology for the “shame and guilt its members experienced due to the promotion of sexual orientation change efforts and reparative theories that were stigmatizing.” Upon receiving this news of the organization's closure Attila recalled, “There were a lot of PLWHA in the ‘ex-gay’ world, and after ____ closed, we felt like the rug was pulled out from under us.” He explained that currently both LGBTQIA+ and “ex-gay” leaders have “banned anything that has to do with helping people that want help with this issue,” which leaves individuals like him feeling a sense of “double shame or double stigma,” not knowing where to fit in or where to go for help and support.

Various participants reported diverse marital statuses. For instance, Csaba, Harold, and Emanuel are all currently married with children. Csaba and Harold work directly with ministries that support PLWHA and/or those living with various addiction issues. Ivan, however, is single and strives to practice sexual purity. He is occasionally involved with a support group for “sexual brokenness”. Emanuel is focused on “restoring his health and his family.”

All five participants discussed the complexity of navigating both evangelical and LGBTQIA+ communities. Attila noted. “I think people in evangelical churches want to love people that are self-identifying as gay or even “ex-gay,” but they just don’t know what to do with them.” These participants indicated feeling estranged, misunderstood, and *still* yearning for a sense of community.

Jakob, Liam, and Kristof identify as LGBTQIA+ but currently struggle to find their place among the evangelical community. They each stated that past judgment and condemnation from their congregations have forced them to transition to either affirming congregations or to stop attending church altogether. Jakob explained that his status as a leader within the church kept him "somewhat protected" yet did not permit him to discuss his sexual orientation. Instead, church leaders encouraged him to keep it a secret. He explained his situation this way:

> I didn't completely get ostracized because of my status at the church. I think I was somewhat protected. But I can tell you if I didn't have that status, I would never have been protected. People are mean and they're just vicious because that's just the human condition. And I know many people at that same church that walked away from God because they were treated terribly. I talked to a number of people at that church that hate God now. So, I think that because of my status, I was somewhat protected, which was just kind of a shame. Kind of like "Don't talk about it." In fact, I was told many times not to talk about it. By leaders and senior pastors. I think that the church tends to marginalize gay "sin." And because I spent my entire life working with leaders of the church, they told me, "Don't talk about the gay thing. Don't talk about the gay thing!" (Jacob)

After fully coming out and having his beliefs questioned by his faith community, Jakob left the church. He stated, "Christian evangelicalism is not my tribe anymore." Kristof also discussed the marginalization that gay Christians experience in evangelical congregations. He recalled his experiences being alienated:

> Being openly gay, people put you in a different category than anyone else. You know, folks can get pregnant without being married, they can abuse children, and all that kind of stuff and it's OK. It's overlooked. You can still be a leader in the church because "God will forgive you." But God forbid you're openly gay in the church. Oh, "you're going to hell" and "there's no redemption for you whatsoever!" (Kristof)

Finally, Liam says he had been "[f]ighting to find a place in the body of Christ for 20 years." He expressed that "living between two worlds" was exhausting. Liam consistently experienced disproportionate, disparaging attitudes towards the LGBTQIA+ community. He created a four-session series for church leaders that provided honest, open, and non-judgmental dialogue about sexuality and the church. To his dismay, his curriculum was met with animosity, and he eventually left his church community. These participants indicated feeling marginalized, oppressed, and alienated from their congregations. They *still* yearn for a sense of community.

Mortality With Eternity in Mind

The participants' personal faith experience after an HIV diagnosis also included the complex relationship between their acceptance of their mortality and their beliefs about eternity. All 12 participants stated that their diagnosis of HIV gave them a sense of purpose and direction in their lives. Some alluded to finding a faith relationship while others experienced a deepening of their faith. For example, Bela stated, “Through dealing with my mortality, I found eternity with Jesus. That was important for me because that provided hope. And hope is what is so important for everybody, regardless of your faith. Hope changed everything for me.” In recalling his first night alone after receiving his HIV diagnosis, Jakob explained, “I sensed the presence of God, and I knew I just had to keep keepin’ on.” Harold added, “The only thing I could hold on to after my HIV diagnosis was God.” Moreover, Emanuel expressed that his HIV journey revealed the “hand of God showing me He cares for me and loves me.” Finally, while Csaba felt that his HIV diagnosis gave him a “second chance at life,” Liam said his diagnosis became the “core drive for educating the church and getting involved with prevention and social support efforts.”

Additionally, participants elaborated on the ways that living successfully with HIV changed the trajectory of their lives and has allowed them to help others. Gabriella explained her life’s change in direction:

> My father was a minister. He traveled all over the world and served God and you know, always in the church. And I said, “Daddy, why us? You know you have cancer and I have HIV, you know, the worst of the worst?” And he said, ‘Why not us?’ Which I really couldn't answer. He said, “God doesn't allow you to go through anything that he doesn’t expect you to use.” And so it was a paradigm shift for me at the time. I committed to tell other people and talk to women about this. I went on an entirely different path than I was on. And looking back now,

> it's like I wouldn't have told it any other way. This is such a fulfilling life I have. I hate to say it's a blessing because people think I am like, crazy, but the things I wanted to be able to achieve, without HIV, I would have never been able to achieve. Before my father passed away, he said, “I need you to answer a simple question. If you did what you loved and didn’t worry about how to get paid, what would you do?” And this would be it! This is so rewarding. To empower people where everything has been taken away, their self-worth, who they are. They feel like they're damaged. They feel like they don't deserve to live a life. They don't deserve to have a partner. They don't deserve anything… Yes, this would be it. (Gabriella)

Dora helps coordinate care for PLWHA via government referrals and the provision of mental health, housing, and counseling services. She expressed her new role this way:

> It has been incredibly fulfilling to work with people daily, knowing that I’m also in the same situation. I’ve been in the room when someone is newly diagnosed, to tell them I’m living; to give them hope. Sometimes, this helps people change their perspective. That brings me a lot of joy, to see people change. They’re comin’ in with no hope, suffering. They leave the program with hope. Six or seven months later, they have a new apartment, and their families are restored. That changes people’s quality of life. And, I had a part to do with it! Being a care coordinator; a wounded healer, we MUST have faith *for* other people. (Dora)

Felica’s creation of an HIV ministry helped her understand her “life wasn’t in vain,” “she wasn’t her mistakes,” and she was “doing something constructive for others and myself.” Meanwhile, Jakob fights to decriminalize HIV. He stated, “To criminalize HIV means to stigmatize the individual; to stigmatize the individual means to say that some aspect of your life is shameful. You can’t escape stigmatizing the individual if non-disclosure laws exist.” After learning of his HIV diagnosis, Liam began contributing to international HIV relief work creating HIV testing centers, educating communities on the importance of medication adherence, and conducting Global AIDS conferences. Gabriella established support groups for PLWHA 50 years of age and older. She expressed well why the support groups are important: “My long-term survivors are adhering to medication but dealing with other psycho-social issues. Their friends are mostly dead and they’re lonely.” Kristof, moreover, recalled how God directed his path even in moments of despair. He described his “hunai auntie” as a voice of support and encouragement during trials.

> She would say to me “You’re anointed. You’re going to go through some things but you’re going to survive and have a big influence on people’s lives.” I would look at her like she was crazy, but I’d hear that still small voice throughout my life. During my trial with the church as a gay man, my HIV diagnosis. What I didn’t realize during those times is that God was using me in those moments. The work in ____ [city], the work at _____ [ASO], the work in _____[churches], the work in _____[country]. We were reaching out, helping people, and teaching them how to survive and protect themselves. We did it locally. We did it globally.

> Through my being gay, and being HIV positive, God used me to get His work done. (Kristof)

In summation, most participants conveyed that if they had to do it all over again, they wouldn’t have it any other way.

Conclusion

This chapter described the 12 participants in this study and gave voice to their journeys, experiences, and perspectives on social support within evangelical congregations. These perspectives revealed six main themes regarding the multifaceted stigma PLWHA experience, the power they seek to attain amid the oppression they face, their roles as educators in their churches and communities, their successes and failures at finding belonging, and the ways they live in the liminal space between their mortality and beliefs about eternity. Chapter six analyzes and compares these themes to the literature on social support and PLWHA.

CHAPTER 6

DISCUSSION OF FINDINGS

Multifaceted Stigma

Multifaceted Stigma emerged as the most prominent theme. Although a few participants felt accepted and supported by their congregations, the majority experienced rejection, isolation, and being afraid to disclose their HIV status. Underpinning these experiences, according to the participants in this study, were congregational discrimination, ignorance, and negative attitudes or beliefs about HIV based on a general lack of knowledge about the virus. Such behavior on the part of their congregations promoted stigma and feelings of shame.

The experiences of the participants are consistent with the literature (DeSantis & Barroso, 2011; Lapinski et al., 2010; Shehan et al., 2005). Congregational views towards PLWHA are highly associated with HIV risk behavior (Bluthenthal et al., 2012; Muturi, 2010; Qiao et al., 2014). Several participants acknowledged this to be accurate, especially those who contracted HIV through male-to-male transmission. According to the participants, most of their congregations adhered to a set of conservative theological positions that contribute to stigma and shame, based solely on sexual orientation. Participants felt these congregational positions negatively impacted their health, created fear around disclosing their illness, and made them hesitant to seek out critical support systems.

The findings align with Serovich's consequence theory of HIV disclosure (Serovich et al., 2008) and the literature in terms of a high correlation between HIV stigma and HIV disclosure. Negative congregational responses resulted in spiritual distance and, for some, changing places of worship.

Participants expressed the importance of having honest conversations about HIV stigma, prevention, sexual health, and sexuality to critically confront the virus. They expressed that many of their congregations were unsuccessful in facilitating these discussions. This led to dispositions of "don't ask, don't tell", deterring them from revealing their sexual orientation, and their HIV status: a double stigma. Their experiences are consistent with findings in the literature suggesting that congregations refusing to discuss issues pertaining to sexuality will also not discuss HIV (Adedoyin, 2013; Aholou et al., 2011, 2016; Bauer, 2013; Brennan et al., 2010; Derose et al., 2010, 2011; Frenk & Trinitapoli, 2013; Green & Ruark, 2008; Leong, 2005, 2006; Mulye et al., 2005; Tesoriero, 2000). Multifaceted stigma contributes to feelings of shame, self-condemnation, and negative self-image for PLWHA.

Psycho-Social Stressors

Participants also discussed a variety of psycho-social stressors associated with their HIV diagnosis. Depression and/or anxiety were most prevalent, followed by complex trauma, grief, and loss. They expressed the importance of holistic care that focuses on physical, mental, *and* spiritual support. They reiterated the presence of social support services and safe spaces where they can process hurt, and pain, and seek restoration. These supports, according to the participants, are beneficial to reducing symptoms of depression, anxiety, and stigma related to HIV. As persons of faith, most participants expressed the importance of having these networks within their faith-based community or congregation.

Received and Perceived Support

The literature suggests congregations as potential sources of support for PLWHA (Lichtenstein et al. 2010; Reed & Miller, 2013; Rajabiun et al., 2021; Rosenthal, 2023). Supports such as received and perceived support can improve quality of life while decreasing at-risk behavior and HIV stigma (Alsubaie et al., 2019; Helgeson, 2003; Li et al., 2021; Reilly & Woo, 2004; Siegel & Schrimshaw, 2002; Szkody & McKinney, 2019,). For participants, received supports in the form of involvement with HIV ministries, HIV treatment teams, ASO's, and HIV peer support groups are most beneficial. Three participants identified having received support within their congregational setting: Emanuel, whose family and lay leaders partnered together to provide emotional, medical, and spiritual support; Kristof whose affirming congregation took a very active role in HIV advocacy, support, education, and prevention; and Gabriella, who led support groups for women living with HIV.

Few participants experienced having a sense of perceived support within their congregations. They felt their congregational networks would not be supportive in helping them navigate and/or buffer the psycho-social stress associated with HIV/AIDS. Neither did they perceive their congregations as HIV-competent communities or safe spaces to disclose or discuss HIV/AIDS. Lack of perceived support made it difficult for these participants to cope with feelings of denial, anger, fear, and isolation.

Congruent with the literature (Thoits, 2011, 2021; Szkody & McKinney, 2019) participants identified the importance of having primary and secondary sources of social support. Primary support such as family and friends who are allied to PLWHA allowed participants to be vulnerable, open, and honest regarding their HIV journey. As a result, they felt valued, loved, and accepted. Secondary sources such as peer support groups, networking with other PLWHA, and interacting with individuals who are knowledgeable about HIV were viewed as valuable resources by the participants. They all agreed that primary and secondary sources of support provided them with a sense of self-worth, acceptance, and belonging. Having these support networks and relationships significantly reduced their anxiety, HIV stigma, and contributed to improving their overall well-being. Participants also acknowledged the importance of emotional, informational, and instrumental support. Such supports, they said, help with adherence to medication, access to health care, self-management of HIV, emotional well-being, and overall quality of life. In addition to these supports, participants expressed the importance of having access to culturally relevant, up-to-date information about HIV that reflects the demographics of their church. Tangible support such as monetary funds to offset the cost of medication, medical costs, and other health needs was also mentioned.

Evangelical congregations are vital avenues for building community and social supports. When these supports are not available, according to many of the participants, they found themselves alone in navigating their illness. For these participants, it was important for them to act on their own behalf. As such they assumed roles within their congregations to educate about HIV and facilitate opportunities for the provision of social support to PLWHA. The action taken by these participants moved their congregations toward being more supportive of PLWHA and being more HIV/AIDS competent. Their experiences suggest that congregations are well-positioned to provide network or community support to PLWHA. Congregations have the potential to be collaborative partners in creating community resources; to help people seek treatment, adhere to treatment, and decrease at-risk behavior (Frenk & Trinitapoli, 2013; Rajabiun, 2021; Reese & Kaplan, 2000; Rosenthal, 2023). Historically, according to the participants, this potential has been overlooked and congregations have not been responsive or sensitive to the many challenges faced by PLWHA.

Spirituality and AOP

Congregational leader responses to HIV/AIDS attributed to participants feeling either empowered or oppressed within their respective congregations. These beliefs align with the literature about cultural oppression and AOP (Canda, 2008; Dominelli, 2002; Marsigha & Kulis, 2009; Mullaly, 2010). Dominant evangelical negative cultural structures and stereotypes were the norm within most participants' respective congregations. Often, their congregations would determine whose voices were heard or silenced, ultimately limiting the provision of social support. At times, they exhibited social control by trying to restrict or control behavior associated with HIV. As a result, participants frequently felt isolated, blamed, and judged. Some participants, however, reacted by way of resistance, challenging congregational negative attitudes, beliefs, and stereotypes. They sought to empower others whose stories were like their own. There was a distinct difference between participants who empowered themselves to advocate versus those who still live in fear. For example, some participants were fearful of rejection from others, or how disclosure of HIV might impact their career. However, others overcame barriers related to HIV and found the power within to make positive changes in their circles of influence.

Engaging in active HIV advocacy roles within their congregations and/or communities provided a sense of purpose to participants. These roles include directing community ASO's, creating support groups for those living with chronic illness, creating HIV/AIDS-specific church ministries focused on education and prevention, and advocating for policy change regarding STD and HIV criminalization laws. Remaining active in HIV work equipped participants to create positive health outcomes while providing hope and encouragement to PLWHA.

For some, religiosity and/or spirituality improve quality of life as they live with HIV/AIDS. In fact, every participant in this study expressed having found spiritual meaning in response to their HIV or AIDS diagnosis. For some with a previous faith relationship, their faith strengthened. Others renewed their belief in God and/or discovered faith in God for the first time.

Although all participants expressed that their faith was an important component in managing their quality of life, some *still* struggled to find a place of belonging within their faith communities. These participants found complexity in navigating identity conflict with their faith and sexual identity. Living between two worlds, they grappled to understand where they fit in. They did not feel fully a part of the LGBTQIA community, nor did they feel fully a part of the evangelical community. Some navigated to affirming churches, one left the church altogether, and others stayed because there was no other viable option. AOP literature alludes to the notion of simultaneous oppression and empowerment (Caufield, 2015; Sharma, 2008). These participants often experienced the sense of empowering community that historically defined their congregations while simultaneously being subjected to potentially oppressive views about PLWHA from those same congregations.

Significance of the Study

First, this study is significant because HIV is *still* a relevant issue. New HIV transmission rates have only dropped 12% between 2017 and 2021 in the U.S.A. (CDC, 2021). Approximately 1.2 million people in the U.S.A. are currently diagnosed with HIV. People *still* die from HIV/AIDS every year; individuals are *still* unaware of their HIV status; HIV has a disproportionate impact on certain groups; and some individuals are not receiving effective, life-saving treatment (CDC, 2021). In 2019, the U.S. Department of Health and Human Services (HHS) proposed a plan that aims to end the HIV epidemic in the U.S.A. by 2030 (HHS, 2023). Decreasing HIV by 90% in 2030, as HHS suggests, entails innovative, community-driven solutions for reducing HIV transmission. Congregations, based on the views of the participants in this study, are uniquely positioned to respond to the HIV crisis.

Second, this study is presented from an Anti-Oppressive perspective. The findings give voice to PLWHA and provide a glimpse into the individual, cultural, and structural oppression they experienced within evangelical congregations. It also illuminates the ways that PLWHA challenged and combated injustice and oppression within their faith communities to change the status quo. This approach is consistent with the conceptual frameworks of Anti-Oppressive Practice. In addition, the qualitative methodology amplified the voices of PLWHA and their lived experiences of social support within these congregations.

Third, this study can help identify both the congregational stigma of HIV/AIDS, the lack of knowledge pertaining to HIV/AIDS, and avenues of effective social support for PLWHA. Information from this study can provide a good starting point for important and relevant conversations about HIV/AIDS to create impactful, meaningful support for PLWHA.

Implications for Practice and the Social Work Profession

Based on their stories the most valued resource to bring about change in congregations and their communities is PLWHA themselves. As stated by both Liam and Gabriella, a key role for congregations and communities is to recognize and support this most valuable resource. In that sense, congregations are best positioned to create opportunities for PLWHA to discover their power individually and collectively. These opportunities come in the form of collaborative partnerships, building relationships with PLWHA based on reciprocal acceptance, caring, respect, trust, and responsibility as exemplified in the supportive response by Gabriella’s pastor or Felicia’s vulnerability in sharing her story with others. A relationship is not a feeling, it is an action. The social work profession has a key role to play in building relationships and facilitating this action. As a profession it understands that one must act respectfully to gain respect, one must care about others to be cared about, and one has to demonstrate respect in order to be respected. These actions are critical on the part of congregations, lay leaders, clergy, communities and PLWHA. Relationships based on these actions identify with the empowerment of all parties, not just PLWHA but also congregations and their members. Everyone must be empowered to deal with the challenges of the HIV epidemic and for PLWHA. It is not unlike the COVID-19 pandemic. Health officials worldwide recognized the importance of working in partnership with the public to respond to COVID-19. The officials, as the experts in health care promoted awareness, education, cooperation, sensitivity, and necessary actions and behaviors to reduce COVID-19 transmission. PLWHA to be recognized as key experts and leaders within their congregations and communities can do the same. As Dora so eloquently pointed out, “PLWHA must have a seat at the table in creating social support systems for PLWHA in churches.” Inaction creates oppression; therefore, congregations must work in tandem with PLWHA and professions such as social work to provide effective HIV-competent communities.

Ideal HIV-Competent Communities

Participants put forth several suggestions to assist congregations in becoming collaborative partners and being HIV-competent. First, normalize the conversation about

HIV/AIDS, sexuality, and sexual orientation. Normalizing the conversation would help to reduce the transmission of HIV/AIDS, improve health and social outcomes for PLWHA, and better address psycho-social stressors like fear, stigma, and shame (Landry, 2011; McQueeney, 2009; Murr, 2013; Shore-Goss & Bohache, 2013). Second, create faith-based networks that do not conflict with the values and norms of specific HIV people groups, and allow for diversity and tolerance of issues related to HIV. Third, shift from internally focused support to externally focused support. Engaging the community to better understand the multiple layers of oppression experienced by PLWHA can help provide critical HIV community-based support. Providing community linkages to better care for people living with chronic illness, like the Community Care Model, was discussed. According to the literature, within Evangelicalism, the Black Church has made the most strides in creating social service support and creating competent HIV communities. This was evident in participant stories like Dora, Gabriella, and Kristof. The initiatives of the Black Church (Adedoyin, 2013; Aholou et al., 2016; Fulton, 2011) can be a template for what needs to be done in terms of recommendations to policymakers, service providers, congregations, and communities. Several participants strive to bring congregations into the HIV conversation, working to establish community partnerships. However, they voiced that effective HIV education, prevention, and support must be supported and encouraged not only by PLWHA but also by the leaders of the church.

The Social Work Profession and PLWHA

With a dual purpose of enhancing human well-being and functioning and the alleviation of poverty and oppression, the social work profession has a significant role to playing in assisting and supporting PLWHA and their congregations. It is a profession committed to social justice while working with individuals, families, communities, groups, organizations, and society in general. All are important according to the voices and stories of the participants. For example, Ivan stated that his social worker "assessed his need for housing, called him regularly to discuss adherence to medication, and made sure he continued to attend important medical appointments." Ivan received case management for one year after his initial diagnosis. He is now undetectable. Harold was assigned an HIV social worker in the prison system who utilized Ryan White funding to provide lifesaving medication. He is also currently undetectable. Social workers provide lifesaving skills that enhance quality of life for PLWHA. These skills include HIV related case management, counseling, community development, group work, and advocacy. In addition, community partnerships and referrals, continuum of care, and a person-centered approach are critical for working effectively with PLWHA (Poindexter, 2010; Rowan, 2013).

Congregational Social Work

Congregational social workers provide a resource of professional clinical knowledge and skills by striving to understand members' needs, working to connect members to appropriate outside resources, and equipping the congregation for social action (Garland et al., 2008; Garland & Yancey, 2012, p. 320). Garland and Yancey (2012) describe congregations as a unique, holistic, and distinctive context to practice social work. This field of practice can assess the needs and wants of PLWHA who are isolated, stigmatized, or afraid of rejection by others. A social worker engaged in congregational work can build bridges between PLWHA, congregations, and the community at large. They are well positioned to intervene in crises, create safe spaces for PLWHA, provide education and prevention of HIV, and collaborate with other social service programs that would enhance the quality of life for PLWHA (Tan, 2013).

Areas for Future Research

One finding that does not appear in the literature is the complexity involved in PLWHA’s identity conflict between their evangelical faith and their sexual identity. Having one foot in each space makes them feel as though they don’t have a community in either. Further research about identity conflict, specifically with this subpopulation, would prove beneficial. Another key finding that does not appear in the literature is PLWHA’s perception that HIV gave meaning, a sense of purpose, and/or changed the trajectory of their life for the better. All 12 participants alluded to the aforementioned. Further research examining the intersection of faith, life purpose or meaning, and HIV is important to overall well-being and quality of life for PLWHA.

Limitations

There were several limitations to conducting this qualitative study. Although 12 participants were sufficient for the saturation of the data, they may not have been representative of all risk groups for HIV or AIDS. For example, in 2019, the highest rate of HIV infection was among those persons aged 25-34 (CDC, 2021). All the participants in this study were over the age of 35 years of age.

A second limitation of this study was that all participants identified as Evangelical. The voices of PLWHA from different faith perspectives were not represented in this study. Therefore, the findings in this study may not be generalizable to the larger population of faith denominations and congregations.

The third limitation was the format of the interview. Four interviews were conducted face-to-face directly prior to the COVID-19 pandemic. The remainder of the interviews were conducted virtually using Zoom. At times, virtual interviews limited the relational interaction of the researcher and participant. Observances of non-verbal cues and pauses were hard to decipher and may have impacted the collection of important contextual information. At the same time, the use of Zoom as a platform for data collection proved convenient, cost and time-effective, and safe for all parties.

The last limitation of this study was the role of the researcher. Various parts of this study, from data collection to the interpretation of the findings, were shaped by me. My bias, my faith, my identity as a Caucasian female, and my experiences in the HIV and AIDS field of social work all influenced this study. However, I felt it imperative to fully encapsulate the counternarratives of the 12 participants and portray, as best as I could, their lived experiences.

Conclusion

Contemporary society is fraught with difficulties and challenges, indeed in the eyes of many, a society in a state of crisis. The crisis is rooted in political and economic uncertainty, environmental and climate impacts, and tensions at all levels resulting in strained relationships within and between nations throughout the world. Poverty and oppression continue to be the two fundamental barriers interfering with individual and collective functioning. As such, we are a society where there is ample evidence of racism, ageism, sexism, ableism, eroding health, and violence. Amidst these persistent and ongoing crises came the COVID-19 pandemic. COVID-19 taught us many things. It was a virus that touched each one of us individually and collectively. It especially heightened our awareness of how interconnected and vulnerable we are. COVID affected the powerful and the powerless, the rich and the poor, the oppressors and the oppressed, and it respected no borders across the world. It also taught us the importance of individual and collective responsibility and collaboration, and how it is essential to bring together political, economic, community, and spiritual assets and resources to take action for treatment and prevention so all can benefit.

Participants in this study know firsthand what it feels like to be vulnerable, to be fearful, to feel isolation and shame. They know all too well what it takes to find hope when you feel hopeless, to find a sense of belonging when you feel alone, to have a feeling of worth when you feel worthless, and what it takes to find an inner strength to uncover and discover their personal and collective power to support and assist PLWHA. Their stories and experiences suggest a way forward. PLWHA are critical resources and assets in dealing with this illness. Their voices must be heard on their journey to help themselves and others in coping with HIV. It is within the realm of churches, educational institutions, health authorities, human service organizations, and various professional associations such as social work, law, clergy, and many others to create opportunities so PLWHA can be heard in a meaningful way. We all have a role to play in creating HIV-competent communities.

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Appendix A: Invitation to Participate in Research

Date:

My name is Julie Furj-Kuhn. I am a PhD candidate at Memorial University's School of Social Work in Newfoundland and Labrador, Canada. I am writing to invite you to participate in my doctoral dissertation study entitled "Understanding How People Living with HIV/AIDS (PLWHA) Experience Social Support in Evangelical Congregations"

This research study explores the lived experiences of People Living With HIV/AIDS (PLWHA) in evangelical congregations and their social support systems. It involves completing an interview that will take approximately 1-1.5 hours. An eligible participant in this study will have a diagnosis of HIV/AIDS; have a connection to an evangelical congregation; be a minimum age of 18.

Participation in this research is completely voluntary and you may choose to withdraw from the research at any time or not answer questions that you do not feel comfortable answering prior to data collection of the study. Should you choose to participate in this study you will be asked to sign an informed consent form that you can read below. It outlines pertinent information about the study. You may have received this recruitment letter from a community HIV/AIDS service organization or national forum. These groups have graciously agreed to assist me with my study recruitment, but this study is not affiliated with them in any way. Participating in my study is not a requirement of these groups, they will not know who does or does not respond to this letter, and/or participate in the study. If you have any questions, please contact me directly. Likewise, if you know someone interested in this study, please have them contact me directly.

The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics in Human Research and found to be in compliance with Memorial University's ethics policy. If you have ethical concerns about the research (such as the way you have been treated or your rights as a participant), you may contact the Chairperson of the ICEHR at icehr@mun.ca or by telephone at 709-864-2861.

Are you interested in participating?

If you meet the criteria for this study, have any questions about the study and/or are interested in participating, please contact me by phone at 614-806-0493 or by email at jkuhnmun@gmail.com so that we can arrange an interview. You may also contact my research supervisor, Dr. Ken Barter at kbarter@mun.ca if you have any questions or concerns about the study. I value your participation and thank you for your commitment of time, energy, and effort.

Julie Furj-Kuhn, MSW

Associate Professor of Social Work

Southeastern University

PhD Candidate, Memorial University of Newfoundland

Appendix B

Lived experiences of People Living With HIV/AIDS (PLWHA) in evangelical congregations and their social support systems.

This doctoral dissertation study involves completing an interview that will take approximately 1-1.5 hours. Participants will be asked questions about being a part of an evangelical congregation, including provision of social support services and interventions to congregational members who identify as evangelical and are also diagnosed with HIV or AIDS. In addition, PLWHA will be asked about their lived experiences as they've interfaced with evangelical social support systems. Are they empowered or oppressed? Also, do PLWHA feel that their voices are represented in evangelical social support systems and congregations.

Eligibility criteria for the study:

- **18 years of age**
- **A diagnosis of HIV/AIDS**
- **Have a connection to an Evangelical congregation**

All information will be kept strictly confidential. If you may be interested in this study, or if you are unsure if you meet the requirements, call or email:

- Julie Furj-Kuhn, MSW
- PhD Candidate, Memorial University
- Associate Professor of Social Work Southeastern University
- jkuhnmun@gmail.com
- 614-806-0493

Ethics Approval

The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics in Human Research and found to be in compliance with Memorial University's ethics policy. If you have ethical concerns about the research (such as the way you have been treated or your rights as a participant), you may contact the Chairperson of the ICEHR at icehr@mun.ca or by telephone at 709-864-2861.

If you are 18 or older, have a diagnosis of HIV or AIDS and have a connection to an Evangelical congregation, you may be eligible to participate in a research study.

CONTACT: Julie Furj-Kuhn (jkuhnmun@gmail.com)

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http://www.mun.ca/socwrk

Appendix C: Informed Consent Form

Title: Understanding How People Living with HIV/AIDS (PLWHA) Experience Social Support in Evangelical Congregations

Researcher: Julie Furj-Kuhn, MSW
PhD Candidate, Memorial University of Newfoundland
Associate Professor of Social Work
Southeastern University

You are invited to take part in a research study entitled "Understanding How People Living with HIV/AIDS (PLWHA) Experience Social Support in Evangelical Congregations".

This form is part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. It also describes your right to withdraw from the study. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is the informed consent process. Take time to read this carefully and to understand the information given to you. Please contact the researcher, Julie Furj-Kuhn, if you have any questions about the study or would like more information before you consent.

It is entirely up to you to decide whether to take part in this research. If you choose not to take part in this research or if you decide to withdraw from the research once it has started, there will be no negative consequences for you, now or in the future.

Purpose of the Study

This study aims to address four fundamental questions as it pertains to PLWHA who are associated with evangelical congregations. First, Do evangelical congregations provide social support services and interventions to their members who identify as evangelical and are also diagnosed with HIV or AIDS? Second, What are the lived experiences of PLWHA who interface with evangelical social support systems? Third, Do PLWHA feel empowered or oppressed when receiving support within their congregations? Fourth, Are the voices of PLWHA represented in evangelical social support systems and congregations?

Exploring these questions will help to contribute to the research, which is currently limited, around the dichotomy of congregational oppression and empowerment of PLWHA and the psycho-social impact this dichotomy has in relation to HIV health.

About the Researcher

This research is part of my PhD studies at Memorial University of Newfoundland, Canada. I completed my Bachelor's degree in Social Work and Bible at Philadelphia Biblical University and my Master's of Social Work at The University of Pennsylvania. I have been an Associate Professor of Social Work for the past 10 years. Before teaching, I coordinated the Penn Center for AIDS Research Community Advisory Board (CAB) in Philadelphia, PA. In this role, I helped to mediate between the research community and the HIV community, as the CAB's mission was to foster partnerships and maintain open communication between Penn CFAR researchers and the community. My assistance ensured that any study conducted, pertaining to HIV/AIDS in the Behavioral and Social Science Core, included the voice of the HIV/AIDS community in Philadelphia. The CAB was made up of PLWHA, HIV educators, legislators, researchers, faith leaders, and directors of AIDS Service Organizations (ASO).

Summary of Methodology

I plan to interview anywhere from 10-15 participants who meet the criteria for the study. Participants will be accepted by purposive and snowball sampling, meaning that I would like to interview individuals who share a common experience but who also live in various places around the U.S.A. I hope to understand shared meanings and the essence of what it is like for someone living with HIV/AIDS to be a part of an evangelical congregation. You, as a participant, will be asked to recall specific accounts, situations, or events that you experienced as part of an evangelical congregation. I am seeking stories, thoughts, feelings, and behaviors associated with your experience. If you agree to participate in the study, I will contact you by phone to find out more about your placement as part of the selection process. If you meet the selection criteria, I will set up a time to interview you at a location that is convenient for you. If you do not meet the selection criteria, I will send you an email letting you know. I will interview participants, record and transcribe the interviews and draw out themes to develop conclusions.

Inclusion Criteria and Description of Interviews

If you meet the criteria of the study and agree to participate, a time will be arranged for you to meet with the researcher at a location that is convenient for you. You will participate in a one-on-one private interview for approximately one to one and a half hours. You will be asked about your lived experience as a PLWHA who attends (or attended) an evangelical congregation and what types of social support systems were or were not available to you during this time. The interview will be digitally or virtually recorded and transcribed. Your participation is voluntary. You may refuse to answer any question in the study. You may withdraw from participating in the study without question or penalty and all your data will be removed from the study until March 31, 2020.

Following completion of your interview, I will begin analysis of your interview, drawing out themes within and between interviews. Upon completion of this analysis, you will be given an opportunity to see these conclusions in written form and give any more feedback you have on these initial results. At times, a second interview may be pertinent. This can help me deal more effectively with bias, close any gaps in the data, or clarify information discussed in the initial interview. Your feedback will be included as final thematic analysis is developed and conclusions are made. At your request, I will provide a copy of the transcript. Alternatively, a website will be set up to review the findings.

Advisory Committee

A committee will be formed following the completion of data analysis in order to provide feedback regarding perceived social support needs for PLWHA, avenues for evangelical congregations to create social support systems, and paths to create more HIV competent communities. This committee will also offer recommendations for dissemination of research findings to key HIV/AIDS community partners as well as faith-based communities.

This committee will be recommended by the National Center for AIDS Research Community Advisory Board Coalition (NCCC). The committee will consist of no more than six members whose roles in the community include: clergy, PLWHA, and social support workers (non-evangelical and evangelical). No identifying information about research participants will be shared with the Committee without participant consent. All identifying information will be removed from the data and be replaced with a pseudonym. For the purposes of ensuring the proper monitoring of the research study, the Committee will only have access to research data once personal information has been removed.

Confidentiality of Information

Your information will not be shared without your consent unless required by law. All identifying information will be removed from the data and be replaced with a pseudonym. The recording will be transcribed by the researcher or a research assistant who has signed an agreement to keep all information confidential. For the purposes of ensuring the proper monitoring of the research study, it is possible that my supervisor, Dr. Ken Barter of Memorial University of Newfoundland may also have access to your research data once your personal information has been removed.

Reporting of Results

The results of this research will be reported in a written dissertation that will be orally defended and published. The results of this research will also be disseminated through journal articles and professional presentations. Summaries of overall themes and direct quotations will be utilized while keeping confidentiality as names and other identifying information will not be given. In addition, the thesis will be available at Memorial University's Queen Elizabeth II library, and publicly accessible at http://collections.mun.ca/cdm/search/collection/theses .

Storage of Data:

All identifiable recorded and written information will be kept in a locked location only accessible to the researcher. Data will be kept for a minimum of five years, as per Memorial University policy on Integrity in Scholarly Research. If results of the study are published, your name and identity will not be disclosed.

Risks and Benefits

To agree to participate in a phenomenological study can be risky, especially for those who are part of oppressed population groups. Discussing emotional experiences could likewise be perilous for those who are already part of marginalized population groups, such as those living with HIV/AIDS. As a researcher, I want to be cognizant that you may be sharing these experiences for the first time. If you find that you are experiencing distress after the interview, please contact the following organizations that will refer you to an appropriate service or counselor in your local area:

National Alliance on Mental Health (NAMI): https://www.nami.org/find-your-local-nami (click on state, county or region, and call the office for referral information)

Mental Health America (MHA): https://www.mentalhealthamerica.net/

State HIV/AIDS Helpline: https://hab.hrsa.gov/get-care/state-hivaids-hotlines

HIV non-disclosure law:

The Centers for Disease and Control and Prevention report that in 19 states, the law requires persons who are aware that they have HIV to disclose their status to sexual partners. In addition, 12 states require disclosure to needle-sharing partners. If any participant may come under the jurisdiction of these laws when sharing information in this study, I will have no option but to comply. For more information on these laws please refer to this link: https://www.cdc.gov/hiv/policies/law/states/exposure.html

The benefits of this study are believed to outweigh the risks. A basic premise in phenomenological research is to make sense of one's experience. As a researcher, when I seek to reach an understanding of life experiences, the richness of meaning within these experiences emerges. Findings can develop into beautiful stories that encourage, direct, touch, and help others who may be on the same journey. Knowledge from this study can help social workers, lay leaders, and congregants to understand the lived experience of PLWHA. Data from the study could aid assist congregations in advocating for and brokering with members living with HIV/AIDS to help meet their bio-psycho-social and spiritual needs. Religious congregations can provide an HIV support network to its members, and social workers have the unique opportunity to establish a significant relationship with the evangelical community to advocate for HIV-related social support systems, prevention, outreach, ministries, and policies. Information from this study could also provide an excellent starting point for important and relevant conversations about HIV/AIDS within the evangelical community.

Ethics Approval

The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics in Human Research and found to be in compliance with Memorial University's ethics policy. If you have ethical concerns about the research (such as the way you have been treated or your rights as a participant), you may contact the Chairperson of the ICEHR at icehr@mun.ca or by telephone at 709-864-2861.

Consent:

Your signature on this form means that:

- You have read the information about the research.
- You meet the criteria that was outlined for participation in this study.

- You understand what the study is about and what you will be doing.
- Any information you provide, including your identity, will be held in the strictest confidence and used only for the purpose of this study which was explained to you.
- Your identity will remain confidential.
- The interview may take from 1 – 1 ½ hours to complete and that with your permission you may be contacted for a second interview.
- You can refuse to answer any question you are not comfortable with.
- You will be given the opportunity to review the results of the data during data collection.
- You will have access to study results via a website given to you at the conclusion of your participation.
- You have been able to ask questions about this study.
- You are satisfied with the answers to all your questions.
- You understand that you are free to withdraw participation in the study without having to give a reason, and that doing so will not affect you now or in the future.
- You understand that your participation is voluntary, and you may withdraw at any time up until the end of data collection. The final date for data collection will be March 31, 2020. If you choose to end participation during data collection (prior to March 31, 2020), any data collected from you up to that point will be destroyed. After March 31, 2020, all data collected from you cannot be removed.

I agree to be audio-recorded ☐ Yes ☐ No

I agree to the use of direct quotations ☐ Yes ☐ No

By signing this form, you do not give up your legal rights and do not release the researchers from their professional responsibilities.

Your Signature Confirms:

☐ I have read what this study is about and understood the risks and benefits. I have had adequate time to think about this and had the opportunity to ask questions and my questions have been answered.

☐ I agree to participate in the research project understanding the risks and contributions of my participation, that my participation is voluntary, and that I may end my participation.

☐ A copy of this Informed Consent Form has been given to me for my records.

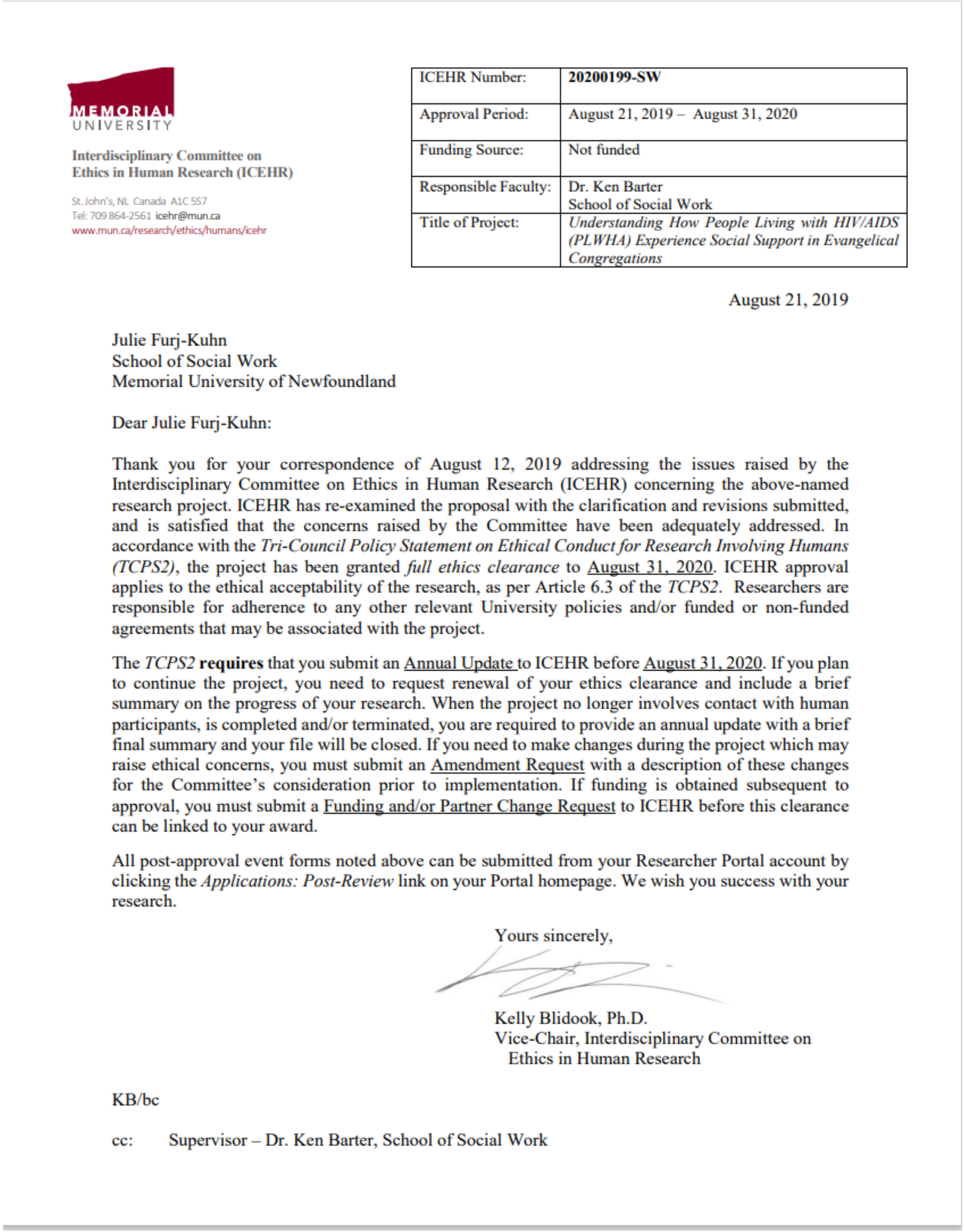
Signature of Participant Date

Researcher's Signature:

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

Signature of Principal Investigator Date

Appendix D: ICEHR Approval Letter



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**Interdisciplinary Committee on
Ethics in Human Research (ICEHR)**

St. John's, NL Canada A1C 5S7
Tel: 709 864-2561 icehr@mun.ca
www.mun.ca/research/ethics/humans/icehr

ICEHR Number:	**20200199-SW**
Approval Period:	August 21, 2019 – August 31, 2020
Funding Source:	Not funded
Responsible Faculty:	Dr. Ken Barter School of Social Work
Title of Project:	*Understanding How People Living with HIV/AIDS (PLWHA) Experience Social Support in Evangelical Congregations*

August 21, 2019

Julie Furj-Kuhn
School of Social Work
Memorial University of Newfoundland

Dear Julie Furj-Kuhn:

Thank you for your correspondence of August 12, 2019 addressing the issues raised by the Interdisciplinary Committee on Ethics in Human Research (ICEHR) concerning the above-named research project. ICEHR has re-examined the proposal with the clarification and revisions submitted, and is satisfied that the concerns raised by the Committee have been adequately addressed. In accordance with the *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (TCPS2)*, the project has been granted *full ethics clearance* to August 31, 2020. ICEHR approval applies to the ethical acceptability of the research, as per Article 6.3 of the *TCPS2*. Researchers are responsible for adherence to any other relevant University policies and/or funded or non-funded agreements that may be associated with the project.

The *TCPS2* **requires** that you submit an Annual Update to ICEHR before August 31, 2020. If you plan to continue the project, you need to request renewal of your ethics clearance and include a brief summary on the progress of your research. When the project no longer involves contact with human participants, is completed and/or terminated, you are required to provide an annual update with a brief final summary and your file will be closed. If you need to make changes during the project which may raise ethical concerns, you must submit an Amendment Request with a description of these changes for the Committee's consideration prior to implementation. If funding is obtained subsequent to approval, you must submit a Funding and/or Partner Change Request to ICEHR before this clearance can be linked to your award.

All post-approval event forms noted above can be submitted from your Researcher Portal account by clicking the *Applications: Post-Review* link on your Portal homepage. We wish you success with your research.

Yours sincerely,

Kelly Blidook, Ph.D.
Vice-Chair, Interdisciplinary Committee on
Ethics in Human Research

KB/bc

cc: Supervisor – Dr. Ken Barter, School of Social Work

Appendix E: ICEHR Amendment Virtual Interviews

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Interdisciplinary Committee on Ethics in Human Research (ICEHR)

St. John's, NL Canada A1C 5S7
Tel: 709 864-2561 icehr@mun.ca
www.mun.ca/research/ethics/humans/icehr

ICEHR Number:	**20200199-SW**
Approval Period:	August 21, 2019 – August 31, 2020
Funding Source:	Not funded
Responsible Faculty:	Dr. Ken Barter School of Social Work
Title of Project:	*Understanding How People Living with HIV/AIDS (PLWHA) Experience Social Support in Evangelical Congregations*
Amendment #:	***01***

November 8, 2019

Julie Furj-Kuhn
School of Social Work
Memorial University of Newfoundland

Dear Julie Furj-Kuhn:

The Interdisciplinary Committee on Ethics in Human Research (ICEHR) has reviewed the proposed modifications for the above referenced project, as outlined in your amendment request dated October 29, 2019, and is pleased to give approval to the addition of virtual interviews, as described in your request, provided all other previously approved protocols are followed.

If you need to make any other changes during the conduct of the research that may affect ethical relations with human participants, please submit an amendment request, with a description of these changes, via your Researcher Portal account for the Committee's consideration.

Your ethics clearance for this project expires August 31, 2019, before which time you must submit an annual update to ICEHR. If you plan to continue the project, you need to request renewal of your ethics clearance, and include a brief summary on the progress of your research. When the project no longer requires contact with human participants, is completed and/or terminated, you need to provide an annual update with a brief final summary, and your file will be closed.

Annual updates and amendment requests can be submitted from your Researcher Portal account by clicking the *Applications: Post-Review* link on your Portal homepage.

The Committee would like to thank you for the update on your proposal and we wish you well with your research.

Yours sincerely,

Kelly Blidook, Ph.D.
Vice-Chair, Interdisciplinary Committee on
Ethics in Human Research

KB/bc

cc: Supervisor – Dr. Ken Barter, School of Social Work

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Appendix F: Informed Consent Form Addendum

Title: Understanding How People Living with HIV/AIDS (PLWHA) Experience Social Support in Evangelical Congregations

Researcher: Julie Furj-Kuhn, MSW
PhD Candidate, Memorial University of Newfoundland
Associate Professor of Social Work
Southeastern University

You are invited to take part in a research study entitled "Understanding How People Living with HIV/AIDS (PLWHA) Experience Social Support in Evangelical Congregations".

This form is part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. It also describes your right to withdraw from the study. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is the informed consent process. Take time to read this carefully and to understand the information given to you. Please contact the researcher, Julie Furj-Kuhn, if you have any questions about the study or would like more information before you consent.

It is entirely up to you to decide whether to take part in this research. If you choose not to take part in this research or if you decide to withdraw from the research once it has started, there will be no negative consequences for you, now or in the future.

Purpose of the Study

This study aims to address four fundamental questions as it pertains to PLWHA who are associated with evangelical congregations. First, Do evangelical congregations provide social support services and interventions to their members who identify as evangelical and are also diagnosed with HIV or AIDS? Second, What are the lived experiences of PLWHA who interface with evangelical social support systems? Third, Do PLWHA feel empowered or oppressed when receiving support within their congregations? Fourth, Are the voices of PLWHA represented in evangelical social support systems and congregations?

Exploring these questions will help to contribute to the research, which is currently limited, around the dichotomy of congregational oppression and empowerment of PLWHA and the psycho-social impact this dichotomy has in relation to HIV health.

About the Researcher

This research is part of my PhD studies at Memorial University of Newfoundland, Canada. I completed my Bachelor's degree in Social Work and Bible at Philadelphia Biblical University and my Master's of Social Work at The University of Pennsylvania. I have been an Associate Professor of Social Work for the past 10 years. Before teaching, I coordinated the Penn Center for AIDS Research Community Advisory Board (CAB) in Philadelphia, PA. In this role, I helped to mediate between the research community and the HIV community, as the CAB's mission was to foster partnerships and maintain open communication between Penn CFAR researchers and the community. My assistance ensured that any study conducted, pertaining to HIV/AIDS in the Behavioral and Social Science Core, included the voice of the HIV/AIDS community in Philadelphia. The CAB was made up of PLWHA, HIV educators, legislators, researchers, faith leaders, and directors of AIDS Service Organizations (ASO).

Summary of Methodology

I plan to interview anywhere from 10-15 participants who meet the criteria for the study. Participants will be accepted by purposive and snowball sampling, meaning that I would like to interview individuals who share a common experience but who also live in various places around the U.S.A. I hope to understand shared meanings and the essence of what it is like for someone living with HIV/AIDS to be a part of an evangelical congregation. You, as a participant, will be asked to recall specific accounts, situations, or events that you experienced as part of an evangelical congregation. I am seeking stories, thoughts, feelings, and behaviors associated with your experience. If you agree to participate in the study, I will contact you by phone to find out more about your placement as part of the selection process. If you meet the selection criteria, I will set up a time to interview you at a location that is convenient for you. If you do not meet the selection criteria, I will send you an email letting you know. I will interview participants, record and transcribe the interviews and draw out themes to develop conclusions.

Inclusion Criteria and Description of Interviews

If you meet the criteria of the study and agree to participate, a time will be arranged for you to meet with the researcher at a location that is convenient for you. **Participants can also opt for an interview through Zoom virtual conferencing. Participants can choose either an audio or video interview via Zoom. The virtual audio or video interview will be recorded and saved to the researcher's personal computer.** You will participate in a one-on-one private interview for approximately one to one and a half hours. You will be asked about your lived experience as a PLWHA who attends (or attended) an evangelical congregation and what types of social support systems were or were not available to you during this time. The interview will be digitally or virtually recorded and transcribed. Your participation is voluntary. You may refuse to answer any question in the study. You may withdraw from participating in the study without question or penalty and all your data will be removed from the study until March 31, 2020.

Following completion of your interview, I will begin analysis of your interview, drawing out themes within and between interviews. Upon completion of this analysis, you will be given an opportunity to see these conclusions in written form and give any more feedback you have on these initial results. At times, a second interview may be pertinent. This can help me deal more effectively with bias, close any gaps in the data, or clarify information discussed in the initial interview. Your feedback will be included as final thematic analysis is developed and conclusions are made. At your request, I will provide a copy of the transcript. Alternatively, a website will be set up to review the findings.

Advisory Committee

A committee will be formed following the completion of data analysis in order to provide feedback regarding perceived social support needs for PLWHA, avenues for evangelical congregations to create social support systems, and paths to create more HIV competent communities. This committee will also offer recommendations for dissemination of research findings to key HIV/AIDS community partners as well as faith-based communities.

This committee will be recommended by the National Center for AIDS Research Community Advisory Board Coalition (NCCC). The committee will consist of no more than six members whose roles in the community include: clergy, PLWHA, and social support workers (non-evangelical and evangelical). No identifying information about research participants will be shared with the Committee without participant consent. All identifying information will be removed from the data and be replaced with a pseudonym. For the purposes of ensuring the proper monitoring of the research study, the Committee will only have access to research data once personal information has been removed.

Confidentiality of Information

Your information will not be shared without your consent unless required by law. All identifying information will be removed from the data and be replaced with a pseudonym. The recording will be transcribed by the researcher or a research assistant who has signed an agreement to keep all information confidential. For the purposes of ensuring the proper monitoring of the research study, it is possible that my supervisor, Dr. Ken Barter of Memorial University of Newfoundland may also have access to your research data once your personal information has been removed.

Reporting of Results

The results of this research will be reported in a written dissertation that will be orally defended and published. The results of this research will also be disseminated through journal articles and professional presentations. Summaries of overall themes and direct quotations will be utilized while keeping confidentiality as names and other identifying information will not be given. In addition, the thesis will be available at Memorial University's Queen Elizabeth II library, and publicly accessible at http://collections.mun.ca/cdm/search/collection/theses .

Storage of Data:

All identifiable recorded and written information will be kept in a locked location only accessible to the researcher. **If the participant chooses a virtual audio or video interview via Zoom conferencing, all audio or video recordings will be stored and kept confidential**. **The Zoom audio or video conferencing tool allows the researcher to record the virtual interview, save, and store it locally. Locally recorded meetings can only be accessed on the computer that recorded the meeting, in this case, the researcher's personal computer. Zoom audio or video conferencing does not store recorded meetings on any type of server.** Data will be kept for a minimum of five years, as per Memorial University policy on Integrity in Scholarly Research. If results of the study are published, your name and identity will not be disclosed.

Risks and Benefits

To agree to participate in a phenomenological study can be risky, especially for those who are part of oppressed population groups. Discussing emotional experiences could likewise be perilous for those who are already part of marginalized population groups, such as those living with HIV/AIDS. As a researcher, I want to be cognizant that you may be sharing these experiences for the first time. If you find that you are experiencing distress after the interview, please contact the following organizations that will refer you to an appropriate service or counselor in your local area:

National Alliance on Mental Health (NAMI): https://www.nami.org/find-your-local-nami (click on state, county or region, and call the office for referral information)

Mental Health America (MHA): https://www.mentalhealthamerica.net/

State HIV/AIDS Helpline: https://hab.hrsa.gov/get-care/state-hivaids-hotlines

HIV non-disclosure law:

The Centers for Disease and Control and Prevention report that in 19 states, the law requires persons who are aware that they have HIV to disclose their status to sexual partners. In addition, 12 states require disclosure to needle-sharing partners. If any participant may come under the jurisdiction of these laws when sharing information in this study, I will have no option but to comply. For more information on these laws please refer to this link: https://www.cdc.gov/hiv/policies/law/states/exposure.html

The benefits of this study are believed to outweigh the risks. A basic premise in phenomenological research is to make sense of one’s experience. As a researcher, when I seek to reach an understanding of life experiences, the richness of meaning within these experiences emerges. Findings can develop into beautiful stories that encourage, direct, touch, and help others who may be on the same journey. Knowledge from this study can help social workers, lay leaders, and congregants to understand the lived experience of PLWHA. Data from the study could aid assist congregations in advocating for and brokering with members living with HIV/AIDS to help meet their bio-psycho-social and spiritual needs. Religious congregations can provide an HIV support network to its members, and social workers have the unique opportunity to establish a significant relationship with the evangelical community to advocate for HIV-related social support systems, prevention, outreach, ministries, and policies. Information from this study could also provide an excellent starting point for important and relevant conversations about HIV/AIDS within the evangelical community.

Ethics Approval

The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics in Human Research and found to be in compliance with Memorial University’s ethics policy. If you have ethical concerns about the research (such as the way you have been treated or your rights as a participant), you may contact the Chairperson of the ICEHR at icehr@mun.ca or by telephone at 709-864-2861.

Consent:

Your signature on this form means that:

- You have read the information about the research.
- You meet the criteria that was outlined for participation in this study.
- You understand what the study is about and what you will be doing.
- Any information you provide, including your identity, will be held in the strictest confidence and used only for the purpose of this study which was explained to you.
- Your identity will remain confidential.
- The interview may take from 1 – 1 ½ hours to complete and that with your permission you may be contacted for a second interview.
- You can refuse to answer any question you are not comfortable with.
- You will be given the opportunity to review the results of the data during data collection.
- You will have access to study results via a website given to you at the conclusion of your participation.
- You have been able to ask questions about this study.
- You are satisfied with the answers to all your questions.
- You understand that you are free to withdraw participation in the study without having to give a reason, and that doing so will not affect you now or in the future.
- You understand that your participation is voluntary, and you may withdraw at any time up until the end of data collection. The final date for data collection will be March 31, 2020. If you choose to end participation during data collection (prior to March 31, 2020), any data collected from you up to that point will be destroyed. After March 31, 2020, all data collected from you cannot be removed.

I agree to be audio-recorded ☐ Yes ☐ No

I agree to be audio-recorded via Zoom conferencing ☐ Yes ☐ No

I agree to be video-recorded via Zoom conferencing ☐ Yes ☐ No

I agree to the use of direct quotations ☐ Yes ☐ No

By signing this form, you do not give up your legal rights and do not release the researchers from their professional responsibilities.

Your Signature Confirms:

☐ I have read what this study is about and understood the risks and benefits. I have had adequate time to think about this and had the opportunity to ask questions and my questions have been answered.

☐ I agree to participate in the research project understanding the risks and contributions of my participation, that my participation is voluntary, and that I may end my participation.

☐ A copy of this Informed Consent Form has been given to me for my records.

Signature of Participant Date

Researcher's Signature:

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

Signature of Principal Investigator Date

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Appendix G: Invitation to Participate in Research Addendum

Date:

My name is Julie Furj-Kuhn. I am a PhD candidate at Memorial University’s School of Social Work in Newfoundland and Labrador, Canada. I am writing to invite you to participate in my doctoral dissertation study entitled “Understanding How People Living with HIV/AIDS (PLWHA) Experience Social Support in Evangelical Congregations”

This research study explores the lived experiences of People Living With HIV/AIDS (PLWHA) in evangelical congregations and their social support systems. It involves completing an interview, either face to face, or virtually by way of Zoom virtual conferencing. Participants can choose either the audio or video interview via Zoom. The interview will take approximately 1-1.5 hours. An eligible participant in this study will have a diagnosis of HIV/AIDS; have a connection to an evangelical congregation; be a minimum age of 18.

Participation in this research is completely voluntary and you may choose to withdraw from the research at any time or not answer questions that you do not feel comfortable answering prior to data collection of the study. Should you choose to participate in this study you will be asked to sign an informed consent form that you can read below. It outlines pertinent information about the study. You may have received this recruitment letter from a community HIV/AIDS service organization or national forum. These groups have graciously agreed to assist me with my study recruitment, but this study is not affiliated with them in any way. Participating in my study is not a requirement of these groups, they will not know who does or does not respond to this letter, and/or participate in the study. If you have any questions, please contact me directly. Likewise, if you know someone interested in this study, please have them contact me directly.

The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics in Human Research and found to be in compliance with Memorial University’s ethics policy. If you have ethical concerns about the research (such as the way you have been treated or your rights as a participant), you may contact the Chairperson of the ICEHR at icehr@mun.ca or by telephone at 709-864-2861.

Are you interested in participating?

If you meet the criteria for this study, have any questions about the study and/or are interested in participating, please contact me by phone at 614-806-0493 or by email at jkuhnmun@gmail.com so that we can arrange an interview. You may also contact my research supervisor, Dr. Ken Barter at kbarter@mun.ca if you have any questions or concerns about the study. I value your participation and thank you for your commitment of time, energy, and effort.

Julie Furj-Kuhn, MSW

Associate Professor of Social Work

Southeastern University

PhD Candidate, Memorial University of Newfoundland