HIV AND AIDS, DISCLOSURE, STIGMA,
AND SOCIAL SUPPORT WITHIN CHURCH COMMUNITIES

BY

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DISSERTATION

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ABSTRACT

For most, an HIV or AIDS diagnosis is difficult to manage without social support and
healthy coping strategies. Churches are one place to which people living with HIV or AIDS
(PLWHA) may turn for supportive resources. Churches are located in virtually every town in the
United States, with many providing resources for the marginalized within their communities;
however, resources for PLWHA are not as common. PLWHA also may avoid churches due to
the stigma often associated with HIV or AIDS within these communities. Little currently is
known about the relationship between church communities and PLWHA. Even less is known
about the relationship between HIV or AIDS, disclosure, stigma, and social support within these
communities.

Three issues were explored in this study–the stigmatizing experiences of PLWHA within
church communities; the influence of HIV and AIDS stigma on disclosure behaviors within these
communities; and the role that these communities, as well as their belief systems, play in the
daily lives of individuals living with HIV or AIDS in terms of social support. This study was
designed to assess the perspectives of PLWHA ($n = 21$), as well as the perspectives of church
members ($n = 21$) not infected with HIV or AIDS. A qualitative approach consisting of
interviews with these individuals was employed for data collection. The interviews focused on
stigmatizing experiences and disclosure behaviors of PLWHA, the role of religious faith in the
lives of people with these illnesses, and the barriers to increasing churches' roles in providing
social support. The interviews were transcribed and coded for themes related to the proposed
research questions. These data provide key insights into using churches to improve the quality of
life for PLWHA by providing supportive resources. The church is an organization positioned
well to address these needs with its global presence and universal mission of serving others;

however, identifying the barriers to support increases our understanding of how to execute such an approach successfully.

The themes that emerged during the analysis revealed that PLWHA generally perceived churches as sources of support. Supportive messages about HIV or AIDS increased the likelihood that people affected by the virus would seek support through disclosure. Increased disclosure resulted in greater access to supportive resources available within churches. Unsupportive messages communicated by church organizations about HIV or AIDS, however, decreased the likelihood of disclosure among those affected by the virus. Decreased disclosure resulted in less access to supportive resources made available through churches. Improving their communication of support, or enacting support, is one way for churches to address these unsupportive messages. Participants identified a number of strategies for enacting support. Employing strategies to enact support for PLWHA will improve the identity of churches in relation to HIV and AIDS, increasing the likelihood that people affected by these illnesses will seek support through disclosure to gain access to the supportive resources available within church communities.

To Mom and Dad – who paved the way

so that I could "run with perseverance the race marked out for [me]."

Hebrews 12:1

For Dale Brashers (1959-2010) – who shared his passion for community change with me and

encouraged me to go and do it.

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CHAPTER ONE: INTRODUCTION

Current estimates indicate that 56,300 people are infected each year with HIV in the United States (H. I. Hall et al., 2008). This infection rate contributes to the already reported 1.5 million individuals living with HIV or AIDS in the US at the close of 2007 (Centers for Disease Control [CDC], 2009). These numbers are alarming and raise important questions about the growing population of people living with HIV or AIDS (PLWHA), as well as prevention. For instance, what are the illness-specific support needs of people living with HIV or AIDS? Why does knowing how to prevent the transmission of HIV not translate to actually doing so? One concept that emerges in response to both of these questions is disclosure. Disclosure is a communicative tool that can increase access to social support for PLWHA and reduce transmission through the disclosure of one's status to at-risk individuals (R. Smith, Rossetto, & Peterson, 2008). The goal of this project is to better understand the relationship between HIV and AIDS, disclosure, stigma, and social support within church communities for the purpose of improving the quality of life for people affected by these illnesses.

Drawing from common definitions of disclosure (Derlega, Winstead, Wong, & Greenspan, 1987; Jourard, 1959; Petronio, 2002; Stiles, 1978), the term generally refers to sharing or revealing information about oneself with someone who would not otherwise have access to that information or the discloser's perspective. In this case, it concerns one person revealing to another that he or she is living with HIV or AIDS. Although disclosure can serve as a preventative communication tool that reduces the spread of the virus, the continued transmission of HIV through sex and drug-use is evidence that these types of disclosures do not always take place (Serovich & Mosack, 2003). On the surface, placing a person at risk for

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contracting HIV may appear selfish or malicious in nature; however, a closer look at this issue

reveals other contributing factors to nondisclosure such as guilt, fear, a lack of social support,

and especially stigma, to name a few (R. Smith et al., 2008). Understanding the reasons for

nondisclosure is important for intervening to improve HIV prevention; however, understanding

the daily realities of living with these illnesses is important for intervening to improve the lives

of PLWHA. This project will focus on the latter by exploring the relationship between stigma

and disclosure as it relates to acquiring social support.

PLWHA have an increased need for social support in comparison to people with other

chronic illnesses because they tend to exhibit worse physical and emotional health (Hays et al.,

2000). PLWHA specifically experience decreased physical functioning, psychological health,

and independence as the disease progresses (Kalichman, DiMarco, Austin, Luke, & DiFonzo,

2003; Rai, Dutta, & Gulati, 2010). PLWHA also may experience suicidal thoughts and

depression (Kalichman et al., 2003). Their perception of available social support also can affect

their health. For example, decreased perceived support has been linked to increased depression,

and a decreased sense of control in managing the illness (Kelly et al., 1993). PLWHA also need

support to manage the effects of HIV and AIDS stigma in addition to the support needs

associated with these illnesses. For example, stigma is highly correlated with depressive mood

symptoms (Greene, 2000; Simbayi et al., 2007), need for psychiatric care, inconsistent treatment

adherence, and high risk behaviors (e.g., unsafe sex practices and drug use; Chesney, Folkman,

& Chambers, 1996; Rintamaki, Davis, Skripkauskas, Bennett, & Wolf, 2006). Understanding

and fighting the effects of stigma on PLWHA is necessary to address their support needs

successfully (Chesney & Smith, 1999; Herek, 1999; Parker & Aggleton, 2003; Simbayi et al., 2007).

HIV and AIDS stigma also makes it more difficult to build social support due to the social risks involved such as loss of relationships, resources, and further disclosures of one's illness (Chesney & Smith, 1999; Greene, 2000; Emlet, 2006; R. S. Lee, Kochman, & Sikkema, 2002). The expectation of stigmatization results in many PLWHA concealing their illness from others. To ensure that PLWHA conceal their status from their employers, many pay out-of-pocket for care, forcing them to limit their health care options (Chesney & Smith, 1999), which compromises their health care. Not disclosing one's illness to avoid stigma affects other aspects of life for PLWHA in addition to acquiring support. For instance, nondisclosure can interfere with treatment adherence (Stirratt et al., 2006). That is, a person may choose not to take his or her medications to conceal the illness from others. HIV and AIDS stigma also can lead PLWHA to isolate or withdraw from others (Buseh & Stevens, 2006). In fact, the more PLWHA experience stigma the less they disclose about their illness to friends, family, co-workers, and others (Vanable, Carey, Blair, & Littlewood, 2006). Additionally, there are financial risks to consider when deciding to disclose such as job loss, rejection for health and life insurance, and denial of health care (Chesney & Smith, 1999; Emlet, 2006; Herek, 1999; Simbayi, et al., 2007; Swendeman, Rotheram-Borus, Comulada, Weiss, & Ramos, 2006). Thus, increasing the disclosure of infection requires expanding the conversation beyond the prevention of HIV transmission to also include the quality-of-life experienced by PLWHA.

The need to enlist more individuals to provide supportive resources for these individuals requires a closer look at those institutions that have access to and influence over large

populations. One such institution is the church, as highlighted in a special issue of the *Journal of Internal Medicine* on spirituality, religion, and the quality-of-life of patients with HIV or AIDS (Tsevat, 2006). I chose to focus on Christian churches because they are prominent throughout the Midwest (54% attendance rate; Barna, 2006) and Illinois is in the Midwest. Increasing the role of churches in providing social support may increase the ability of PLWHA to manage the complexities of the disease and its stigma, improving their quality of life. It also could be that increased support results in increased disclosure to at-risk individuals, which could decrease HIV infection.

In this project, I examine the relationship between HIV and AIDS, disclosure, stigma, and social support within church communities. To better understand this relationship, this study will (a) explore the stigma experiences of PLWHA with church communities; (b) describe the influence of stigma on disclosure patterns within these communities; and (c) describe the role that these communities, as well as their belief systems, play in the daily lives of PLWHA. The long-term goal of this study is to improve the quality of life for PLWHA by increasing access to supportive resources.

The following chapter is an overview of HIV and AIDS research within the context of disclosure, stigma, social support, and church organizations. Following the overview is a brief rationale for a study to investigate the associations between those key concepts and an explication of the research questions that guided the study. The third chapter describes the methods for an interview study of 21 PLWHA and 21 church leaders, designed as a grounded theory investigation using constant comparative techniques. The fourth chapter presents the

results in response to each research question. The fifth chapter is a discussion of the theoretical

and practical implications of the data.

CHAPTER TWO: LITERATURE REVIEW

This chapter provides an overview of the existing literature to lay a foundation for the

present topic. The first section reviews disclosure and related issues such as health disclosure,

disclosure benefits, disclosure barriers, and strategies for overcoming these barriers. This section

also reviews social support in relation to disclosure. The second section reviews literature about

HIV and AIDS stigma including current definitions and causes of stigma, as well as living and

managing the stigma. The third section focuses on how spirituality and religion are discussed in

the literature, the impact of religious faith on the health of PLWHA, and the existing barriers that

complicate the relationship between PLWHA and churches. The chapter ends with a rationale

that ties the preceding sections together.

Disclosure

Humanistic psychologist Sidney Jourard once said that "the courage to be [entails] the

courage to be known" (Jourard, 1959, p. 505). He argued that individuals not only have a desire

to be known, but that ignoring this desire negatively affects their health and well-being (Jourard,

1958; Jourard & Lasakow, 1958). If what Jourard said is true, if disclosing is necessary for the

health of the discloser, then why not encourage all people to disclose in all circumstances?

The short answer to this question is that there are many circumstances in which

disclosure can cause a person emotional, mental, physical, and relational harm. People, therefore,

should not be encouraged to disclose everything, all the time. If disclosure indeed relates to a

healthy existence, then it is important to understand the conditions, circumstances, and

environments in which disclosure is likely, encouraged, and in some cases required, to promote

the well-being of others. These include various types of interpersonal relationships, support groups, medical and religious communities, and social service organizations, to name a few. The processes, purposes, and outcomes of disclosure within these settings are essential to understanding the barriers that inhibit certain disclosures and how people attempt to address those barriers (Ignatius & Kokkonen, 2007).

The purpose of exploring the relationship between HIV and AIDS, stigma, and disclosure in church communities is not to ensure that everyone discloses, but to ensure that everyone has the option to disclose and receive supportive resources that improve their quality of life. The effects of exercising the freedom to disclose have been beneficial for some and detrimental for others. For example, HIV disclosures can improve or worsen one's treatment, mental health, and relationships (Almeleh, 2006; Medley, Garcia-Moreno, McGill, & Maman, 2004). The following section will highlight the benefits of disclosing within health contexts, followed by a discussion of the costs of disclosing.

Health Disclosure

Frattaroli (2006) stated in her meta-analysis of health disclosure research that:

[i]t is believed that disclosing information may allow people to free their mind of unwanted thoughts, help them to make sense of upsetting events, teach them to better regulate their emotions, habituate them to negative emotions, and improve their connections with their social world, all of which can lead to beneficial effects on health and well-being. (p. 823)

As discussed earlier, Jourard (1959) believed in the health benefits of disclosing for the discloser. This notion was rooted in a fundamental belief that people have a mental, emotional,

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and physical need to be known (Jourard, 1958; Jourard & Lasakow, 1958). These benefits come through engaging in the process of disclosure and most likely occur when people disclose about difficult topics commonly avoided (Jourard, 1958; Pennebaker, 1993). Pennebaker, another notable scholar in this area of research, argued that people who do not talk about emotional turmoil or tragic events work to keep the effects of the turmoil from emerging, which may negatively affect them both cognitively and physiologically (Pennebaker & Beall, 1986)

Research shows that the process of disclosure allows individuals to engage issues emotionally and cognitively (Pennebaker, 1993; Pennebaker & Seagal, 1999). Disclosure enables people to gain new insight into the disclosure topic, which helps people to better process the event (Burton & King, 2004; Honos-Webb, Harrick, Stiles, & Park, 2000; Mendes, Reis, Seery, & Blascovich, 2003; Murray & Segal, 1994); and facilitates the process of making sense of, organizing, and integrating an event into a person's life (Frattaroli, 2006; Pennebaker, Kiecolt-Glaser, & Glaser, 1988). Within the context of HIV and AIDS, disclosing allows people to receive better treatment, improve their psychological health, and further develop meaningful relationships (Almeleh, 2006; Medley et al., 2004). A more detailed discussion of these outcomes occurs in the following section.

Disclosure Benefits

There are a number of benefits of disclosing HIV and AIDS. Disclosing is a way of becoming known and accepted by others, gaining support from others, and engaging in advocacy and prevention efforts for others. The following sections present the benefits of disclosure, illuminating its role in helping PLWHA to feel valued (self-worth), obtain support, and change people's lives through advocacy and prevention.

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Self-worth. Although being known as a person with HIV or AIDS can liberate a person from guilt, fear, or the burden of concealing their illness (Almeleh, 2006), it also can be risky due to the stigma associated with these health conditions (R. Smith et al., 2008). Not only can an HIV-positive status cause people to feel negative about themselves, but negative responses by those to whom they disclose their status also can negatively affect their self-worth. Li and colleagues (2009) demonstrated this in their study of PLWH in a rural Chinese community in China. They interviewed 322 individuals about their experiences with disclosing and living with HIV in a community with the highest rates of infection in the country. Their results revealed that 73% of the participants felt lower self-worth, 82% had a greater need to feel valued by others, and 61% were not willing to disclose because of stigma. Researchers reported in study of Asian-Americans in New York, that HIV stigma lowered self-esteem because the participants (a) internalized their pre-existing knowledge of HIV stigma once they became infected and (b) experienced stigma after disclosing their status (Kang, Rapkin, & DeAlmeida, 2006).

Issues of self-worth are psychological in nature and understanding the psychological effects of stigma on PLWHA is necessary for developing effective interventions (Kang et al., 2006). Feelings of self-worth can increase through disclosing one's illness because it can reduce anxiety and lessen depressive symptoms (Medley et al., 2004). Another way of enhancing self-worth is through publicly disclosing one's status. A study including PLWHA from a number of countries showed that public disclosure not only increased support for others, but it also provided the disclosers with a greater sense of self (Paxton, 2002). In another study, Africans with HIV and AIDS in London experienced higher social support satisfaction, reduced anxiety, and less stigma resulting from disclosing (Calin, Green, Hetherton, & Brook, 2007). These studies

reinforce the idea that being known as a person with HIV or AIDS is psychologically costly and that environments that allow for such disclosures without psychological risks can increase the well-being of PLWHA. It is for this reason that it is important to identify organizations in which these types of environments are possible.

Gaining support. Social support is a broad construct that refers to the behaviors and messages performed by supportive others to benefit another person's well-being (Goldsmith, 2004). There are different types of social support such as emotional support (showing concern or compassion), informational support (giving information or advice), tangible support (providing physical assistance), appraisal support (offering a fresh perspective), and esteem support (affirming one's sense-of-self; Goldsmith, 2004). Once a need for support has been identified by the person in need or supportive others, social support is performed through messages that provide the recipient(s) of the support with a new perspective, helpful behavioral changes, skill refinement, or a safe space to release internal tension (Albrecht & Goldsmith, 2003).

Social support and HIV or AIDS disclosure are closely related, because seeking treatment or support necessitates some level of disclosure (Almeleh, 2006; Norman, Chopra, & Kadiyala, 2007; Slade, O'Neil, Simpson, & Lashen, 2007). Social support reduces the negative effects of crisis in people's lives by changing their situation or state of mind through affirming their sense of worth, value, esteem or acceptance, or membership in a supportive network (Albrecht & Adelman, 1987; Cobb, 1976). The benefits of social support have improved the physiological, cognitive, and emotional states of individuals facing a number of issues (Burleson, Albrecht, Goldsmith, & Sarason, 1994). These benefits show the potential that social support has to prevent the negative effects of difficult life experiences such as living with a stigmatized illness.

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According to an extensive review performed by the World Health Organization on HIV and AIDS disclosure, PLWHA who disclose their status are more likely to receive tangible and emotional support (Medley et al., 2004). Researchers who conducted a study of South African women with HIV or AIDS concluded that disclosing one's status led to better emotional and tangible support from family members and health care professionals; increased family support, access to support groups, and utilization of health care resources; and credibility that enabled these individuals to support others (Norman et al., 2007). Delaney, Serovich, and Lim (2008) found that mothers who disclosed their status to their children received hugs and comfort from them. The authors of a study of intravenous drug users with HIV uncovered a relationship between disclosure and reconciliation with family members, which can lead to greater social support (Valle & Levy, 2009). This relationship occurred when concern for the individual outweighed the pain caused by the person's drug use, which enhanced his or her available support. Additionally, perceived social support is higher among PLWHA who have disclosed to family and friends (Kalichman et al., 2003).

Disclosure can be a prerequisite to receiving support or access to resources (e.g., governmental aid, support groups; Almeleh, 2006; Norman et al., 2007; Slade et al., 2007). These supportive resources may lead to other benefits. For instance, Almeleh (2006) found that PLWHA who attended support groups were more likely to adhere to their treatment. In another study, cancer patients attended support groups for a safe place to disclose their fears and concerns (Iredale et al., 2006). Finally, Brashers and colleagues (2004) found that social support assisted PLWHA in "information seeking and avoiding, providing instrumental support, facilitating skill development, giving acceptance or validation, allowing ventilation, and

encouraging perspective shifts" (p. 323). Disclosure can open the door to having needs met that may not be visible to others by creating access to supportive resources.

*Advocacy and prevention. T*he relationship between social support and disclosure also can influence the public sphere. For example, there are PLWHA who participate in prevention programs (e.g., programs aimed at increasing condom use; Ijumba, Gamieldien, Myer, & Morroni, 2004; Medley et al., 2004). Some PLWHA also disclose to educate others about HIV and AIDS, which helps to reduce misinformation and stereotyping (Almeleh, 2006), often increasing both perceived and actual social support for PLWHA (Almeleh, 2006; Norman et al., 2007). In a study about HIV disclosure, respondents indicated strong support for disclosing as a cathartic release, out of a sense of duty, and for educating others (Derlega, Winstead, & Folk-Barron, 2000). Lastly, there are PLWHA who disclose to increase support for others with HIV and AIDS. The Treatment Action Campaign in South Africa is one example of how disclosure can lead to activism (http://www.tac.org.za/community). This organization of AIDS activists advocate for increased access to antiretroviral treatment. Thus, advocacy leads to increased social support, which leads to increased disclosure that can eventually result in broader based support through various activists groups and government policies (see Brashers, Haas, Klingle, & Neidig, 2000; Brashers, Haas, Neidig, & Rintamaki, 2002).

Disclosure Barriers

There are many risks to consider when disclosing an HIV infection such as pain, loneliness, and poorer health. Some PLWHA have determined that the costs of disclosing are not worth the benefits. As Valle and Levy stated (2009), "many reasons exist for not letting others know about the private and secret parts of ourselves" (p. 157). PLWHA must balance their need

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for support with the potential risks involved in disclosing (Kalichman et al., 2003). For example, fear of rejection or judgment by friends, family, and even spouses has resulted in nondisclosure (Buseh, Kelber, Hewitt, Stevens, & Park, 2006; Chesney & Smith, 1999; Calin et al., 2007; Simbayi et al., 2007; Simoni et al., 1995). Privacy and self-esteem issues were highly ranked reasons for not disclosing an HIV diagnosis in another study (Derlega et al., 2000). Some PLWHA do not disclose their status to protect their families from stigmatization and to protect others from experiencing distress because of their illness (Calin et al., 2007; Delaney & Serovich, 2008; Forrest et al., 2003; Simoni et al., 1995). PLWHA also may conceal their status to avoid rejection from sexual encounters (J. T. Parsons, VanOra, Missildine, Purcell, & Gómez, 2004). People tend not to disclose if they are ashamed of having the illness, of not preventing the illness, or of how they contracted the illness (Serovich & Mosack, 2003). Still, the greatest relational risk is an inability to control what happens to the information once it is shared (Buseh & Stevens, 2006; C. Lee & Johann–Liang, 1999; Simoni et al., 1995).

Other disclosure barriers associated with misinformation about disease transmission (Herek, 1999) are fear of being associated with stigmatized groups commonly linked to HIV and AIDS (e.g., gays and drug-users; Calin et al., 2007; Coleman, 2004) and general societal ignorance (Simoni et al., 1995). Some do not disclose to conceal how they became infected (Zea, Reisen, Popen, Bianchi, & Echeverry, 2005). This is unfortunate, because nondisclosure of high maintenance illnesses, such as HIV or AIDS, usually indicates that the person is not receiving proper care, or fully adhering to his or her treatments (Almeleh, 2006). Difficulty accepting one's condition or a negative self-image resulting from the illness makes speaking about one's condition very difficult (Buseh & Stevens, 2006; Fesko, 2001; Forrest et al., 2003), because

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internalization of stigma influences a person's perception of how others will respond to his or her

disclosure. Additionally, many PLWHA perceive that disclosing will be a stressful situation, and

hence choose not to disclose at all (Kalichman et al., 2003). This includes disclosing to health

care professionals due to negative medical experiences (Rintamaki, Scott, Kosenko, & Jensen,

2007; Wong & Wong, 2006) or distrust (Herek, 1999).

Overcoming Disclosure Barriers

Despite these barriers, many decide to disclose because they believe the benefits

outweigh the risks. In one study, it was determined that there was a *calculus of disclosure*, a

decision-making method for disclosing HIV when the benefits outweighed the costs (Black &

Miles, 2002). The study was about the disclosure patterns of African-American women with

HIV. The authors described three general disclosure patterns – secretive, selective, and full

disclosers – among the participants. Secretive disclosers revealed their diagnosis to one or two

other people, minimizing the possibility of experiencing stigma or receiving adequate support.

Selective disclosers were willing to disclose to intimate others, such as family members,

increasing their access to support and vulnerability to stigma. Finally, full disclosers disclosed to

other adults, allowing them to receive and provide support and greatly increasing their

vulnerability to experiencing stigma. Charmaz (1993) discussed similar disclosure patterns in her

book *Good Days, Bad Days: The Self in Chronic Illness and Time*, which is about experiencing

chronic illness. She wrote about two types of disclosures – spontaneous and protective. The

former refers to vulnerable disclosures made about an illness that expresses one's true emotions

without giving much thought to how to deliver these disclosures. The latter refers to calculated

disclosures that are more informative than revelatory about the discloser's thoughts and feelings

about the health issue. Protective disclosures, by design, protect both the discloser and the disclosure target(s) from experiencing negative emotions.

Others may disclose because they agree with Jourard (1964), who saw nondisclosure as starving oneself of a basic human need, hindering personal growth and healthiness. Some have spoken of nondisclosure as a type of bondage that can only be broken through disclosing (Almeleh, 2006; Calin et al., 2007; Norman et al., 2007). Disclosure also has been described as treatment for one's mind, reducing the psychological stress of having an illness (Almeleh, 2006). In another study, PLWHA saw disclosing as a type of catharsis (Derlega et al., 2000; Derlega, Winstead, Greene, Serovich, & Elwood, 2004). Regardless of the reason, many PLWHA decide to disclose. The goal of this project is to determine ways to make illness disclosure more accessible and beneficial for people who feel restricted from doing so. This requires a closer look at stigma, a key deterrent of HIV and AIDS disclosure.

Stigma

As Rüsch, Angermeyer, and Corrigan (2005) stated, "[w]hether patterns of behavior, thinking and feeling are being noticed at all and if so, whether they are described in moral, psychosocial or medical terms is influenced by societal discourse and usually varies over time" (p. 530). This statement highlights the complex nature of stigma, partly because it is not always readily identifiable or consistent throughout society. Stigmatized conditions also are not always visible to the naked eye. This type of stigma also is referred to as invisible stigma (Goffman, 1963/1990). Managing one's stigma, visible or invisible, is an additional burden of living with a stigmatized condition. This section will specifically address stigma as a concept, the effects of

stigma, managing stigma, and implications for health care professionals, as well as for people living with HIV or AIDS.

Stigma Defined

HIV and AIDS are considered the most stigmatized illnesses in the world (Simbayi et al., 2007). One widely used definition of stigma is "an attribute that is deeply discrediting" (Goffman, 1963, p. 3). Society deems this attribute as unacceptable (Weiss, Ramakrishna, & Somma, 2006). The stigmatized condition may be rejected or found to be objectionable based on some criterion to which those living with the stigma may or may not subscribe. Stigma is the combination of labels, stereotypes, discrimination, categories, and status, or lack thereof, guided by those with access to power (Link & Phelan, 2001). According to Parker and Aggleton (2003), stigma is what one would find at the intersection of culture, power, and difference. It is something that society disdains at such a level that it removes any credibility the individual once had (Herek, 2002).

Link and Phelan (2001) summarized the key elements of stigmatization, saying that it occurs when: "(1) people distinguish and label human differences; (2) dominant cultural beliefs link labeled persons to undesirable characteristics…; (3) labeled persons are placed in distinct categories…; (4) labeled persons experience status loss and discrimination…;" and is "(5) …entirely contingent on access to social, economic, and political power that allows the identification of differentness, the construction of stereotypes, the separation of labeled persons into distinct categories, and the full execution of disapproval, rejection, exclusion, and discrimination" (p. 367). Put another way, stigmatization "begins with cues, or [labels], that signal subsequent prejudices and discrimination" (Corrigan & O'Shaughnessy, 2007, p. 90).

Stigma can become attached to an individual in such a way that it becomes the defining characteristic by which a person is identified (Rüsch et al., 2005). This identification is a way of separating "us" from "them" and is guided by the beliefs attached to the characteristic or label (Link & Phelan, 2001).

Stigmatization is perpetuated through communication (Corrigan & Rüsch, 2002; Parker & Aggleton, 2003), especially within health contexts because societal understandings of health conditions are influenced by how they are discussed. For example, AIDS used to be referred to by the medical community as the Gay Related Immune Deficiency Syndrome, which communicated that AIDS only affected gays, stigmatizing the community as a whole (Elmore, 2006). This example also illustrates how the powerful can perpetuate stigma (e.g., health care professionals, medical staff, social workers, or media). Their access to the public combined with their credibility allows the powerful to establish and promote their ideas on a larger platform than someone without an authoritative position. Society endorsed these messages, consequently, by stigmatizing these individuals (Corrigan & Rüsch, 2002; Gray, 2002; Rüsch et al., 2005). As R. Smith (2007) stated, "stigma communication needs to provide content that gains attention quickly, encourages stereotyping and perceived entitativity [sameness] of a stigmatized group, and provides reasons and emotional reactions for barring access of stigmatized groups from society to protect the community" (p. 467-468).

Causes of Stigma

Alonzo and Reynolds (1995) summarized the causes of HIV stigma, saying that HIV disease is

> "(1) associated with deviant behavior, both as a product and as a producer of deviant behavior …; (2) viewed as the responsibility of the individual …; (3) tainted by a religious belief as to its immorality … or thought to be contracted via a morally sanctionable behavior … and therefore thought to represent a character blemish; (4) perceived as contagious and threatening to the community; (5) associated with an undesirable and an unaesthetic form of death; and (6) not well understood by the lay community and viewed negatively by health care providers …" (p. 305)

They described stigma as something that evolves during the course of HIV illness (at-risk, diagnosis, latent, and manifest stages). Cogan and Herek (1998) postulated that AIDS-related stigma is a form of prejudice aimed at those stereotyped as having HIV or AIDS, along with their significant others, associates, social groups, and communities. Researchers attribute HIV and AIDS stigma to fears of contagion, ignorance about transmission, and moral judgments made about the groups of people most affected by the virus (Bogart et al., 2008; Buseh & Stevens, 2006; Cogan & Herek, 1998; Crandall, Glor, & Britt, 1997; Emlet, 2006).

Stigmatizing attitudes often are rooted in one's fear of HIV and AIDS and one's feelings toward groups closely associated with these illnesses (Herek, 1999). The virus also has varying levels of stigma due to the variety of ways to contract HIV, which reflects varying attitudes towards some of the risky behaviors associated with infection (Bogart et al., 2008; Bush & Stevens, 2006; Corrigan et al., 2003; Greene, 2000). For instance, a person who is born with

HIV, or acquires it through a blood transfusion is not as stigmatized as one infected through sexual activity or drug use (Elmore, 2006; Greene, 2000; Herek, 1999; Swendeman et al., 2006). Those who disclose that they acquired the illness through more stigmatized means have a harder time building social support and risk losing relationships (M.A. Chesney & Smith, 1999; Greene, 2000; R. S. Lee et al., 2002; Poku, Linn, Fife, Azar, & Kendrick, 2005; Rintamaki et al., 2006). This issue will be discussed in more detail in a subsequent section as it relates to spirituality and religion. PLWHA also experience stigma through judgmental or critical attitudes, feelings of being tainted or discredited, or beliefs that their illness is deserved (Aranda-Naranjo, 2004). Blaming PLWHA for their illness and a lack of education about transmission further drives illness related stigma (Herek, Capitanio, & Widaman, 2002).

The discussion will now focus on stigmatizing experiences had by people with these illnesses. The experience of living with stigma paints a clearer picture of what stigma looks and feels like. It is impossible to make prescriptions for disclosure without understanding the costs of disclosing. Expecting PLWHA to disclose for any reason with little information about the costs is not only unwise, but uncaring, for it is these experiences that play a critical role in the poor quality of life experienced by many PLWHA.

Living with Stigma

Living with HIV and AIDS presents many obstacles for PLWHA, particularly within the context of stigma. There are three types of stigma generally associated with HIV and AIDS in the literature – felt (perceived/self), enacted (discriminating behaviors), and courtesy (discrimination against those associated with PLWHA; Alvidrez, Snowden, & Kaiser, 2008; Bogart et al., 2008; Emlet, 2006; Gray, 2002). The experience of discrimination can lead to a

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number of negative outcomes for PLWHA. HIV and AIDS stigma are related to illness symptoms, avoidance, shame, sex-bartering, rejection, smaller social networks, and injection drug use (Swendeman et al., 2006). Stigma also makes it more difficult for people to seek support or continue treatment (Alvidrez et al., 2008; Sirey et al., 2001; Weiss et al., 2006).

Vanable et al. (2006) surveyed 221 patients living with HIV about their experiences with stigma to understand how these experiences affected a variety of health behaviors ranging from disclosure to sexual risk behaviors. They found that greater disclosure was correlated with more frequent stigmatizing experiences; and that these experiences were correlated with trouble adjusting both psychologically and behaviorally to living with HIV, affecting their treatment adherence and psychological well-being (Vanable et al., 2006). In another study, stigma resulted in less social support and treatment adherence (Rintamaki et al., 2006). The authors pointed out that not adhering to HIV treatment can hinder one's ability to fight the virus, also known as having viral resistance (i.e., the medication becomes ineffective in treating the virus). Lastly, the authors of a study who surveyed 726 PLWH found that HIV-related stigma significantly contributed to lower quality of life (Holzemer et al., 2009).

As if it were not enough to manage one's medical condition, one also must manage his or her stigmatized identity with little or no direction in doing so. Stigma is society's penalty for imperfections for any number of reasons – fear, judgment, tradition, or ignorance. These penalties affect their social and financial well-being, as well as their healthcare.

Social and Financial Well-being

Avoidance, ostracism, and verbal insults all are interpersonal manifestations of stigma (Bogart et al., 2008; Buseh & Stevens, 2006). Stereotypes associated with how one becomes

infected, rejection, separation or loneliness due to self-stigma, and homophobia are other forms of stigma experienced by PLWHA (Buseh & Stevens, 2006; Elmore, 2006; Emlet, 2006). Some even have encountered violent attacks (Herek, 1999). As a result, PLWHA may exhibit inconsistent disclosure patterns with romantic partners or drug dealers by taking steps to prevent transmission while never disclosing their status; for example, using a condom, but hiding one's medication (Chesney & Smith, 1999). Finally, when the desire to be accepted outweighs the potential benefits of disclosure (Caughlin & Petronio, 2004), individuals choose to keep their diagnosis to themselves.

The effects of stigma make it more difficult for PLWHA to build social support due to the social risks involved, such as the loss of relationships (Chesney & Smith, 1999; Greene, 2000; R. S. Lee et al., 2002). PLWHA experiencing high levels of shame due to the stigmatizing behaviors experienced from friends and family consequently are least likely to take advantage of available resources (R. S. Lee et al., 2002), especially if they are members of more than one stigmatized group (Bogart et al., 2008; Buseh & Stevens, 2006; Corrigan et al., 2003; Emlet, 2006; Fesko, 2001). Stigma is highly correlated with depressive mood symptoms (Greene, 2000; Simbayi et al., 2007), need for psychiatric care, inconsistent treatment adherence, and high risk behaviors (e.g., unsafe sex practices and drug use; Chesney et al., 1996; Rintamaki et al., 2006). Stigma also is associated positively with poor coping skills, self-destructive behaviors, and passive-problem solving, all of which relate to one's mental health (R. S. Lee et al., 2002). Furthermore, although PLWHA commonly have mental health issues, the stigma associated with mental illness keeps PLWHA from seeking treatment (Yannessa, Reece, & Basta, 2008).

Healthcare

PLWHA experience stigma from their physicians, nurses, dentists, hospital staff, case managers, and social workers (Schuster et al., 2005). Studies about rural hospital staff have reported poor training and preparedness to treat PLWHA, negative stereotyping about people with the virus, and discrimination against these individuals to deter them from seeking treatment at their facilities (Vance & Denham, 2008; Yannessa et al., 2008). Some HIV-positive patients have reported being ignored, lower quality care (e.g., spending less time with patients), treatment denial, and even physical abuse (Rintamaki et al., 2006; Rintamaki et al., 2007). Others have observed a level of discomfort, inferiority, avoidance, and service refusal from heath care providers (Schuster et al., 2005). Patients also noted (a) shifts in their health care professional's demeanor after revealing their HIV-positive status; (b) unethical labeling tactics, such as referring to patients by their sexual identity; and (c) excessive safety measures, such as wearing additional "protective gear" (Rintamaki et al., 2007, p. 261). Others have reported overly complex health care systems and insensitive care from health care professionals as deterrents for seeking both testing and treatment (Blake, Jones Taylor, Reid, & Kosowski, 2008; Vance & Denham, 2008).

Concealing one's illness to avoid HIV and AIDS stigma interferes with treatment adherence and perpetuates a culture of nondisclosure (Stirratt et al., 2006). Some people with the virus conceal symptoms indicative of AIDS from health care professionals to avoid the increased stigma of having AIDS versus HIV (Herek, 1999; R. S. Lee et al., 2002). Nondisclosure also occurs because PLWHA cannot prevent further disclosure of their status to others without their permission (Emlet, 2006). For example, Valle and Levy (2009) shared the story of a woman in

their study about HIV disclosure among injection drug users. After she disclosed to a family member, that person disclosed to neighbors, whose responses ranged from staring to throwing bottles at her. This is just one example of how disclosers cannot control what others do with the disclosed information.

<div align="center">*Managing Stigma*</div>

Managing stigma is challenging because when stigma is not explicitly expressed, it is difficult to identify and address, causing some people to manage stigma in ways that compromise their health, relationships, and overall quality of life (Buseh & Stevens, 2006). As a result, some seek support through support groups of other PLWHA, safe family members, and prayer (Buseh & Stevens, 2006; Elmore, 2006). Confronting the stigma, disclosing strategically, and redefining stigma as ignorance are other ways PLWHA have managed stigma (Buseh & Stevens, 2006).

Anti-stigma efforts can be an effective way to manage stigma; however, there are many obstacles to doing so. For instance, the fact that medical professionals endorse the same stigmatizing beliefs as the public hinders their abilities to challenge them (Lauber, Anthony, Ajdacic-Gross, & Rössler, 2004). The same is true for PLWHA who endorse the stigma (Buseh & Stevens, 2006). Given these challenges, there are specific steps that can be taken to reduce stigma.

Increased contact and education are effective stigma-reducing strategies for individuals involved in providing care and support for PLWHA (Bogart et al., 2008; Elmore, 2006; Estroff, Penn, & Toporek, 2004). As one person stated, his daughter began to treat him a lot better once she was educated about HIV transmission and no longer had unrealistic fears about becoming infected (Bogart et al., 2008). Some social service providers incorporated testing into various

health fairs along with other screenings (e.g., blood pressure, tuberculosis) or testing for other

sexually transmitted infections to reduce the stigma (Elmore, 2006). Lastly, it was noted in one

study that HIV education; nonjudgmental reactions; and emotional, spiritual, and social support

were instrumental in managing both stigma and HIV and AIDS (Dunbar, Mueller, Medina, &

Wolf, 1998). One of the most intriguing management strategies was spiritual support because

people often receive it in churches, which have a reputation of rejecting PLWHA (Genrich &

Brathwaite, 2005). The following section will look more deeply into this area of research.

Church

Some may challenge the notion that PLWHA should be involved in churches because of

their reputation for stigmatizing PLWHA (Genrich & Brathwaite, 2005); however, conducting

research on improving the quality of life of any group requires that researchers explore those

places in which people choose to live their lives. PLWHA should have the freedom to live their

lives wherever they choose, and many choose to have churches as an integral part of their lives.

In her article about improving the quality of life of PLWHA, Aranda-Naranjo (2005) provided

recommendations for providers that included identifying those places that PLWHA turn to for

support and developing patient-centered solutions. With these two recommendations in mind, I

will explore issues of stigma and disclosure within church communities, because religion and

spirituality are two things to which PLWHA turn for support.

Two areas of life that often become more significant once an individual receives an HIV

or AIDS diagnosis are spirituality and religion (Tsevat, 2006). There currently is a need to

understand the role of spirituality and religion in the lives of PLWHA (S. K. Parsons, Cruise,

Davenport, & Jones, 2006). To be clear, the words *religion* and *spirituality* are not synonymous,

despite the fact that some studies use them as such. The former refers to "practices, beliefs, and experiences pertaining to organized religions or beliefs systems;" the latter refers to "the domain of life beyond the body and mind" (Levin, 2001, p. 10). Religious engagement can be measured by prayer, worshipping God, church attendance, scripture reading, and meditation (Levine & Schiller, 1987; Rogers, Malony, Coleman, & Tepper, 2002; Zinnbauer et al., 1997). It consists of behaviors associated with organized religion (e.g., churches), whereas spirituality does not. Spirituality can be determined and practiced individually (Levine & Schiller, 1987). It is more private, personal, and tends not to adhere to traditional beliefs about God (Zinnbauer et al., 1997). According to a review of the literature concerning the connection between health and religion, or the epidemiology of religion, religious involvement promotes well-being and protects against illness (Levin, 2001). Whether a person is religious or spiritual, both require a belief in something other than what can be seen with the human eye. I am interested in better understanding the effects, benefits, and barriers to being spiritual or religious for PLWHA within the context of Christianity.

Effects of Religion and Spirituality on the Health of PLWHA

There are a number of benefits associated with spirituality and religion for PLWHA. In 2006, the *Journal of General Internal Medicine* published a supplement on issues related to HIV and AIDS, quality-of-life, and spirituality and religion (Tsevat, 2006). The supplement consisted of two studies described in several articles. The participants ($n = 550$) were asked about spirituality and religion within the context of quality of life issues. The majority of the participants belonged to an organized religion and believed that having a spiritual component in their lives improved their ability to cope with having HIV and AIDS (Tsevat). In another study,

PLWHA reported that religion, namely Christianity, and religious faith expressed through prayer, scripture reading or religious literature, and church attendance had a positive effect on their quality of life (Flannelly & Inouye, 2000). In one other study, a group of women living with HIV expressed that holistic health was important in managing their illness, stigma, and daily routines. Faith in God and spiritual involvement provided a source of strength for them that kept them physically healthy, mentally strong, and spiritually engaged (Blake et al., 2008).

Researchers have documented the physical, mental, and relational benefits for PLWHA who participate in a religious or spiritual routine in a number of studies (see Levin, 2001). Investing in a spiritual life allows PLWHA to better transition into living with the illness (Siegal & Schrimshaw, 2002). PLWHA have reported that spirituality improves their health, increases their life span, decreases their psychological distress (Simoni, Martone, & Kerwin, 2002) and promotes psychological growth (Coleman, 1999; Pargament, Smith, Koenig, & Perez, 1998). A weaker connection between HIV and sin in church teachings, as well as frequent church attendance, were associated in one study with quicker treatment initiation, better treatment adherence, and consistent medical care among women (S. K. Parsons et al., 2006). The deep meaning and sense of purpose rooted in spirituality also has been attributed to a reduction in HIV symptoms and depression (Coleman, 1999), and increased longevity (e.g., people living with HIV for 7 or more years; Barroso, 1999). Finally, in a study of people living with HIV or AIDS, spirituality provided these individuals with the strength to engage in family relationships, self-care, and goal formation, and to come to terms with their mortality (Tarakeshaw, Khan, & Sikkema, 2006).

Church settings also can play a crucial role for PLWHA who belong to an organized

religion. One researcher stated that "[t]he social support available through the church community

and the regular reinforcement of spirituality provided by organized religion can be seen as

contributing assistance and both physical and emotional strength to those with HIV or AIDS"

(Morse et al., 2000, p. 276). Church communities can serve as a type of home, where PLWHA

experience fellowship, acceptance, and affirmation (Siegal & Schrimshaw, 2002). For example,

the people in a church in Los Angeles encouraged honest disclosure about HIV and AIDS by

holding a service for sharing one's personal testimony concerning his or her illness,

discrimination experiences, financial difficulties, relationships, and so on (Leong, 2006). The

freedom to disclose one's experiences of living with HIV or AIDS helps to create an

environment in which the treatment of the illness is no different from other health conditions.

Religion also has a stress-buffering effect on people with these illnesses, particularly those with

lower levels of education and income (Ironson et al., 2002).

The clergy and congregation also are a source of social support (Levin, 2001; Pargament

et al., 1998; Siegal & Schrimshaw, 2002). Siegal and Schrimshaw (2002) found that a number of

participants in their study preferred talking to a religious minister instead of a secular counselor.

The church's focus on forgiveness provides an emotional outlet for PLWHA, as well as a

connection to the spirit realm, cleansing via religious behaviors, and a redemptive paradigm

allowing them to see positive things related to living with HIV or AIDS (Pargament et al., 1998).

Other countries have experienced the benefits of faith-based interventions. According to

Green and Ruark (2008), in Africa,

Christian churches – indeed, most faith communities – have a comparative advantage in

promoting the needed types of behavior change, since these behaviors conform to their

moral, ethical, and scriptural teachings. What the churches are inclined to do anyway

turns out to be what works best in AIDS prevention. (p. 22)

 The same may hold true in the United States; yet, AIDS church ministries are rare (Leong,

2006). While studying a church with an AIDS ministry, Leong (2006) stated that this church

"transcend[ed] constraints imposed by traditional religious institutions; address[ed] the health,

spiritual, and social needs of its parishioners without losing sight of its religious traditions; and,

at all times, maintain[ed] an AIDS-activist orientation" (p. 296).

Religion's ability to effectively get people to adhere to lifestyle changes highlights the

platform that religious faith has in the lives of people and the church's ability to inspire people to

action through their faith (Levin, 2001). Levin begins each chapter of his book, *God, Faith, and

Health,* with a narrative that illustrates the positive effects of religion and spirituality on one's

health before presenting supporting research. He began chapter one with a story about a man

named Michael who "smoked cigarettes, drank too much, ate poorly, and was overweight"

(Levin, 2001, p. 19). Michael agreed to reconnect with the Catholic Church if God brought his

son back safely from the Persian Gulf War. After his son's safe return, Michael became an active

church member. His desire to live according to what he was reading in the Bible and learning in

church grew, and he soon quit drinking, smoking, and began eating better and exercising.

 Churches have the potential to be a launching site for innovative interventions that

reduce HIV stigma (Haddad, 2005; Tsevat, 2006) and increase supportive resources. HIV and

AIDS stigma in some church communities unfortunately may undermine attempts to serve

people with these illnesses, posing a serious problem for African-Americans who have both the highest rates of infection (CDC, 2007) and church attendance (Barna, 2006).

Barriers of Spirituality and Religion

Churches, specifically African-American churches, historically have served their communities through education, social activities, support, and financial assistance during tough times (Coleman, 1999; Morse et al., 2000). They also have opened their doors to those living in the margins of society (e.g., homeless, drug addicted, and prostitutes). Conversely, churches have excluded gays and bisexuals; however, research suggests that these individuals seek religious and spiritual means of coping despite being rejected (Genrich & Brathwaite, 2005; Siegal & Schrimshaw, 2002; Tarakeshwar, Pearce & Sikkema, 2005). One study demonstrated that "organized religion acted as a barrier to attaining spirituality [for PLWHA] until their anger was ameliorated [by discerning] that the beliefs of the religions that labeled and persecuted them were in themselves flawed by their absence of caring and authenticity…" (B. A. Hall, 1998, p. 152). Additionally, a lack of training, skepticism, or differing beliefs may create discomfort on the part of the clinician to incorporate spiritual support into one's treatment plan (Dunbar et al., 1998; Mueller, Plevak, & Rummans, 2001). Thus, it is very important to stress the positive role that church leaders can play in the lives of PLWHA (S. K. Parsons et al., 2006).

Unfortunately, for most, stigma makes living with HIV or AIDS difficult to manage, due to the risk of being rejected by those to whom PLWHA reach out for support. HIV and AIDS stigma attitudes often are rooted in one's fear of the disease and one's feelings toward groups closely associated with the illness (Herek, 1999). As stated earlier, due to the variety of ways one can contract HIV and AIDS, the illness also has varying levels of stigma, which reflect varying

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levels of attitudes towards some of those behaviors (Elmore, 2006; Greene, 2000; Herek, 1999; Swendeman et al., 2006). This same hierarchy exists in churches. In a study among churches about HIV and AIDS as sexually transmitted infection, the most stigmatized subgroups were those infected through non-marital heterosexual or homosexual sex (Genrich & Brathwaite, 2005). Contracting HIV through a behavior considered sinful is more likely to incur judgment and blame from churchgoers and leaders (Haddad, 2006). Thus, fears of the social consequences of having HIV or AIDS may outweigh the potential physiological, cognitive, and emotional benefits of disclosing one's status (Poku et al., 2005). Any attempts to address HIV or AIDS stigma must identify the differences experienced between various subgroups to address issues of stigma adequately.

There also is evidence that PLWHA experience varying degrees of stigma across the spectrum of Christian denominations. According to a study about sex, religion, and HIV, individuals who identify as homosexual or bisexual are less likely to be members of evangelical denominations (e.g., Apostolic, Assemblies of God, Baptist) and more likely to be affiliated with other Christian denominations, (e.g., Disciples of Christ, United Church of Christ, Episcopalian; Galvan, Collins, Kanouse, Pantoja, & Golinelli, 2007). This divide likely relates to the fact that evangelicals tend to regard the Bible as a literal text; whereas those denominations considered "other Christian" tend to not (Barna, 2001). Each perspective leads to different interpretations of the text and different conclusions about right and wrong. Because of their literal teaching of the Bible, evangelical denominations run the greatest risk of stigmatizing those who identify as homosexual or bisexual because they often are unwilling to endorse their sexual identities (Genrich & Brathwaite, 2005). Many evangelical churches also invest a lot of time promoting

abstinence, which is not a relevant message for those who are not able to marry by law, or who choose to be sexually active (Genrich & Brathwaite, 2005). Another pastor remarked that "We are not going to tolerate at all any sexual activity outside of the bonds of marriage. We go in accordance with what the Word, [Bible], says…" (Genrich & Brathwaite, 2005, p. 5). Despite these attitudes and beliefs, a number of people living with HIV or AIDS have sought out spiritual means to cope with their diagnosis, both within and apart from a church, which suggests that spirituality could be an important component of coping (Tsevat, 2006).

Just as one would not expect to encounter stigma in a health care setting (see Rintamaki et al., 2007 for exceptions), one would not expect to encounter stigma in a church. Chesney and Smith (1999) called for political leaders and health care professionals to fight stigmatization by confronting

> their own prejudices, and address[ing] any fear, ambivalence, or hostility toward people living with HIV that they harbor, so that they can openly demonstrate or model the compassion and caring for persons who are living with HIV disease that is so critically needed. (p. 1170)

Church leaders should be added to this charge, as churches strive to be a symbol of compassion and care for *all* people and may prove to be an asset in the fight against HIV through community interventions. Luckily, extending love and compassion does not require churches to agree on every issue or to agree with one another concerning their differences. Expressing love and compassion simply requires that they are willing to "…become the model of the Kingdom of God here on earth, where each person is treated with the dignity of one who is created in the image of God" (Haddad, 2005, p. 34). This type of Kingdom theology, or a theology of

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extending God's Kingdom principles on Earth, (G. E. Ladd, 1959) permits the Christian church to look beyond philosophical differences to address the needs of the communities they desire to serve. Social support and education are two primary ways the church can make a difference in the lives of PLWHA and those affected by HIV or AIDS. This will require church communities to acknowledge, understand, and ultimately address the presence of stigma within their own faith communities.

Stigma is a powerful phenomenon that "affects marriage, interpersonal relationships, mobility, employment, access to treatment and care, education, leisure activities and attendance at social and religious functions" (Van Brakel, 2006, p. 327). Although the church should be a place characterized by love and acceptance for all people, it can be a place riddled with "stigma," "prejudice," and "rejection" as Anglican priest Haddad (2005, p.33) noted. Stigma forces individuals to withhold portions of information about themselves in order to avoid stigmatizing experiences, which can result in isolation and alienation (Emlet, 2006; Poku et al., 2005). Leong (2006) used the words "alienated" and "estranged" to describe the relationship between individuals with HIV and the church, placing PLWHA who embrace religion and spirituality in a difficult position, both socially and psychologically (p. 295). For instance, a number of PLWHA were asked to discontinue their church membership after disclosing that they were HIV positive (S. K. Parsons et al., 2006). In another study, individuals who were older than 50 years old were less likely to disclose to church members because of stigma (Emlet, 2006). The teachings regarding HIV or AIDS also can perpetuate stigma, particularly when the illness is presented as a punishment from God, rather than a consequence of any number of behaviors or circumstances. Authors of one study reported that a close relationship between HIV and punishment from God

resulted in lower treatment adherence, or a delayed initiation of medical treatment (S. K. Parsons et al., 2006). Some individuals felt alienated from their place of worship because of their diagnosis (Tsevat, 2006). For these reasons, it is important to understand the environments in which individuals may seek, or be encouraged to seek holistic care (Coleman, 2004).

Rationale

In this study, I explored the relationship between HIV and AIDS, stigma, disclosure, and social support within church communities to enhance future intervention efforts that might increase supportive resources and ultimately improve the quality of life for PLWHA. Stigma and disclosure research (e.g., understanding stigma experiences) allows researchers to identify barriers to disclosure. Identifying these barriers within specific contexts should make it possible to address them directly. Addressing these barriers can decrease HIV and AIDS stigma by challenging those barriers that are stigmatizing and increasing the freedom to disclose among PLWHA, allowing them to access the supportive resources available within church communities that can improve their quality of life.

Some may argue that decreasing the stigma associated with HIV and AIDS may increase the stigmatized behaviors associated with the disease (e.g., drug use or unsafe sex). Yet, church teachings of serving the disenfranchised has resulted in churches reaching out to prostitutes, the homeless, convicted criminals, and drug addicts, to name a few. Addressing stigma in church communities will enable them to deter these behaviors in healthier ways, instead of demonizing the individual. One woman reported her church experience saying, "[t]alk about fear, rejection and bigotry. You are not going to find a more bigoted place than the house of God" (Peterson, 2009, p. 311). Challenging churches to address issues of stigma resulting in rejection,

discrimination, and judgment not only will enable churches to better carry out their own mission of justice and compassion (Claiborne, 2006; Perkins, 1982), but it will allow the church to explore those issues that lead people to place themselves at-risk; fighting the spread of HIV at its roots.

Christian churches currently hava a reputation of stigmatizing PLWHA, rather than helping them (Genrich & Brathwaite, 2005). Reducing church stigma will be helpful for those who wish to grow spiritually as they struggle to cope with and adjust to their illness. This unique approach to increasing the quality of life for PLWHA may be particularly helpful for African Americans, who presently experience the highest rates of HIV infection, commonly distrust the health care system, and frequently participate in organized religion (Coleman, 2004). This study will extend the current literature by providing first-hand accounts of stigma experiences from PLWHA within churches, exploring the role of religious faith in the lives of PLWHA, and understanding the barriers that prevent people with the illness from seeking support through disclosure in churches.

The church and its members are an understudied environment ripe with intervention capabilities; however, there are a number of barriers preventing the church from fully serving in this capacity. As Haddad (2005) stated, "[t]he church must see its ministry in an HIV-positive world as a place where sexuality is celebrated in its goodness, and challenged where it brings death" (p. 35). By understanding the stigmatizing experiences of PLWHA and disclosure barriers within church communities, researchers can begin to devise effective interventions that are sensitive to the unique components of this environment. Moreover, according to the Centers for

Disease Control (CDC), seeking to improve the well-being of PLWHA has the potential to strengthen prevention efforts (CDC, 2003).

Although stigma research often is illness specific, it rarely has been context specific (Van Brakel, 2006), making it difficult to apply research findings practically. It is important, therefore, to narrow the scope of the construct by situating stigma within a particular context. This study does just that, by situating stigma within church communities. Understanding stigma within a specific locale increases the applicability of the findings, making it easier to challenge and remove the stigma.

I will explore the relationship between HIV and AIDS, stigma, disclosure, and social support within church communities with the following research questions:

RQ1: Why are churches perceived as having a supportive function?

RQ2: How are HIV and AIDS stigma communicated within church communities, decreasing the likelihood of disclosure among PLWHA?

RQ3: What types of social support do PLWHA receive within their church communities?

RQ4: What changes need to be made so that churches can more effectively communicate support to people affected by HIV and AIDS?

CHAPTER THREE: METHOD

In this chapter, I describe how the study was developed and conducted. This includes a discussion of the theoretical framework used in this study, as well as the participants, data recruitment, collection, and analysis of the data. I also review the interview schedules. Finally, I describe the sample using demographic information collected during the interviews.

This was a qualitative study in which I used semi-structured interviewing for data collection. The interviews were rooted in a grounded-theory approach, which allows researchers to identify themes and patterns presented in the data gathered directly from participants (Corbin & Strauss, 2008). These themes were created by performing constant comparative analyses, or identifying categories of ideas within the interviewees' responses. The interviews allowed the participants to both create and inform the stigma experiences of PLWHA. Interviewing both PLWHA and church leaders provides invaluable insight into how stigma influences disclosure patterns within a particular context from two perspectives.

Participants

PLWHA

Twenty-one participants currently diagnosed with HIV or AIDS were recruited within Champaign and Urbana, Illinois, as well as Chicago, Illinois. They were reimbursed $25 for participating in the study. The inclusion criteria were as follows: the participant (a) is infected with HIV, (b) has no apparent dementia, (c) is able to speak and read English, and (d) is age 18 or over. These requirements were necessary because of the subject matter and data collection process. Participants had to be able to clearly understand the interviewer to respond. They also

had to function at a level that allowed them to engage in in-depth interviews, complete short questionnaires, and offer consent.

Interviews

Semi-structured interviews with PLWHA were audio-recorded, transcribed, and analyzed through constant comparative analyses to explore the relationship between HIV and AIDS, stigma, disclosure, and social support within church communities. Prior to the start of these 60 to 90-minute interviews, informed consent was obtained from participants. The consent forms were read orally and (a) briefly described the study, including the procedures and possible risks and benefits, (b) informed the participants that they will be reimbursed $25 for their participation; (c) stated that participation was voluntary; (d) stated that participants may withdraw from the study at anytime, for any reason; and (e) informed the participants that they could contact the researcher or the IRB for further information about the study, including email and toll-free phone number contact information.

Interviews were conducted at a location on the campus of the sponsoring institution or in a private room at one of the two public libraries. Although the campus was extremely accessible, most of the participants preferred to meet at the public libraries because they were more familiar with them. After obtaining informed consent and completing the interview, participants were asked to complete a short questionnaire containing demographic questions (see Appendices A & B). Questionnaires were labeled with a number that also was written on the audio file of that participant's interview. These numbers allowed me to track the interviews without any identifying information on the questionnaires or files.

Recruitment

Recruitment for PLWHA occurred in Champaign and Urbana, Illinois, as well as some Chicago sites. The Chicago locations were added due to difficulties in recruiting a large enough sample in Champaign and Urbana. Recruitment flyers were posted in strategic locations to elicit participation. The locations were a local AIDS service organization (ASO) office, food banks, and public libraries. The flyers (a) stated that the study concerned issues of religious faith, HIV and AIDS, stigma, and support; (b) informed participants that they would be paid $25 for an interview; (c) provided my contact information; (d) stated that this project was connected to the University of Illinois at Urbana - Champaign; and (e) ensured that their participation would be kept confidential.

Interview Schedule

A semi-structured interview schedule was created with questions generated from previously cited literature on the effects of stigma on disclosure patterns of PLWHA (see Appendix C). In addition, appropriate wording for the interview schedule was informed by previously cited literature concerning PLWHA, as well as my personal experiences with working and researching marginalized populations (i.e., people with bipolar disorder, homeless individuals, and PLWHA). The interview schedule also was piloted and revised prior to data collection. The first section of the interview schedule built rapport with questions about their personal backgrounds. The second section of the interview addressed religious faith. The third section was concerned with church communities and stigma. The fourth section dealt with issues of support and the church. Finally, the fifth section gave the interviewees an opportunity to share

their own insights about these issues, as well as to ask questions about anything related to the study.

<div align="center">*Church Leaders*</div>

The global presence of churches positions them well to address the needs of people living with HIV or AIDS. More specifically, Christianity is an ideal religion in which to focus these efforts, specifically in Illinois, for a number of reasons. First, according to the Barna Group, a research group that targets issues of religion and spirituality in the United States, 47% of American adults attend church regularly (Barna, 2005), only 7% identify with a religion other than Christianity (Barna, 2007), and 89% of Christian church attendees are either strongly (56%) or moderately (33%) committed to their faith (Barna, 2007). Second, church services are attended regularly by Blacks (52%), Whites, (49%), and Asians (29%; Barna, 2006). Few organizations have such access to the public at large and span such a large number of ethnicities. Third, Illinois is a part of the Midwest, which has a 54% regular church attendance rate, the highest of any region in the United States (Barna, 2006). Finally, Christianity is a religion founded on principles of love, compassion, and service. Although the practices of some churches may not reflect these principles, poor practices do not change the foundations of an organization, but provide an opportunity for change.

Twenty-one church leaders were recruited within Champaign and Urbana, Illinois. The term "church leader" refers to individuals who held leadership positions within their churches. They were reimbursed $25 for participating in the study. The inclusion criteria were as follows: the participant was (a) not infected with HIV, (b) an active member a church community, (c) able to speak and read English, and (d) 18 years of age or older. These requirements were necessary

because of the subject matter and data collection process. Participants needed to be able to clearly understand the interviewer to respond, complete short questionnaires, and offer consent.

Interviews

Semi-structured interviews with churchgoers were audio-recorded, transcribed, and analyzed through constant comparative analyses to explore the relationship between HIV and AIDS, disclosure, stigma, and social support within church communities. Prior to the start of these 60 to 90-minute interviews, informed consent was obtained from participants. The consent forms were read orally and (a) briefly described the study, including the procedures and possible risks and benefits; (b) informed the participants that they will be reimbursed $25 for their participation; (c) stated that participation was voluntary; (d) stated that participants may withdraw from the study at anytime, for any reason; (e) informed the participants that they could contact the researcher or the IRB for further information about the study, including email and toll-free phone number contact information. After obtaining informed consent, the participants then were asked to complete a short demographic questionnaire.

Recruitment

Twenty-one participants were recruited using a snowball sample generated from within the interviews. Once an interview was completed, I would ask for recommendations for other people to interview. I then contacted these individuals for an interview. Because of my previous relationships with many church leaders in the area, it was not difficult for me to approach these leaders directly about participating in the study or recommending people for this study. As a result, I easily was able to interview the desired number of participants.

Interview Schedule

Because I am not aware of any studies that have specifically explored church stigma in the United States by documenting church member attitudes, the interview schedule was based on the literature concerning church stigma of PLWHA and my personal involvement with both secular and Christian groups in dealing with social justice issues (e.g., race, poverty, HIV or AIDS, mental health). This study is about the stigma experiences of PLWHA within church communities and the effects of these experiences on disclosure. Based on the literature, one's attitude towards these illnesses, as well as one's knowledge about them, greatly influenced stigma. Denominational beliefs and theological teachings about HIV and AIDS also may influence one's attitudes and beliefs about the virus and people living with the virus. The interview schedule was developed with these factors in mind. The first section of the interview schedule built rapport with the participants with questions about their personal backgrounds (see Appendix D). The second section concerned the church's role in serving the HIV and AIDS community. The third section dealt with the role of the interviewee's church in serving people with HIV or AIDS. The final section gave the interviewee an opportunity to provide personal insights about these issues and to ask questions about anything related to the study.

Data Analysis

A professional transcriptionist transcribed the data for analysis. After the transcripts were completed and checked for accuracy, recordings of the interviews, transcripts, and questionnaires were stored in a locked filing cabinet in the researcher's office to ensure the confidentiality of the participants. Then, the data were coded using constant comparative analysis, which involved

comparing the substance of the interviews for similarities and differences (Corbin & Strauss, 2008).

There are three stages of coding – open, axial, and selective. Open coding is used to categorize the general components of the data. Axial coding is used to construct the data according to the relationships between the codes or categories developed in open coding. Lastly, selective coding is used to identify the overarching themes that can be used to organize each of the categories, which will serve as the basis for a grounded theory (Corbin & Strauss, 2008). Studies do not always use the three levels together. For example, Emlet (2007) only used open and axial coding in his multi-method study about the stigma experiences of older individuals living with HIV and AIDS. He coded his transcripts for stigmatizing ideas, events, and experiences to bolster his quantitative findings. All three levels of coding were used in this study.

The research team consisted of two colleagues trained in constant comparative analysis. They first performed open coding on a sample of the data using the research questions as a guide for identifying the general components of the data. The research team coded the transcripts for these components one research question at a time. For the first round of coding, the team coded the interview transcripts for perceptions of the church as expressed by the participants. The second round of coding addressed how church communities communicated HIV and AIDS stigma. The third round of coding concerned the types of social support that PLWHA received within their church communities. The fourth round of coding identified ways to improve how churches communicated support for PLWHA. These components were then developed into themes. Next, we met to discuss our findings and to reach a consensus about the findings.

Axial coding was the next level of coding. At this level, the themes were organized according to their relationship to one another within the context of each research question. That is, the themes developed in accordance with each research question were organized in terms of their similarities to and differences from one another so that they could be integrated into broader concepts.

Finally, I performed selective coding using the broader concepts developed during axial coding. These broader concepts were taken out of the context of the specific research questions to understand their relationship to one another apart from the questions. This allows for the development of overarching themes. These themes were organized and developed into a theory based on their relationships to one another. This theory is presented in the results chapter.

Sample Demographics

PLWHA

Of the 21 PLWHA interviewed in this study, eleven of these individuals were between the ages of 31 and 50, the rest were 50 years of age or older. The majority of the participants were male ($n = 14$ male; $n = 7$ female). Racially, 15 of the participants identified as African American and six as White. In response to an item about sexual orientation, five individuals identified as gay, 15 as heterosexual, and one did not choose any of the options. All of the participants attended Christian churches at one time in their lives. A majority of the participants considered themselves Christians ($n = 15$), six indicated "other" for their religion; however, only one participant named another religion during the interview. The other five individuals who indicated "other" were no longer attending church, which may explain why they did not identify

with a particular religion despite having attended a Christian church in the past. The majority of the participants (*n* = 15) were on disability, making less than $15,000 a year.

In terms of their illness, 10 people were diagnosed within the last 10 years, eight were diagnosed between 1990 and 2000, two between 1980 and 1990, and one between 1970 and 1980. Fifteen of the participants had HIV, five had AIDS, and one did not indicate either (see Table 1). In addition to their HIV or AIDS medications, nine individuals also were on medication for depression or anxiety. About half of the participants attended support groups (*n* = 11) and 18 had friends with HIV.

Table 1

Demographics of PLWHA

Variable	Categories	*n*
Age	31 – 50 years of age	11
	50 years of age or older	10
Sex	Male	14
	Female	7
Race	African American	15
	White	6
Sexuality	Heterosexual	15
	Homosexual	5
	None	1*
Religion	Christian	15
	Other	6**
Illness	HIV	15
	AIDS	5
	None	1*
Diagnosis	Within the last 10 years	10
	Between 1990 and 2000	8
	Between 1980 and 1990	2
	Between 1970 and 1980	1

*Participant did not indicate an answer on the demographic survey, although the item did apply to him/her.
**Only one participant was practicing another religion; the others indicated "other" because they currently were not attending a church.

Church Leaders

The majority of the church leaders were between the ages of 18 and 30 ($n = 13$); the other participants were between the ages of 31 and 50 ($n = 4$) or older than 50 ($n = 4$). About half of the participants were male ($n = 11$). Racially, 11 of the church leaders identified as White, eight as African American, and two as Asian American. All but one of the participants had college degrees, including eight with graduate degrees (see Table 2).

In terms of their religious faith, seven became Christians in the 1980's, six in the 1990's, four in the 1960's and 70's, and four within the last ten years. The majority ($n = 17$) of the participants held positions within their churches with official titles. Some of these participants were formally trained pastors, but many of them were church members whose leadership roles emerged out of work they already were doing. Outside of Sunday church services, 18 individuals regularly participated in smaller groups within the church (e.g., committees, Bible study groups, health clinic volunteers, choir members, church greeters). In response to an item asking them to rate their church's community outreach to the marginalized in comparison to Biblical teachings, the responses were evenly divided between low ($n = 7$), medium ($n = 7$), and high ($n = 7$). The participants also were asked if they knew anyone with HIV or AIDS, to which 12 people responded yes. Lastly, because the issue of HIV and AIDS commonly is linked to sexual identity within church communities, I asked the participants to indicate if they knew anyone who identified as LGBT. All indicated that they did.

Table 2

Demographics of Church Leaders

Variables	Categories	*n*
Age	18 – 30 years of age	13
	31 – 50 years of age	4
	50 years of age or older	11
Sex	Male	11
	Female	10
Race	African American	8
	White	11
	Asian American	2
Education	High School Diploma	1
	Bachelor's Degree	12
	Graduate Degree	8

CHAPTER FOUR: RESULTS

The purpose of this study was to explore the relationship between PLWHA and church communities. There were four primary goals of this project – to explore the potential benefits of involving churches in efforts to increase social support for PLWHA, to identify the challenges of increasing church involvement in issues related to these illnesses, to understand the types of social support that PLWHA receive through their church communities, and to highlight changes that should be made so that churches can more effectively communicate support to people affected by the virus.

The results are divided into four sections that are structured to address each research question, respectively. The first section addresses why churches are perceived as having a supportive function according to PLWHA in this study. The second section highlights the communication of HIV and AIDS stigma in church communities. The third section reveals how PLWHA experience the church as a source of social support. The final section contains ways in which the church can more effectively communicate support to PLWHA. Throughout these sections, it is important to note that although there are a number of ways to refer to the concept of God (i.e., higher power), the term "God" will be used because the participants most frequently mentioned it. The names used for both people and places throughout the results and discussion chapters are pseudonyms.

Why Churches are Perceived as Having a Supportive Function

The church's reputation for helping people in need does not necessarily extend to PLWHA (Genrich & Brathwaite, 2005); therefore, it is important to establish the church as a possible source of support for PLWHA. This section provides reasons for involving the church

using statements made by PLWHA. For them, enlisting churches was about realigning them with their own mission. It became apparent throughout the interviews that the participants views of church had more to do with their experiences with and understanding of God, rather than their experiences with people in the church. For that reason, it is important to understand the role of God in the lives of people with HIV and AIDS because these experiences shape their perceptions of the church.

Experiencing God as a Source of Social Support

As stated earlier, there is much research that examines the relationship between spirituality, religion, and health (Levin, 2001). This section provides a unique perspective of people speaking explicitly about the ways in which God directly has provided them with social support in relation to their illness. These responses were coded according to traditional categories of support – tangible, emotional, informational, appraisal, and esteem (Goldsmith, 2004).

The participants generally sought support through praying or reading scripture, which is apparent in the narratives shared throughout this section. Although participants sometimes highlighted a specific support-seeking behavior during their interviews, there was no evidence that the support function was in some way dependent on a particular support-seeking behavior. There were many times when no support-seeking behavior was mentioned, suggesting that a general faith in God also could result in social support.

Tangible Support

Tangible support refers to statements about how God has supported these individuals physically or instrumentally (by providing services or resources; see Goldsmith, 2004). These include things related to their health, relationships, or physical circumstances (i.e., resources).

What is unique about tangible support within the context of this faith tradition is that it includes statements about health stability or improvement resulting from seeking support from God. For example, Annette attributed her health to God: "I believe that God has blessed me because here I am. I'm almost five years into it, [living with HIV], and I'm still – besides my other physical ailments, as far as HIV goes, I'm very healthy." Others described God's tangible support as life-saving, as Rick explained:

 I think that if it wasn't for God, I don't think I would have made it as long as I have, because I've got friends that have been HIV positive, found out and died within a year, a lot of them. But this is going on 21 years for me. I think that it has to be God, because I don't take my medicine the way I'm supposed to. My doctor says this is where you were six months ago and this is where you are now. I'm like well, God works for me. God's got me healthy. I've never been sick. I've never had a bout with a sickness. You know the things that come along with AIDS, pneumonia and all that. I never had that. I never had to be hospitalized.

Roslyn felt that God's support enabled her to live with a number of health issues without having to be heavily medicated. She described it as a gift:

Since I've been a little kid coming from Mississippi, I haven't really had nobody to talk to but God himself. That's the only person that was always there for me no matter what. I know he's going to be there for me. I believe that that's why I'm not on any medicine. Since 1992—it's going on 12 years. November 12th of 1992 I found out I had HIV, and I've never been on any medicine for that. That ain't nothing but a gift from God Himself!

Apart from a person's illness, there may be other things that PLWHA have to manage, especially if they are engaging in risky sexual behaviors or abusing drugs. Sheri highlighted how God's support came in the form of health-promoting behavioral changes:

God saved me and God's healing me, so I'm excited about that—by living right, I mean living stress free, not drinking and drugging and just exercising and being in the right mental state. A lot of that stuff comes with being with Christ. It's scary to say that a lot of people think they can do it without Him. A lot of people do, they live their lives, but in the end, what's next?

Another issue that PLWHA commonly encounter is stigma from friends, family, and even health care providers (Rintamaki et al., 2007). Sylvia was unsure about how or when she contracted the virus. She also was married at the time of her diagnosis to someone who was not HIV positive. Once his family found out about her diagnosis, they began to treat her negatively. She sought support through prayer and saw a change in their behavior, which she attributed to God:

I just prayed to God that any bitterness in their hearts that they had towards me, to remove it or just make them my enemies. Make them stay away from me. God finally stepped in and did His part, and they finally started coming around to the point that now, they accept me as their sister-in-law, all of them do. God turned that around and now we get along good.

Sexuality frequently came up during these interviews, because many evangelical churches believe that homosexuality is a sin. Although this issue will be discussed in greater detail in the next section, I did want to highlight that some of the participants who had same-sex

partners at one time in their lives also believed that homosexuality was a sin. For them, their

Christian faith was a source of strength to overcome their sexual struggles. Jerry shared about

how God supported him as he attempted to "free" himself from homosexuality through prayer

and fasting. He said,

> I've been free from homosexuality for five, six years, but it took time and constant prayer
>
> and fasting. I would get up in the morning at 5:00 and walk to the church and just lay out
>
> before God and just pray, and I would just pray. That kept me focused and kept me to
>
> abstain being with men or having those desires or the thoughts. My mind and my heart
>
> was focused on God and being with God. I am free from it. You can change.

These examples of tangible support show a broad range of the support needs that PLWHA may

have in relation to their illness. Their faith in God to address these needs shows that they depend

on God to take care of them. This dependence also may indicate a lack of support in their lives

from friends and family, social service providers, and health care professionals.

Emotional Support

Emotional support refers to instances in which seeking support from God resulted in a

positive change in one's emotional state. Their emotions often changed from a negative

emotional state to a positive one. This happened before my eyes during an interview after I asked

Sylvia why she began going back to church after experiencing rejection in her old church for

disclosing her diagnosis.

> Interviewer: After having that bad experience, why did you go back to church at all?
>
> Sylvia: It wasn't the church. It was the people in the church. People are corrupted. A lot
>
>> of people are so corrupted. When it's like that, it makes everything look

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corrupted, even the church look corrupted, when it's not. The church is just a

building or temple that we go to give thanks to God…

Interviewer: What are you thinking about that's making you cry?

Sylvia: I just get joy and I feel the presence of God flow over me when I cry. It's a

peace. I apologize for that—no, I don't apologize. It's just the Spirit and the

anointing of God flowing over me.

Laura shared a similar experience when the Holy Spirit, or the Spirit of God, impacted her. She

said "[the] Holy Spirit came into my body and fulfilled me, and it was so powerful in me that it

made me cry tears of joy."

Some participants also talked about feeling relieved of depression because of God:

Interviewer: What do you do to deal with your depression?

Rick: I read my word [the Bible].

Rick's depression was relieved when he connected with God through reading the Bible, or His

word. Participants also discussed God's emotional support as a buffer against stress. After asking

Stacy what she would lose if she walked away from her Christian faith, she said

I know one day that I probably will get to the point if they don't find a cure that I'll

probably have AIDS. So I'm thinking if I walk away from all that now, then my health

will probably go downhill drastically because I have a prayer book that I constantly read,

and stress is a big factor, they say, with handling even cancer or any type of disease. Any

anxieties, depression; so I think I'd be overwhelmed with stress because I would have

nobody to talk to or help me with it.

Emotional support was not always immediately attributed to God, particularly when individuals had negative emotions about becoming infected. Reconciling an HIV diagnosis with one's faith in God can be difficult when the infected individual does not believe that he or she engaged in risky behaviors. Although I did not interview participants who blamed God for their diagnosis, at least not at the time of the interview, one participant did share how he re-directed his anger from God to the person who infected him:

> I don't read my Bible as often as I should because I'm so depressed right now with this recent news that I've gotten [about my diagnosis]. To be honest with you, I was kind of mad at the Lord. I thought I was doing everything right. I took my marriage seriously and my vows seriously. I felt like it was a slap in the face, like He [God] let me down. I was mad at Him for a little while. Then, I started reading some scriptures in the Bible and I just took the anger away from Him and channeled it towards my wife now. "How could you do this to me?" … It helps me–I feel like I'm not really angry no more. I'm depressed. When I talk to the Lord, I feel like He hears me. It just takes some of the pressure off me.

Lastly, the very idea or nature of God acted as a source of emotional support because it allowed these individuals to hope for what could be. Roger said "I do feel one day, God is going to...come up with a cure." Faith in God can provide a way for people to cope with the uncertain future of their health status because of the support they already have received from God. It is as if God's support gave them reason to hope for more.

Appraisal Support

There were many statements about appraisal support, which occurred when God played a role in changing a person's perspective about his or her illness. Some felt that God allowed them to find purpose in their illness. For example, Sean, an HIV and AIDS educator, said, "I feel comfortable enough doing it, and I feel that there's something—I feel like I'm still the same person, but there's something that's helping guide me to do this. It's my purpose." This connection between illness and purpose was made by others, such as Annette:

> I thought that was what God gave me the purpose to do was to be an advocate for these
> people that can't speak for themselves. I believe the Lord has given me this for a purpose.
> I've felt like I've never found a purpose for my life, and so that's why I believe the
> Lord—He knows I have the strength and the ability to speak for people that aren't able to
> speak for themselves.

Stacy expressed similar feelings as she tried to make sense of her illness. She felt that the reason she had not developed AIDS was because God wanted to use her for a specific purpose. She explained,

> I just feel like all this happened for a reason. It wasn't nothing that I've done bad. Maybe
> this is the way that God wanted to use me to speak out to other people, to help other
> people, and I know it's a big reason. He has not brought me 12 years later to still have
> HIV, because the same guy who I got it from has full blown AIDS, and the lady that he
> married, but he didn't tell…in two years, she had full blown AIDS. I don't believe that
> He has brought me this far just to say, "Here, I'm going to give you this disease or you've
> got this disease and you're not going to be able to do any type of footwork with it."

Other's felt like their illness served as a wake-up call from God so that they would not miss their life purpose. Their illness caused them to seek appraisal support from God because believing in God automatically meant that one's illness was inherently more than an illness. As Steve explained,

> I feel like I have to hurry up now to try to make something of myself. I feel like I don't have a lot of time left now, so I've got to double up and speed up and get off my behind and try to ask what the Lord wants me to do or get out here and try to find it. I've got to speed it up now. I ain't got time to waste. Every minute counts now.

> Some went so far as to thank God for the illness because they now saw it as an

opportunity presented to them by God. Rick said,

> I thank God for this thing that I'm going through because it connects me and helps me be more focused on Him. Because I can talk to Him about it, and I do believe God understands, and it makes our relationship closer.

A similar idea was expressed by Roger, who viewed his illness as a part of his life journey through which God was guiding him:

> But there's a reason why he's taking me down this road, and I don't question him… I'm 54 and I'll be 55 this year. Now, I take a different perspective in my life and I'm trying to tell other folks "don't go down this road with these diseases out there."

Esteem Support

Esteem support refers to support provided by God that positively affected a person's view of him or herself in relation to his or her diagnosis. Sean felt encouraged by God in his work to educate others about HIV through sharing his own story. He said,

I really don't think I could be doing what I am today, being able to get in front of 100, 200 people and say I'm HIV positive and not know something's out there saying yeah, you're doing the right thing, Sean.

Others experiences esteem support through having an ongoing relationship with God in which they felt loved and accepted. Jerry said, "I know that there is hope and that there is a God that loves me more than any human being, and I've got to answer to him, nobody else." Stacy expressed a similar sense of support after I asked her why people turned to God when circumstances in life were difficult:

Just so they can feel like they don't have to handle this on their own and that there's one person in this whole world that—even if you don't want to talk to counselors and doctors—there's one person or one thing that's higher than you, that you can always talk to, that's not going to say a word to anybody, and that's not going to judge you whatsoever, and is always going to be there, no matter what to listen to you.

The participants with HIV or AIDS in this study experienced God as a source of social support, apart from engaging in any particular type of support-seeking behavior. These examples provide the foundation for how they expect the church to function as a source of support. The next section reviews the themes about their views of the church.

Defining the Church by its Purpose

The participants' definition of church reflected a belief that it should be an extension of their relationship to God. This section only concerns the views of PLWHA because it is important to establish that they believe that church organizations should function as supportive

resources for people affected by the virus. PLWHA in this study defined the church as a source

of social support, a welcoming community, and a refuge or hospital for the sick.

Social Support

Daniel expressed a desire for churches to function as he once experienced them, as a

supportive community to help people deal with their problems:

I think we need to get back like years ago when we cared about people. We cared about

people and you're problem was my problem. My problem was your problem. I mean,

time can change because I shudder to think, and I feel one of these days, we're all going

to stand before God one of these days.

His statement reflects a belief that the church should be a source of social support to help people

through hard times. He connected a lack of church support to God's judgment, indicating that

this is God's expectation for the church as well. He goes on to say that this support should not

waver based on a person's sexuality or illness:

We all fall, but there's times when we've got, and you may not want to get up, but you've

got someone that comes along and says "Hey. Look. I love you. I care for you. I'm

concerned about you. Hey, get up. Let's go. Limp along with me until you're ready to get

you know, get your way back." God has been trying to help. The devil has been trying to

destroy me. I can't allow that. I hope a person would come to me and say, "I'm gay. I'm

HIV." "Well, hey, let me tell you what. Let me introduce you to some people that don't

care what you are."

John described the church as being a place that reaches out to others through providing

informational support about sex. He stated that "The church is the community, reaching out to

one another that you might see on a daily basis, giving them a reminder of safe sex or abstinence, however it goes, is the key factor." The church, therefore, could be an educational resource within the community, contributing to support and prevention efforts.

Welcoming Community

Another theme that emerged was a belief that the church should be a welcoming community. The participants felt the current messages about HIV and AIDS were incongruent with God, and consequently, the intended purpose of the church. This largely was because many of the messages were stigmatizing. For example Matt said,

One thing they [the church] should try to do is pattern their lives after Jesus, because Jesus didn't care what kind of disease you had. You're talking that talk again, but you ain't walking the walk. You accept us…That person may have AIDS or HIV or they may be a prostitute or drug addict or alcoholic or whatever. You don't judge. You reach out to them and let them know who loves you. Jesus loves you.

Annette expressed a similar view saying, "God loves all people. You shouldn't have a stigma. There should be no stigma within the church. If there's a stigma within the church, something is wrong." That is, the church should be a stigma-free environment, so that all feel welcomed and loved. If God loves all people, then Christians should love all people too.

Others spoke about the church being a place where a person could enter without any prerequisites; a welcoming community for all. Tony expressed this when he said "You know, the Lord said come as you are. When I did go to church, I'd walk in there with my gym shoes and blue jeans on and sit down." Roslyn made a similar point in reference to sexuality saying "God made us from the womb. He don't say nothing about homosexuality. Come in as you are. It don't

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say whether you're homosexual, it says as you are." These comments express a belief that the church should welcome people regardless of whether they dress or believe like other members.

Refuge or Hospital

The final theme that emerged in reference to the purpose of the church was that it should serve as a refuge or a hospital. That is, the church should be a place of protection and a place for the sick. Jerry's definition of church emerged as he explained why he had not disclosed his status within his own church community:

> Church people are supposed to be your strong tower …this is supposed to be a place where you can come for refuge. They [people in the church] don't know how to reach out to people, and the church [should be] like a hospital. It should be open to anything and everything. My pastor always talks about being ready to deal with any and every kind of people.

Later when I asked him about ways in which he could use support, he spoke about his fear of disclosing because he does not feel that the church is a safe place. He said,

> I think if I just had one friend that was going through the same thing I was going through, somebody that I could hang out with and talk to, like a best friend kind of thing, I think that would be the best thing for me right now. But the thing is, I haven't put myself out there to find out if that could happen.

Although he defined the church as a place in which he should be able to find support, ultimately his fear of the consequences of disclosure prevailed. Because of the negative identity of many churches in regards to HIV and AIDS, it is difficult for PLWHA who attend churches to feel safe

disclosing their illness. The things that contribute to this negative identity are discussed in the following section.

The Communication of HIV and AIDS Stigma within Church Communities

Although many of the participants believed that churches should be more welcoming for PLWHA, they also provided reasons for why this currently is not the case. The challenges of creating a welcoming environment for PLWHA are many and varied. This section is divided into two parts with each part containing a number of themes that highlight issues that complicate the current communicative climate regarding HIV and AIDS in churches. The first part contains issues that decrease the likelihood of disclosure of one's HIV-positive status and is presented from the perspective of PLWHA. The second part of this section contains issues that were coded from my interviews with church leaders from evangelical churches. These sections combined provide a snapshot of the complexities of enlisting churches in HIV and AIDS related work.

Decreasing the Likelihood of Disclosure for PLWHA

The barriers of utilizing churches as sources of support for public health issues related to HIV and AIDS are organized by the three levels at which participants with the virus experienced church – church, congregation, and pastor. Church refers to issues related to the church as an organization; much like a person may express an opinion about the business practices of a company. Experiences at this level concern the church's ability to manage their identity as a system. Congregation refers to experiences with or observations about people that attend a particular church. Pastor refers to experiences with or observations about the pastor(s) of a particular church.

Church

Two themes emerged at the church level–lack of community outreach and the presence of HIV and AIDS stigma among or within the church. The issues raised in these examples communicated to the participants with HIV or AIDS that churches are not supportive of PLWHA. These examples also are inconsistent with the definitions of church provided earlier by people with the virus. Only comments made by PLWHA are included in this section.

*Community outreach. A*lthough many churches participate in community outreach, the services that they provide do not necessarily communicate a genuine concern for the people within in their communities who are in need of support. Sean shared about his attempts to get a church involved in helping PLWHA:

> Unless you're really persistent about bringing it up week after week after week, it just falls off by the wayside, because it's something that yeah, "we know it happens and we have a lot of empathy for those people, but what are we going to do for the next chicken noodle dinner?"

Sean's comments suggest that, although the church was reaching out to the community, their unwillingness to shift their focus to people with HIV or AIDS cast a negative light on the community outreaches they were doing. Additionally, if this unwillingness was aimed at these individuals specifically, it not only could decrease the likelihood of disclosure, it also could decrease the likelihood of a person remaining in a Christian church. For example, Eric decided to change religions because of the church's stance on homosexuality and their lack of support for people with HIV. He explained, "I was actually more drawn to the Unitarian side after I was diagnosed than staying within…They were more accepting [of the LGBT community]. They

would do more for people with HIV than other groups." The issue of support was highlighted by another participant who said, "Then they have the Christian and Catholic schools that don't believe in homosexuality, so they don't want to support HIV or AIDS, so therefore they would not support budget—." Because churches have a reputation of financially supporting people in need, these participants see the lack of financial support for PLWHA as intentional because of other issues related to the illness or general apathy.

    HIV or AIDS courtesy stigma. Courtesy stigma is defined as discrimination against those associated with a stigmatizing condition such as HIV or AIDS (Bogart et al., 2008). The second theme was concerned with a person's fear of experiencing courtesy stigma within a church community for being associated with HIV or AIDS. As David explained,

> I think a lot of them; a lot of churches don't want to get involved. Well, I think a lot of churches …they're not willing to face the consequences it's going to bring. Okay, let's say Fourth Baptist Church in town decides to open up the doors. Any person with HIV or homosexuality is welcome at the doors of this church. Can you imagine what that church is setting itself up for? Everybody in town, "You know that church over there? That's where all the queers, all the gays and eh, eh, eh." I mean you're the talk of the town. You're the talk of the community because you've got people that don't understand. And I think a lot of churches; they don't want to face the consequences.

Thus, a congregation's lack of involvement with issues related to HIV and AIDS may have less to do with their beliefs and more to do with managing an identity, which does not send a welcoming message to PLWHA.

Congregation

Four themes emerged at the congregation level that decreased the likelihood of disclosure among PLWHA. These themes include experiences of discrimination, influence of the devil, fear of gossip, and experiences of courtesy stigma among their family members. These themes only consist of statements made by PLWHA.

Discrimination. Some participants talked about incidents of discrimination committed by members of their congregation. Jerry said, "They're ignorant about how you can catch this disease, so they're afraid to shake hands or drink after or eating with the same—lack of education." Sean shared a similar experience:

> [the church] is not always the best place to disclose your status. You can get this "aw"
> kind of look from people, but then it's like—when you go up to shake their hand
> afterwards, there's always some reason for them not to shake your hand or something like
> that. It's irritating, but it's kind of like, "whatever." You have to have a tough skin,
> basically, and not be too offended by it.

Discrimination also occurred against gays. Rick shared about a time when he heard that a gay couple was asked to leave a church because of their sexuality:

> All the churches that I've ever been to or belonged to don't approve of it,
> [homosexuality]. I even heard one guy say, "We had a couple of them up in this church,
> but we got rid of them." Even a gay person goes through something, even without the
> virus, but to be gay and to have HIV virus, that's a double whammy because you're
> dealing with sexuality and dealing with the AIDS virus.

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Discrimination was related to fears of contagion and beliefs about homosexuality. The first issue can be addressed through education. The second issue is little more complicated to address because of the spectrum of beliefs regarding sexuality; however, the Bible does not "easily lend [itself] to justifying poor treatment of the outcast" (Regnerus & Salinas, 2007, p. 388).

Devil's influence. Some participants cited the influence of the devil as a reason for not wanting to seek support within their church communities. That is, the negative behaviors of church members toward people with HIV or AIDS were attributed to the devil's influence on people, as John explained:

> I wouldn't feel comfortable in a church surrounding speaking about that [my status] only because I know that the devil is sometimes in the church. He is ever present there… the devil is everywhere, and you try to keep away the negative thoughts that could run rampant and you're jumping out the window because some people are just mean spirited and don't know the difference between right and wrong. When the devil is pushing them, you never know how far they'll go.

Jerry also made reference to the devil as his reason for only disclosing his status to the pastor and his wife. He said, "My pastor knows and his wife knows. That's good enough. Church people are supposed to be your strong tower, but the devil's right there, too." Whereas God loves all people, the devil does not. The belief that the devil can influence church members to treat PLWHA poorly can cause these individuals to seek support from God, apart from church organizations. This trend already has been identified among PLWHA (Cotton et al., 2006).

Gossip. The fear of church members gossiping about their illness also decreased the likelihood of disclosure among participants. Jerry said, "If they said you have AIDS and want

prayer, come up, I wouldn't. I wouldn't put myself on front street like that because people gossip. They gossip." Steven also expressed this fear saying: "I can't go up for prayer because the congregation will talk about you."

Another participant commented on the reality of gossip, but felt that PLWHA should risk the cost of disclosing because it is not unlike other risks they may have taken in the past. Her advice is rooted in her personal story and based on her own experience of disclosing within her church community:

> Some people are afraid because of the gossip, and I understand that, but they have to take a chance. They took a chance on all those other things, all the drugs, all the alcohol, all the needles, all the hopping in the cars with guys who could have killed them. People's gossip can't kill them. If they allow it, it can, but the reality, the worst hurt can bring down nations if you allow it to. You have to take all that negative and put it into something positive so you can start to reach more people out there like we were, to bringing them into the salvation of the Lord and to bring them into the goodness and the fullness and try to get some of the good stuff while it's still available.

Although some may choose to live with or confront the gossip, it is easier to avoid it and the effects of it. For example, gossip may negatively affect people's self-esteem and perceived stigma and support.

*Courtesy stigma. B*ecause it is common for families to attend church together, the possibility of one or more family members experiencing courtesy stigma may increase if a person decides to disclose. Sylvia shared about a time when she felt that God led her to disclose

her status with her church community, which resulted in negative treatment of her son by the congregation:

> I got up one day and I testified because God put it in my heart to testify that I had HIV, and I testified to that, that I had that. And the congregation said I was looking for pity and sympathy and was trying to use my sickness to get over on the church…Then, they went to talking about my son. It was just unbelievable, [the] things that were coming out of their mouths, and they were saying that they were sanctified and holy and filled with the Holy Ghost, and I left there and I stayed out of church for a long time.

The congregation's reaction led to negative repercussions for her son, and to her leaving the church.

Pastor

The pastor is the designated leader of church organizations. As such, his or her words and actions have a lot of influence within the church. Four themes about challenges associated with creating a welcoming environment for PLWHA emerged at the pastor level: negative statements about homosexuality, a lack of sermons about HIV and AIDS, negative framing of HIV and AIDS, and privacy violations related to disclosure. This section only includes experiences shared by PLWHA.

Homosexuality. The issue of homosexuality is a complex one within the church due to the wide range of beliefs about whether or not identifying as a non-heterosexual is acceptable within Christianity. Although the majority of the participants in this study identified as heterosexual, they still measured how welcoming a church was towards PLWHA by how they addressed the issue of homosexuality. For example, after Sylvia began bringing some of her gay friends to

church, her pastor decided to confront her actions indirectly through a sermon. She was appalled by his actions:

> The pastor spoke in the sermon one day…he knew it was me, but he just said … "I'd appreciate it if you all stop bringing all these gay people to my church." I'm like, "no he didn't. How could you say you're a man of God? These people are just like you as a person." You know what I'm saying?

Steven shared about his church experiences when the issue of homosexuality was included in a sermon. He said, "There have been quite a few times where he's talked about homosexuals and how God hates that and how they're not going to get into heaven if they don't stop what they're doing and stuff like that."

Rick, a gay male who believed that homosexuality was a sin, said, "I haven't heard a whole sermon [about homosexuality], but I've heard that it's a curse, that because of being involved in a gay relationship sexually and that's God's curse, God's punishment for you." Although he held similar beliefs as the church about homosexuality, he did not necessarily approve of how pastors chose to address the issue. He shared an experience he had with a pastor after he volunteered to receive prayer from the pastor along with other members of the congregation:

> So she got to me and she bent down and whispered in my ear. She said, "God told me to tell you that he made woman for man." That was the last time I went back to that church…I don't think God told her nothing like that. She just assumed. She just assumed. That's why I say that people can look at you and judge and say, "I know what's going on." I think that's what she did. And so she was asking me to become involved in the

church ministries, and I was getting excited because their praise team was awful and I knew I could do something with them. I was getting excited about that. And then when she said that to me; it was over.

Invisibility. Some participants were hesitant to seek support within a church community because the topic of HIV and AIDS was largely absent from the pastor's sermons and activities. The invisibility of HIV and AIDS communicated that the church was not interested in supporting people with this illness, as Matt stated:

I've never really heard too many sermons about HIV or AIDS. I think that's a taboo to them. I've never heard it out of these people I watch on TV mention that. Drugs, prostitution, cigarettes, alcohol, pornography – pornography is what I hear a lot about. That's it. Out of all the years, never have I heard AIDS. I've never heard pastors at any churches I have visited preach about HIV or AIDS.

Interviewer: What do you think it would mean if you turned on the TV and Joyce Meyer [a popular televangelist] was saying, "Today is World AIDS Day and today I want to talk about people that are struggling with illness?"

Matt: I'd get on my cell phone to that 1-800 number down there and let those people know my situation; the whole situation, how it happened, my financial—everything.

Matt was one of the individuals I spoke with who had never disclosed his status to anyone before me. In this example, the importance of visibility coupled with intentionality could make the difference between him disclosing or not disclosing to acquire support.

The issue of invisibility also may be linked to a general ignorance about the prevalence of HIV and AIDS in one's own community. Rick said,

I love my pastor, and he's awesome, and I believe that if it was something in the church

that would bring to his attention to do something like that, to talk about HIV and getting a

support group and all that stuff, I think he would, but I don't think it would ever come

across to him to do that. I don't want to be the first one to do it.

Framing. Getting pastors to talk about the illness is one thing, how they decide to talk

about it is another. Rick felt that when pastors did talk about HIV or AIDS, they framed it in a

negative way, which he believed decreased the likelihood that a person would disclose their

status. He said,

I think something that turns me off about pastors—I've heard them say, "You're going

through things right now, AIDS and herpes and all that stuff," and they make it sound

awful…when you come to church and you're looking for support and something to be

said to you that comforts you, somebody that says something that totally messes you up

and you're like I don't think I want to talk to this person about it.

*Privacy. A*nother participant shared his experience of disclosing to a pastor who then

shared it with his wife. He explained what happened after he disclosed:

It was like—basically our relationship didn't change that much [after disclosing], but it

was just the fact that he knew, and he's one of these types of Christians that when you're

married, you're one, and so he told his wife. I felt betrayed by that because I felt that it

was something between me and him. Nobody else should know, not even his wife. I don't

care if you are married. I didn't quite feel right anymore about that. I moved to a new

church.

Identifying Barriers to Change within the Church

This portion of the results section concerns the barriers of creating a church environment in which PLWHA feel comfortable disclosing their status. These themes emerged during the interviews conducted with various church leaders, many of whom were already involved in providing services for people within their communities. Their responses provide an insider's perspective about the church as an organization, as well as access to some of the underlying beliefs about PLWHA among evangelical Christians. These data are divided into six broad categories that consist of a number of themes.

Beliefs about Homosexuality among Evangelical Christians

The discussion of homosexuality was common during the interviews because it often is linked with HIV or AIDS in the United States and is such a controversial issue within the church. Although HIV and AIDS are not exclusive to the gay community, many of the church leaders acknowledged that the primary reason the church largely is absent from the discussion of the virus in the United States is its connection to homosexuality. There were six themes that emerged concerning a range of beliefs about PLWHA among church members. Only comments made by church leaders are included in this section.

Definition of homosexuality. Many evangelical Christians consider homosexuality a sin, or immoral behavior. As Chris stated, "I think it's also important from our perspective to be like, hey we don't accept the lifestyle, we think it's a sin." In addition to this belief, many evangelical Christians also view homosexuality as a lifestyle choice that can be explored and overcome. As Phil explained:

I feel like it's so different with every person because not every gay person knows where

he or she is at, or some are very adamant. Some choose to be there. Some have had these

feelings come from places. Some people are abused. Not everybody is, you know, but

some people. You don't know where it's coming from or how they're struggling with it

or not struggling with it.

Tricia echoed the belief that homosexuality was something to overcome: "The problem is that I feel like with homosexuality, more than other things, we look at the sin rather than look at the way to overcome it."

Not all evangelical Christians believe that homosexuality is a sin. Marsha explained why providing support for PLWHA in the gay community would not work:

Here's how I view the scenario. You figure out a way to do this and you reach out to the

gay, lesbian HIV-positive group of people or individuals or groups, and you offer them a

listening ear and you offer them food from the food pantry and you offer them healing

journey [a class that offers social support]. Except for, you want them to be healed from,

not just really from the physical symptoms of their AIDS, you want them to no longer be

gay. You want them to relinquish all claims and become heterosexual, or no, become

non-sexual, just be a non-sexual being. How long you think that's going to make it?

Marsha's explanation provides an example of a key difference in those who define

homosexuality as a sin and those who do not. The former define it as a lifestyle choice;

the latter define it as an identity. Defining homosexuality as a lifestyle choice implies that

a person who identifies as non-heterosexual can choose differently. For example, Pam

said,

I'm reaching out to those that don't know this [the message of Christianity]. So you go

out to those that may be homosexual. You go out to those that may engage in sinful acts,

because homosexuality is considered a sinful act. You go out to these individuals or to

these different sects to show them a better way and a better—a different lifestyle, a

Christian lifestyle.

She automatically connects homosexuality with engaging in sinful acts. Additionally, there is an

assumption that homosexuals do not know the message of Christianity, are not Christians, and

need to be shown a Christian way of living.

Stigmatization of homosexuality. When talking about sin, Christians believe that all sins

are equal, sometimes expressed by saying "a sin is a sin." Mike used this saying when he talked

about a time he heard a church member share his "struggle" with homosexuality. He said, "I was

just hearing testimonies of people who struggled with homosexuality, understanding the nature

of sin and that sin is sin." Despite the rhetoric among Christians that all sins are equal,

participants admitted that homosexuality was stigmatized among other sins within the church.

Peter explained why stigmatizing homosexuality was hypocritical:

Because church people, we just look at them and in our heads their identity is so strongly

connected to their sexuality that we can't see beyond them. They are just a gay person.

They are just another person, just like me or you. As Christians we believe that all people

are sinful in need of restoration and in need of Jesus. And so in that sense, they are not so

different from other people….The reality is that we are much more lenient on some sins

over others. That's where you have hypocrisy. That's the case in some churches. There

are some sins where we roll over for because they are more culturally acceptable in this church community. That's my view.

Another example of this stigma is in the expectation of people who identify as LGBT to change their sexual orientation. Sin or no sin, this expectation is not held over others to whom the church community may offer support. Martha expressed this point:

I think that people are much more—because I think they view them, [gays], to be completely sinful, living in sin. I mean, I think that they do believe that they should be treated with love and kindness and compassion, but I think that, I mean, if you were to reach out to a poor person or a sick person or person of color or of a different ethnicity, you wouldn't want to make them not be who they were in order to fully join in your life together. But, I think that when it comes to people of anything but heterosexual preference, people feel that of necessity there's a line.

Kevin attributed the stigma of homosexuality to homophobia:

You've got us evangelical Christians; we stigmatized them and we–we're the ones with the issue, homophobia, and so now we can't talk to people from the LGBT community, and we see them as people that have this defect, and it's not even a sin. It's a nuance of a sin, because it's something that takes special care.

What's interesting about his statement is that he stigmatizes homosexuality as a sin of a different nature, which goes away from the belief that "a sin is a sin." In other words, a sin is a sin unless it is homosexuality, then it is a "nuance" of a sin, possibly because it is understood as a coping mechanism or response to some other issue in a person's life.

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The stigmatization of homosexuality also may be because it is more visible than other issues, as Peter explained:

But by just the nature of that it is very difficult. I think you know, you come to church with your partner or something and I think that that's just a very visible thing that probably will get dealt with a little faster. Other issues we do a little better at hiding or concealing or covering up and not that that's right. Just by nature of what it is, it's kind of up front and personal and is something that gets dealt with and addressed probably faster than other issues.

The stigmatization of homosexuality also can lead to increased stigma of PLWHA. This was pointed out by Lisa, who said "Even if it was contracted through homosexual activity or through whatever, why do we get to decide that we'll put a stamp on you because this is how you got your chronic illness? That's what we're saying without saying it." In other words, PLWHA are judged as if the illness differs based on how a person becomes infected.

Expectation of LGBT to passively practice sexuality. Another belief that emerged during the interviews was that if people who identify as LGBT decide to attend a Christian church, they should passively practice their sexuality. That is, they cannot promote or vocalize their desire for homosexuality or related issues to be accepted or acknowledged within church communities. As Shelly stated, "Churches decide what's appropriate behavior. So a lot of churches, the churches I know, would not want people who were practicing their sexuality in a non-heterosexual marriage to probably have much of a public voice." Sam, who co-pastors a church with a person who believes that homosexuality is not a sin, described the type of gay couple that would work well in his church:

I know again, not assuming that everyone with HIV or AIDS is in a same-sex

relationship, but if they were in a same-sex relationship, if they're not agenda pushing

with that, I think [our church] would be a perfect place for them. In terms of agenda

pushing people, I would suggest churches that are more advocates for same-sex

relationship. If you're homosexual, non-agenda pushing, or heterosexual with HIV or

AIDS, then I think [our church] would be perfect for you. Or heterosexual and non-

agenda pushing, too, because depending on what you believe there–anybody with

agendas isn't going to work well, no matter what it is, whether it be about poor,

economic, war, abortion–whatever it is, if you're there to push an agenda, it's not going

to work well.

Thus, a person entering Sam's church should not appear to have an agenda, especially if it differs

from the church, as it could affect how church members welcome that individual. Peter also

described the type of person that would be welcomed into his church community:

I think that they, [LGBT], could stay in our community. I think the person who would

have trouble is the person who came in–I think if someone comes in who is like, "I'm

here to show you guys something, the Church is ignorant, I'm here." You know I've seen

people like that who see themselves as "I'm going to enlighten you, I'm going to show

you"…Real kind of like, "let me tell you how things are because you are kind of in the

dark on all of this." Anyone who enters any kind of community in that spirit is going to

have some trouble. If someone comes in with a certain level of humility, "I'm entering

into your community here; I have an issue, struggle." As long as there is a certain level of

humility to begin with when they are entering into our church community, I think that it

would be fine. I think it would work.

Stan argued that these constraints create an impossible situation for people who identify as

LGBT, unless they view their sexuality as a sin, and are therefore trying to change:

I'd say it's probably almost impossible for a practicing gay person or couple to come into

a church. Now, if they were practicing and they're ambivalent about it and they're

struggling with it, they're welcome, and I happen to know, and I think you do too, there

are gay people in every church in town here, evangelical or not, and they come and they

deal with it before God. In many cases, they're struggling to deal with it as opposed to

just saying I'm gay.

Being passive about a person's sexuality essentially means that a person who does not feel that

their non-heterosexuality is a sin is welcome to attend these churches, as long as they do not try

to change the church's stance.

Interpretation of the Bible. The belief that homosexuality is a sin often is attributed to

scriptures in the Bible. The problem is that different people have different interpretations of the

same text, leading them to draw different conclusions. For example, two different participants

used the same Biblical story about the destruction of a city to emphasize conflicting points. Pam

used this story as evidence that homosexuality is a sin according to the Bible: "Another thing,

you have some churches that may relate HIV or AIDS to homosexuality, and so you think about

in the Bible, Sodom and Gomorrah, how God destroyed Sodom and Gomorrah because the

homosexuality was so rampant…." Sam challenged this interpretation and argued that the city

was destroyed because of how they treated the poor:

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…Even when you look at Sodom and Gomorrah, the first thing we think about is the

homosexual relationship that went on there and that's why they got destroyed. If you

actually look in Ezekiel, Ezekiel points out that one of the main reasons why Sodom and

Gomorrah was destroyed was because of their treatment of the poor and what they were

doing. Up and down the Bible, you'll see many of the reasons why–even the Israelites

were often displaced and put in captivity. A lot of it had to do with how badly they

treated their poor.

Although Sam does believe that homosexuality is a sin, he does not believe that the story of

Sodom and Gomorrah is evidence of this.

Christians who do not believe that homosexuality is a sin risk having their Christianity

invalidated or questioned by other Christians. For example, Kenny said,

I wouldn't say anyone goes to Heaven or Hell because of it, but I would wonder where

their relationship is with the Lord. I would wonder how literal they interpret the word of

God, whether or not they believe everything in it or they believe some things in it.

This relationship likely is cyclical, meaning that the person who does not believe that

homosexuality is a sin may raise the same questions about the Christian faith of the person who

does. Phil shared a story about a gay couple in his church that held the view that it was not a sin:

We had a couple guys that decided to leave our church because they were in a

homosexual relationship and decided that that is how they were going to live their lives,

but knowing that it is wrong. Then again, in our church, we still have gay people in our

church who realize that it's wrong but they still have those feelings and they still struggle

with it. In the case where the guys decided to leave–it was a very sobering thing. Our

pastors dealt with it great. They were very loving, very genuine and sincere with these

guys. It was over a process of months of them meeting with these guys and talking

through it, of them looking at "what does this lifestyle lead to? What led you to this?"

The guys, they kind of made their decision. "I'm going to intentionally live this lifestyle,

even though"–and some of it even came back to what they believed about the Bible. They

felt like the Bible doesn't really teach that it's wrong.

Stan voiced his personal struggle with his belief that the Bible does say that

homosexuality is a sin. He shared, "Now, it's one thing to call homosexuality a sin, which I think

the Bible does and I agree with, although it's a very painful thing to do. It's one of the most

difficult things for any person of conscience to deal with in the present world." Sam explained

the tension surrounding the issue:

With homosexuality, though, there is no base where everyone can agree. It's either you

believe it's okay or you believe it is okay as a justice issue, but it is not okay as a

theological issue. Those things don't match up anywhere. That's the one reason why this

one issue in the church is just so explosive. There's no middle ground to it. The core of it,

you can find–you could find a commonality, but the further you go up into the peripheral

and the details, the more crazy things get.

The issue of homosexuality complicates the relationship between PLWHA and churches.

Discrimination against LGBT. The final theme that emerged regarding beliefs within the

churches about homosexuality was that these beliefs can lead to discrimination against people

who identify as LGBT. This primarily took the form of not allowing these individuals to hold

leadership positions. For example, Kevin said,

Now, if somebody says, "Hey, I have homosexual thoughts and to be honest, I think I am gay. I identify myself as gay, but I'm not practicing." Well, then I think that they very well could participate in leadership just like if somebody says, "Hey, I have lustful thoughts about other people and about other women and I'm married, but I haven't acted out those thoughts." They could participate in leadership, and in fact, those people are participating in leadership. So I think there's a difference how you identify yourself with it. If you identify yourself as practicing or not practicing....

According to Kevin, people who are "practicing" their homosexuality are kept out of leadership because they are choosing to engage in a sinful lifestyle rather than to "not practice" it by repenting, or turning away from, that lifestyle. Peter explained, "… this person is unrepentant and doesn't think that it is a problem. So yeah, come hang out with us, but would they want this person taking on any kind of leadership? Probably not. Would they want that person influencing other people? Probably not." Chris, who is training to be a pastor, explained how he would handle this issue in his own church:

I would say, "You know, this is a sin you're not repenting of it; I can't baptize you faithfully. If you want to continue to stay, it's under the preaching of the gospel, under the preaching of the word. If you want to stay and experience the love and transformative community of the saints of course, you know." Now I want to keep the whole baptism from them. And perhaps that would be a form of discipline that they would recognize as, you know, that this church takes this seriously. Cause you don't want to condone un-repentant sin.

Marsha shared her thoughts about would happen in her church to a LGBT person who did not

believe their sexual orientation was wrong:

> I mean, they certainly couldn't participate in leadership and I think that they would be–I
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> think that their behavior would be watched and I think that they would, unless they
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> decided that that particular part of their lifestyle was something that they were wanting
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> and willing to give up and sacrifice or, I think from the church perspective, we would say
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> to be healed, that eventually it would present itself as an impossible situation. I suppose
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> you'd say murderers and people who are violent, people who are drug users, but I think
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> that homosexuals are put in the same category in terms of gay or lesbian–if you're going
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> to get yourself healed and God's going to change you and then everything will be swell
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> and if that doesn't happen eventually, it doesn't fly–not at this church.

Denying people who identify as LGBT access to leadership prevents these individuals

from being accepted as equal members of a church community. Yet, Peter shared a story about

when an active member of his church who struggled with homosexuality in his past who

attempted to occupy a leadership position that involved him working with the youth. He

recounted,

> He recently got married. And what precipitated was that he was about to be hired by the
>
> church to take an increased leadership role. And so before he did that he wanted to be up
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> front with the elder…One of his roles was going to be to work with a youth group, and
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> several of the leaders in our church felt uncomfortable with that. Even in this guy's
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> position, when the guy hadn't acted out on this; theologically, [he] was on the exact same
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> page—this is not right, this is sinful, need to be repentant and has all of these

accountability structures in place. But they said "No, we don't want you working with us, it's not right or it's not appropriate. It's dangerous, risky, whatever." That really bothered us. That hurt us. There was an arbitrary connection–you aren't worthy to influence our children, so how are you making that connection? Why would you say that? It was kind of this knee-jerk reaction, at least in his perspective, that this is scary, weird, stay away from our kids.

Peter's example illustrates how the stigma of homosexuality can lead to discrimination, even when the person agrees theologically with the church's doctrine regarding homosexuality.

Another example of discrimination concerns the church's role in denying the LGBT community access to the civil rights. Although Stan believes that homosexuality is a sin within the context of Christianity, he also believes that denying individuals of their civil rights is wrong too. He said,

I think that the church has done a horrific job with the gay community. Instead of understanding how painful this is and the message of reconciliation and love that God has, the church has basically been condemning and homophobic and also–this is really sad–taken the lead on smashing gay civil rights.

Stan points out that although churches should respond to homosexuals with love, many churches are responding with condemnation and homophobia.

Communication about PLWHA and Related Issues

This last section deals with beliefs about homosexuality that further complicate the relationship between churches and PLWHA because these illnesses are related closely to the LGBT community. Thus, church attempts to reject homosexuality can become rejection of

PLWHA. This portion of results concerns stigma communication of HIV and AIDS within churches that decrease the likelihood of disclosure. Three themes emerged in this section – invisibility, sermon content and delivery, and suffering and death. The ideas expressed in this section only represent those of church leaders.

 Invisibility of HIV or AIDS. Many of the participants said that HIV and AIDS were not discussed in their churches. Kevin felt that this communicated that churches were not welcoming to PLWHA. He said,

> We talk about anger, lust, finances, how you get to heaven, how not to get to heaven. You talk about everything under the sun…But you don't talk about the LGBT community when that's a huge community. And so we talk about: for God so loved the world and Jesus died for people, love your neighbor as you love yourself, but somewhere in there, in those scriptures, I feel like maybe people think that there's an invisible scripture that says not LGBT people. Love everybody else, but if they're LGBT, then don't reach those people. Don't talk about it.

Unlike Kevin, Luke did not feel that this invisibility was intentional, nor did he feel it was related to homosexuality. He attributed the invisibility to a general ignorance about HIV and AIDS:

> Just be ignorant about it. Never talk about it. We never talk about it, so that would be one way that people would feel unwelcome. I don't feel like we're unwelcoming, but we just don't talk about it. Probably like HIV or AIDS. I don't think I've ever heard anything about HIV or AIDS from the pulpit. Occasionally, you'll hear something from the pulpit on homosexuality, and in general, it's not very welcoming.

Some of the participants provided reasons why churches do not talk about HIV or AIDS. Shelly felt that her church leaders not only avoided HIV or AIDS, but they avoided talking about sickness all together. She stated,

> I don't see our particular church willing to reach out to any particular group of sick
> people. I don't hear disparaging remarks about people with diseases. I just don't hear any
> remarks. So I guess someone could get…[discouraged and think] "nobody ever talks
> about people like me. I'm never mentioned."

Mike's explanation suggests that church leaders avoid the topic because they want to remain ambiguous about the issue of homosexuality. He suggested that being upfront about an issue is more welcoming than being ambiguous:

> If someone comes in the door, I think you should be preaching about it. I don't think you
> should present one façade and then later–not façade. We'll call it doctrine and then–
> which is essentially a doctrine of silence where you don't talk about it and it doesn't
> come up, but then later you find out oh, this is actually what they think about it. So being
> open and honest and upfront in the pulpit, I think, should be happening

Pam felt that the reason for invisibility was because church leaders do not know how to talk about HIV, AIDS, or related issues. She explained,

> Say I do have this information. Now what? They don't know how to deliver it to that
> population. They don't know how to interact with that population. I have the information
> here that I need, but now what? I don't know what to do. Maybe they don't know how to
> administer a program that's geared toward the welfare of those in that population.

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Not knowing how to communicate about HIV or AIDS contributes to the invisibility of the issue within churches.

Sermon content. Sermons about either homosexuality or sex also emerged as potential barriers to welcoming PLWHA within a church community. Shelly attributed part of the problem to that fact that church leaders may be unaware of the impact of the words they use when discussing these topics:

> But people have to be made aware of more alienating terms if they're not in touch with groups who are feeling alienated. Feeling alienated and not coming around, you don't really know what's alienating them because you're not communicating with them. You don't know. You just know that they're not around.

Leanne expressed the view that PLWHA may feel unwelcomed by how issues unrelated to HIV or AIDS are discussed within the context of a sermon:

> There's a lot of judgment that comes across lots of pulpits. Maybe it's as simple as they're beating up on another church, or they're talking about how Democrats or Republicans or whatever have done this awful thing. When you hear judgment of other groups, even if it's not your own group, coming across the pulpit, I think you feel like "When is it going to be my turn? When is that judgment going to turn on me?" I think that's another way that churches are unwelcoming. They're thinking "oh, I'm just speaking my convictions on this thing," but often, that's what can turn other people away because if you have that conviction on that thing, what do you have about my thing?

Along the same lines, Allison said, "I would say that we have something to offer this group of people, but how are we giving it to them? If you're giving it to me in this sort of way, condemning or whatever or just talking and not nurturing, I don't want it. Why would I want it?"

The framing of these issues within a sermon also can be problematic. Carolyn explained that "If there was a sermon on sin or a sermon talking about sin that would be one of the things that's also mentioned alongside of infidelity, lust, pride...." Kenny also raised the issue of framing:

> I think just when people are speaking about the consequences of sin, like unprotected sex or sex out of wedlock, things like that, it's always, "you can get AIDS, or you can get this, or you can get that, and it is a reality. You can get it." But it's always like, vilifying the whole disease and things like that. Some people may or may not have contracted it that way, and so it's like, "if you have it, then that's the only way that you can get it." That's the biggest way is just through speech, and that's really what happens in church is just through talking to people through speech.

The way church leaders generally address sex also was mentioned as a difficulty. Pam explained how sex is a barrier to getting the church involved with work related to HIV or AIDS prevention:

> One major barrier is because if you deal with HIV, nine times out of ten, you have to talk about sex. Sex is a topic that's rarely…discussed in the church because the church… [teaches] to abstain from premarital sex. God made sex lovely for married couples, but to have sex before marriage is an abomination. It's a sin. So the Christian faith always preaches against that, and so if you deal with the topic of HIV or AIDS, then you will

have to discuss sex, safe sex, with consciously using condoms and various different types

of protection mechanisms and even that goes into another corridor of pregnancy. So we

deal with contraceptives, but see, you have a church that has to talk about this. On the

other hand, the church is saying, "Well, we don't advocate premarital sex, so how can we

talk about using condoms to have sex?"

Leanne felt that when sex was addressed, it was handled too simplistically. She noted that there

was a general negative orientation to how sex was discussed:

Usually sex is talked about in terms of bad. Every once in a while we come across a

passage and preach about how sex in marriage is a good thing. You hear that every once

in a while. Mostly, it's either sexual immorality is bad or gay marriage is bad and look at

this as part of the evidence as how our country's going downhill.

Allison illustrated Leanne's point when she talked about having sex as a married woman, which

is an acceptable expression of sexuality within the Christian church. She said, "When I got

married, I was like 'What the heck!' because in my mind, it was 'just don't do it, don't do it'…."

A general stigma about sex can have unintended results for heterosexuals as well.

Teachings on suffering and death. The inability of church leaders to communicate

effectively about suffering and death also emerged as barriers. Shelly explained this:

Well, for one thing, we don't talk about pain and suffering in our church anyway. We

don't have a very good doctrine on suffering, the notion of Jesus as a suffering servant. I

think that's because the particular strain that gave birth to this church congregation was

out of what some people call the faith camp—name it and claim it. God wants you

wealthy and prosperous. If that's what you want, you'll get it. It's a strong strain. So they

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don't talk about suffering very well because accompanying that early strain of their church life was no negative confessions. So to say "I have a cold" was basically to agree that the devil had control of your life. Why would you want to admit that? There's a lot of layers to that. When people have hard times, and I think there's general concern that people should be prayed for and all, and it's a genuine expectation that people will get better, but we don't really tell people how to suffer. A terminal disease, which I think everybody would consider AIDS a terminal diagnosis, although medication certainly can prolong life for a long time, but any kind of disease. We never talk about tuberculosis and we don't talk about mental illness. Those might get mentioned in terms of "come forward for prayer." We might talk about depression, but we don't talk about any other alienating conditions either. So I don't know if it's unique to HIV.

This same view was expressed by Mike, who said, "I think we struggle with those people who are hurting deeply, even in a fatal sense because I don't think we know how to deal with death very well." Although it may be common for pastors to discuss the after-life, it may not be as common for them to talk about issues that may precede the after-life such as pain and death.

General Outreach to the Marginalized

Christianity is a religion rooted in service; however, many participants felt that the church's current approach to serving was a barrier to increasing its role in issues related to HIV and AIDS in the United States. The barriers discussed by the participants were related to one of two issues–comfort and mission trips.

Issues related to comfort. Many felt that a desire to remain comfortable, or complacency, was a barrier to improving the relationship between churches and PLWHA. Tricia noted that,

> I think people really are comfortable and don't want to know that it's there. I don't think they like the idea that there's so much brokenness so close to them. It's hidden in our community. I think that's a big reason. I think it's circular. It's hidden because people don't want it to be out there, but if it's out there, they're scared, so nobody wants to put it out there.

Peter attributed a part of the problem to how churches operate organizationally. He noted that there was little interest in exploring alternative viewpoints:

> Well again, and maybe this is reflective of my ministry, but I think that there is very much a sense of you come to us, if you are interested in being a part of this church community, come to our Sunday service, come on our turf, and explore more of what we are about. Rather than, "Hey, we have some people at the local church here that kind of come to you, spend time on your turf, come to you and befriend you in a context that is more comfortable to you."

The issue of comfort was sometimes related to fear of contagion. Dale explained how he thought comfort affected community outreach:

> If they would just come into contact with one person who had AIDS, I think a lot of their fears and angst and anxiety would change. But it's just because too many times people in religious communities stick to their own comfort zones. They stay in some kind of protective cocoon because they don't want to be tainted with people around them. Too often, they ignore the very calling that we have.

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Some felt that the issue of comfort had more to do with sexuality than HIV or AIDS. Carolyn noted that the presence of gay people was discomforting to members of her church:

But it's almost like the church has excused itself to be okay if people who are gay or LGBT, that section of the world, don't come back, and it's because that's okay. We wouldn't want these poor people not to come back because God says go to the poor. But if these people don't come back, that's okay because clearly, it's going to disrupt our comfy Sunday morning church experience.

Others described the barrier in relation to a fear of courtesy stigma. For example, Sam said,

Some people feel like if they befriend or are part of someone's life who has something like AIDS, that somehow it's going to rub off on them. It all stems from their own insecurity and their own faith, just like with anything. If we're insecure about something, we're more likely not to be able to engage in something that we feel insecure about. We look for comfort, and comfort is definitely not interacting much with people who have life-threatening diseases. And if you just look at HIV or AIDS or any life threatening disease, a lot of people feel uneasy.

Pattern of overseas mission trips. Overseas mission trips, or trips taken to help people in other countries, also were mentioned as a barrier. For example, Kevin believed that PLWHA in the United States were more stigmatized than those living on the continent of Africa in the minds of American Christians, which may result in increased involvement of churches with the epidemic in other countries. He argued that people in the US thought of HIV infection as a choice:

In Africa, it's like maybe people have AIDS through birth. Maybe they have AIDS

through drugs and needles and stuff. Maybe they have AIDS through being raped and

different things like that. And so it's more of a thing where they didn't have a conscious

decision to get HIV or to get AIDS, but people in America, it's more like it was their

decision…connotation over there is just, well, they didn't deserve it. Not only that, but

also the media takes into account, too, because when you see these kids with AIDS, you

see these babies. You see these children with—you can see their ribs. They're hungry.

They've got flies swarming all around them and they have AIDS. And so it's a form of

innocence. Over here it's not a form of innocence because you got what you deserved.

Leanne shared a similar view about the attitudes towards PLWHA in other countries generally

being more positive than attitudes towards PLWHA in the United States:

I think there's still very much of a dominant idea of this is a problem with people who are

gay and lesbian, especially gay. And so those people are immoral, therefore, what's

happening is what they deserve. Where in Africa or other places, oh, maybe people are

victims or they didn't know. There's just a different mindset in terms of the cause for

why they have the disease. I think that's part of it, again, the extreme anti-homosexuality,

homophobic, issues that we have in the church is one of the reasons why there is a

perception that that's a lot of the cause of HIV here and maybe not in other places.

Some other participants felt that mission trips were preferable because they allowed

churches to maintain a safe distance from the illness and issues related to it. Peter shared this

view:

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I think it is easier to send resources overseas because it doesn't require as much of us, it

isn't uncomfortable for us. Certainly, we have some people going over there. We are a

little distanced from what's going on over there. It's not affecting us as much. I think

that's part of it. It's easier to send people resources overseas than to get serious about our

own neighborhood and communities here.

Tricia explained what could happen if the social distance between the church and HIV or AIDS

were decreased:

I think if you start to help people in your community, you can't deny that they're right

there, and then if you do it right, you might start helping one person and you're going to

meet more and have a heart for them. I think your life has to change. I think that if you're

really going to answer that call, I think you can't—I don't think you can feel okay with

just helping out somebody for a week and then leaving them, which is what you do with

missions trips. You go and you help, but you can't help them more because you live

somewhere else, so you go back and you don't feel guilty very much.

Ignorance or Lack of Education

Lack of education about HIV or AIDS among church leaders also was a barrier. As Pam

stated,

You may also have individuals that just don't know how to address the situation. They

may not have any knowledge about HIV or AIDS. Though you have media, internet to

access, but then you say, "Well, who can I trust? Which side can I trust, so I know they're

giving me the accurate information I need?"

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Participants also discussed how a lack of education can contribute to fear, and how fear leads to discrimination. Stan explained this connection:

> But for the church in general, there's so much fear that if you deal with AIDS people locally, you might have to eat with them. You might have to talk to them. They might come around your children. There's so much fear about that. If I'm around an AIDS person, my little kid's going to get AIDS. It's ridiculous, but there's a lot of that.

Jessie, a public health worker involved in her church, said

> I think the resistance comes with them only having a minimum understanding of the disease and transmission. I, myself, have given talks at our teen meetings at church to discuss the various ways of transmission and when I'm talking to the teens, we have several parents that sit in on the talk, and afterwards I've gotten questions like, "Oh, I didn't know that a person could get it through blood transfusion." The only way that they thought someone could contract, that the virus could be transmitted, was through sexual contact.

Although Jessie's church had allowed her to educate the teens within her church, the parents also needed to be educated. The assumption that adults do not need education could be a common oversight made by many organizations.

Blaming PLWHA for their Illness

The possibility of church leaders and members blaming PLWHA for their illness also emerged as a barrier. Some felt this resulted from the assumption that HIV infection occurred through having gay sex. Luke explained,

…there's been a myth for decades about it being directly related to the LGBT community that they feel like we don't have to pay that much attention to it because maybe these people brought it on themselves by a poor choice they made, and that's a sin they have to deal with or something like that. Maybe that sounds harsh, but I think the people might think that.

Pam said, "Many people may say 'well, because you have HIV or AIDS, it's because of your lifestyle, your homosexual lifestyle. It was your fault that you got HIV or AIDS.'"

Some attributed this blame discourse to comments made by well-known evangelical Christians about HIV or AIDS in the media. Chris shared his thoughts:

I think it comes from people like Pat Robinson, um, who's on the *700 Club*. Jerry Fawell. Vocal fundamentalist Christians from the early to mid-eighties who were connecting the rise of HIV or AIDS with a one-to-one ratio quote "with God's punishment." And so what happens is that they view it as, "That God's doing that. How can we stop it? God's doing it." And uh, it's unfortunate.

Dale believed that this blame discourse was rooted in insecurity among Christians. He said,

… insecurity and an inability of Christians to deal with their own mistakes and their own sins. It's very easy to help yourself feel better, feel more adequate when you can blame somebody else or you can make someone else look like a worse type person than yourself.

Blaming PLWHA for their illness is a part of a bigger problem, according to Leanne. She explained how this is related to an overall "system of judgment" that may operate within a church:

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…there are other people who have left church communities just because it was too hard because again, it's not just—it, [sexuality], becomes so essential to their identity, partly because they have to fight it so much. It's not like people are saying "oh, you know, this is a little off." They're saying "this is a fundamentally sinful way to live and it's immoral." The constant system of judgment for people that I know has been too much. So that's the personal experience way to talk about it, but then in general--I guess in general, I'd say the same thing, that if you're constantly feeling judged, the church isn't going to be a refuge for you. It's not going to be a sense of safety and security. It's going to be where you feel under attack. And you already feel under attack in other ways, so I think that makes it.

Assumptions about PLWHA

Throughout these interviews, participants would sometimes reveal certain assumptions about PLWHA that appeared to be unintentional, which suggests that these comments may reflect underlying assumptions about PLWHA among at least some Christians. These assumptions often were related to morality and sexuality and could pose problems to improving the relationship between PLWHA and church members.

PLWHA and immorality. Some participants equated HIV or AIDS with living an immoral lifestyle. This often was related to the assumption that a person with HIV or AIDS also identified as LGBT. For example, Pam assumed that a person living with HIV or AIDS who identified as LGBT did not know the Gospel message, or basic tenants of Christianity. She also assumed that this individual could not be a Christian. She said,

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I'm reaching out to those that don't know this. So you go out to those that may be homosexual. You go out to those that may engage in sinful acts, because homosexuality is considered a sinful act. You go out to these individuals or to these different sects to show them a better way and a better—a different lifestyle, a Christian lifestyle. In the end, you'll get eternal life in heaven… but those who are already on their way to heaven, you don't need the preaching to.

Kevin expressed a similar view in his description of the type of people with whom he believes he should share his Christian faith:

As a Christian, you kind of see yourself as being sent out by Jesus to preach, take the gospel, to all different kinds of people, you know. You are always thinking about those groups of people where the gospel hasn't really penetrated or where there is a disconnect with people, you know, fill in the blanks, people who have AIDS or you know different kinds of groups. So you know, when we want to plant churches in the future, it's something I think about, what it looks like to develop relationships with marginalized populations, to bring the Gospel to them in ways that contextually connect and make sense with where they are at. What are the systematic, cultural obstacles, or boundaries that are kind of there that keep these people from coming together, and um, as someone who wants to go out and see the gospel go out and bear fruit with all kind of people it's something I have to think about—how they overcome these obstacles. What has them underneath, what prevents this group or this group from coming together? So, it's something I am interested in thinking about.

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In his explanation, Kevin assumed that people who were marginalized (i.e., PLWHA, the poor) had not heard about Christianity. Peter made a similar connection as he shared a story about his friend Dave. He said, "Something I found was I had a friend named Dave from Atlanta, who was gay but considered himself a Christian, and very well could have been. They're just people too." Here, Peter questions his friend's Christian identity because of his sexuality.

Carolyn not only equated AIDS with homosexuality, she also described both of them as being wrong, or sinful. She said, "To admit that they've struggled with those same gender attraction issues or have a family member that has AIDS or is gay….The church—some churches have settled in allowing people to tolerate a sinful lifestyle of AIDS and homosexuality…."

Tricia explained how these viewpoints could create a barrier to creating a welcoming environment for PLWHA within a church:

> Not that they're throwing them out, but—so somebody with AIDS is in the church and people associate that with immoral behavior, and I think people just take it—yeah, I think people assume that this person is probably living a lifestyle of sin, and so they don't feel like—they don't do anything to help that person become part of the community because they default to that verse. They're still living this lifestyle of sin, so what can I do?

Jessie spoke about how this barrier existed among conservative churches:

> Something as controversial as AIDS, the more conservative churches are going to be less apt to be involved because they're going to automatically tie AIDS into sin in some way or another.

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HIV or AIDS and sexuality. The stereotype that HIV infection occurs through homosexual sex also is a barrier. Phil explained why this was the case:

> I think that a lot of times, people will tie the disease straight to a sexual preference or a life decision [to be homosexual] or something like that. I think the stigma is probably much more emotional or just kind of taboo versus "I feel like if I touch you, I'm going to get AIDS" or something like that. I feel like it's more taboo, uncomfortable to where people won't dive in to reaching out to that community.

Phil's point is illustrated by Peter who said, "The thing I keep thinking in my head and the thing I'm reminded by is that there isn't quite the connection between people with HIV and the LGBT community maybe. I almost assume they are the same thing." Carolyn had a similar realization:

> It's funny how quickly my thought goes to homosexuality, actually, not HIV or AIDS because I think that's more the topic of conversation in the church or the ministry, the assumption that those two are always linked going both ways. I haven't known anyone here that has had AIDS.

The close connection between the virus and homosexuality makes it difficult to address one without the other.

Types of Social Support PLWHA Receive within Church Communities

Many of the participants with HIV and AIDS attended church regularly and received social support within their church communities, despite the barriers mentioned previously. As discussed earlier, many of the participants made a distinction between God, the church, and the people in the church. The purpose of the church was an extension of their experiences and understanding of God, rather than an extension of the people running the church, meaning that

the barriers were seen as a misrepresentation of what it meant to be a Christian. The barriers to PLWHA feeling welcomed within their church communities often were attributed to the people in a particular church, rather than the church as an organization. This section strictly reflects the views of PLWHA.

<center>*Experiencing Church*</center>

This section highlights what *is* working within church communities according to PLWHA. These positive experiences provide a vision of the different roles that church communities could play both in the lives of people with HIV and AIDS. These categories represent the positive ways that PLWHA have experienced their church communities. The first section is called "general support" and includes general statements made about one's church community as it relates to social support. The other themes correspond with the traditional categories of social support.

General Social Support

Some participants made general comments about the support they received from their church communities. Annette talked about receiving support from a small group, or group that gathers to study the Bible together and pray for one another. She said, "I felt comfortable sharing with a small group to get the support I needed that maybe my parents wouldn't or my family wouldn't give me because they still had the stigma at first." Roslyn also commented on attending small groups within the church as a form of support:

> I fellowship with women every Saturday; it's called Kingdom Women. And every other Sunday, I'm in a Christ care group where we get to know each other and get to know God more and we pray for other people.

For Rick, these groups were all he had for community. He said, "On Tuesdays, I go to a Bible study. I go to Sunday school. I go to regular church service. I'm involved in the church. That's all I've got."

The church community also increased the access that participants had to social support. This allowed these individuals to develop a support network within these communities for receiving support in relation to their illness. Daniel shared about his network supporting him unconditionally:

I know I've got to realize I've got a pastor I know I can talk to. I've got friends I know. I've got brothers that I know I can; I mean I've got people I can call anytime of the day or night and say, "Hey, could we go over …? I need to talk to somebody." I've even done that you know.

Daniel's church provides him support around the clock, which can heighten his sense of connection and of relational stability.

Tangible Support

Participants also commented on the various forms of tangible support they received from their church communities. For example, Travis shared about the support he received from a church that housed and cared for people without homes or resources:

After that [his stay in the hospital], they knew my HIV status, so I had to go to the doctor every two weeks.

Interviewer: They took you [to the doctor]?

Travis: They did for a while, and finally they told me "here's a bus pass. You go and come back when you come back."

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Informational Support

Informational support refers to times when church leaders or members provided a person with HIV or AIDS information that would benefit their health or well-being. Sylvia credited her pastor's teaching about not claiming her illness for improvements in her health:

> After I got in church, my whole life and my health changed. It's getting better and better. My pastor tells me all the time don't ever claim that stuff. That's what Satan wants to do. God will heal you by the stripes on him. You have to believe that. I do believe that. Like I said, that's where I'm at now. If I didn't have the belief, I wouldn't even be here.

In this example, Sylvia received informational support through the teachings of her pastor that she believed resulted in physical improvements in her health.

Emotional Support

The receipt of emotional support did not always require a specific support-seeking behavior outside of church attendance. The experience of the church service each week often was enough for the participants to experience emotional support. Thus, emotional support may be one of the easiest forms of support that church communities can provide.

Some talked about the impact of church music. Sean said, "Sometimes that can help me transcend beyond everything else. I don't care what the words are. Music is wonderful." Others talked about the pastor's preaching, as well as the music. Jerry shared how these things gave him hope: "Just the choir, the preaching—the preaching is amazing. It's like life. When the word comes forth, it gives some hope."

In addition to preaching, some spoke of supportive interpersonal interactions they experienced within their church communities. John described his experience of support in his church community:

Just being around other people that can encourage me and some people that have an insight, they see things. They come up and say "I see you going through this. Don't worry about it. It's going to be okay." Sometimes, a sinner can come up to me and say "man, don't worry. You look like you're down or whatever. Don't worry about it." They'll tell me something out of the clear blue that the preacher had told me a few days ago. I'm like "wow, this is a confirmation. He's not even going to church and he's going to tell me what my pastor just told me a few days ago." That's deep. It blows my mind at times.

Annette shared about a time that she felt supported by her pastor. This occurred when she received prayer from him about her illness at the end of a church service. She said,

He didn't judge me, and he prayed that God would lift this from me, even though I don't know if that's a possibility, but that gave me hope. That is one of the biggest things that a church can give to people is hope.

An important part of the lives of these individuals was attending church and church related events. The accessibility of churches and their activities makes it easy for PLWHA to receive support without making their diagnosis known. Steven talked about the benefit of attending church:

I feel good all week. I feel like I've accomplished something when I go on a Sunday. I don't go every Wednesday night, but I do try to make three Sundays out of a month, or

four. I try to go pretty much every Sunday. It makes my week go better. It's like fuel for

me. When I get low on fuel, I go to Wednesday night Bible study. That's more fuel. I just

feel better.

Another participant, Rick, described the impact of church attendance on his struggle with

depression:

Interviewer: So what do you do to deal with your depression?

Rick: I go to church every Sunday. I read my word [the Bible]. It takes me out of myself.

I do have a relationship with the Lord. Even while I'm doing my devotions in the

morning and reading the word and going to church every Sunday and being active in

church, it's hard to deal because I have to come home. While I'm at church and I'm

involved and participation, I'm not thinking about it…Whenever I go, it seems like

something that's said connects with me. So most of the time when I go to church and I

come home, I feel good.

Attending church services had a positive effect on Rick's well-being.

Another form of emotional support discussed was physical touch. As was stated in the

previous section, people who are uneducated about the illness or believe infection occurs through

physical touch may choose not to physically interact with PLWHA. Receiving physical contact

in any form can be an important source of support for people treated like an untouchable. Sheri

talked about her first experience in her church, which greeted new people with hugs:

They didn't even know I was positive, but they gave me a big hug. Then, when they

found out I was, because I felt so bad about it, maybe two months from when I first got to

church, they didn't treat me different; they just wanted to know more about it.

It meant a lot to Sheri that these people would physically embrace her without knowing anything about her: She felt accepted.

Appraisal Support

Appraisal support allows people to view a tough situation or circumstance from a different perspective. Daniel explained how a sermon given by his pastor gave him a new perspective about God's role in his illness:

> So a couple of weeks later, the pastor was preaching and he said, "When the physician closes his eyes and he says I have done all I can do." He said, "That is when the Master Physician opens his book and he says, 'let's see what I can do. I made this body. I created this body. I know every inch, blood vessel and vein and arteries in this body. Let's see what I can do'." [I told him], "Pastor, you don't realize it, but I just pulled that out of your hand. Clung to it you know…."

The message provided by his pastor helped Daniel to see his illness through the eyes of God. This gave him hope because he felt nothing was too big for God to handle, including HIV.

Esteem Support

Esteem support communicated to the participants that their church community did not see them, nor would they treat them any differently because of their diagnosis. Travis said, "They opened up their arms to me and they understood me. They didn't judge me for it." Annette also spoke about the acceptance she experienced in her church:

> But when I went to the church and I learned their philosophy, I found out they love everybody regardless. They try and reach out to you and accept you as you are. They

show you that God accepts you as you are and loves you for who you are. The support is

there.

These examples show how esteem support is dependent upon the response of church member's

to a person's disclosure of his or her diagnosis. An encouraging response had a positive effect on

how these individuals felt about themselves and their diagnosis.

Some participants linked esteem support to specific interactions they had with their

pastors. Jerry shared the responses of both his current and previous pastors to his diagnosis

disclosure:

He, [his pastor], said, "I ain't going to stop eating your cookies because of that. They're

still good." …I had another pastor who was a female, and she was my worker for a while.

Anything I wanted…She said "I'm there for you." Her brother died [of AIDS].

David provided two examples of esteem support. First, he described how members of his prayer

group responded to him disclosing his diagnosis:

Well, one of the guys, one of the greater friends I have, he said…. "Well, I think we just

need to get around really for him." He says, "We need to show him that God loves him

and we love him, too." And he says, "He isn't going to be one of those friends who ever

failed." And he said, "Every one of us."

David went on to share another form of esteem support that he experienced through having

access to leadership opportunities within his church. He said, "Well, I have been, you know,

proud to say since before September or since August, my pastor asked me if I would be the

coordinator of the church military ministries, which I am…." Allowing David to lead a ministry

communicated to him that he was a valued member of their community.

Strategies for Communicating Support as an Organization

This final section of results contains ideas from both PLWHA and church leaders about what churches should do to improve their identity as a supportive organization for PLWHA. The church is an organization that strives to be a welcoming environment for everyone; however, the reality is that some groups feel more welcomed than others do. Section two was dedicated to the ways in which churches are unwelcoming to PLWHA. This section is about how to overcome or replace those unwelcoming messages with more welcoming ones.

The same themes emerged from both groups of participants regarding things that could or should be done to communicate support. Some of the suggestions came from things that the participants have done with or observed from other churches. Other suggestions were based on the participants' thoughts, ideas, or personal experiences. The themes will contain statements made by both groups to provide two perspectives for each theme.

Advocating for PLWHA

Advocating for increased funding and resources for PLWHA is a clear way of communicating support for people affected by HIV and AIDS both in the United States and abroad. Advocacy also can have a broader impact on those affected by HIV and AIDS, due to the influence of church organizations in the United States.

PLWHA

Eric explained the potential impact of advocacy on PLWHA:

My church is very active in HIV or AIDS awareness as well as advocacy. Seeing them at the various HIV or AIDS functions—fundraisers, walks, even ones not done by church out in the community. So I know they're open people.

Church Leaders

Marsha talked about the impact of advocating for changes in legislation:

Well, if they were willing, they could do advocacy. There's all kinds of advocacy. You

need advocates for the healthcare community. There is advocacy in terms of living

situations. I just think that—employment. There's got to be all kinds of places and then

there's legislation. So, you could.

Advocacy can span a number of issues that could improve the quality of life for PLWHA.

Partnering with HIV or AIDS Social Service Organizations

Another way of communicating support is to partner with organizations that already

provide support for those directly or indirectly affected by these illnesses.

PLWHA

Some participants with HIV and AIDS suggested that churches partner with these

organizations financially. For example, Jerry said, "They could donate $50 a month to a local

AIDS service organization or whatever." Annette added that churches could communicate

support by "…doing the AIDS walk or doing—supporting the AIDS service organization by

attending their gala or donating food to the food bank."

Church Leaders

Church leaders also suggested that churches partner with these types of organizations.

John pointed out the importance of being actively involved in existing organizations:

Well, you have to address it by—any time there was something in a community, any kind

of outreach to that particular part of the community, you would have to go and make your

presence known and say, offer help. Just like you pass out backpacks to people or you

help with medical care. You have to step in to something that was ongoing.

Shevon spoke about how collaborating with HIV or AIDS social service organizations could

decrease social distance between many church members and PLWHA:

…maybe it's partnering with the AIDS service organization or partnering with an

organization that wants to relieve the AIDS epidemic or create awareness about it, in

effect to that partnership. I think the church will become more aware about it….

Some participants shared ways in which their church has already partnered with different

organizations. Dale shared his view:

This last May, we brought several of our students over and a few families from the

church and we had a big barbecue right there on the driveway where the AIDS service

organization office is, and we just hung out for three or four hours. It was funny, because

you could tell right away that there was a little bit of anxiety coming out. Why are these

church people coming? Primarily, one of the ladies who lived at the house who was

helping facilitate it—it took a long time to win her over, but by the end, she was laughing

and joking around with us.

Pam, who leads the health ministry at her church, described a health fair that they put on:

During that, we disseminated the information, and that was held in March. And we had

an event where we hosted Donnie McClurkin [a popular Gospel recording artist] at one

of the local churches here, and we had the health department also come out to provide

health information on HIV and if they were interested in being screened, we also had that

readily available. Also, we've had STD screenings and HIV screenings readily available

for those who wanted to do screens.

Jessie, a public health worker, also described her church's efforts to promote testing:

Now, our church, Riverton Baptist Church, they've been involved with a couple of

programs to promote people being tested and I think the pastor really feels that it's

important that people get tested, and whenever there's any information, he wants to give

it out to the congregation.

Improving General Outreach to the Community

Some mentioned the importance of churches being involved in helping those in need

within their own communities as a way of communicating support.

PLWHA

Churches who were actively involved in their communities were seen as being more

likely to reach out to PLWHA. As John said, "As far as the church goes, you can't really get

caught up on church until you see that that church is reaching out to others in every aspect."

This connection also was evident in other statements. John explained,

I lived out in Dottswood, and there was a church that came on the property. They would

bring a choir. On holidays, they'd give the kids Christmas toys. On Thanksgiving, they'd

give the people turkeys. Any other needs that the people had out there at Dottswood

apartments, they have volunteers that would go around and ask the people in that

complex "What are your needs?" They would supply the needs of the people. I joined

that church because I saw that it had the heart of the upliftment of humanity.

Tony mentioned that a church stuck out to him because they were welcoming to alcoholics:

…she said "they go down there in the basement of the church, hold their meeting down

there, you know, for AA and all kinds of stuff like that." She said "that's a good church."

I told her, I said, "you know what, I'll probably see you down there one evening."

Rick explained why he would not hesitate to seek support from his church because of their

community outreach:

I believe that if I needed something, I wouldn't have a problem getting it. They do

believe in helping and sharing. I've seen how they work with the community. They send

out thousands of Thanksgiving boxes. They invite the community to come in for dinner.

They're awesome.

This church's involvement in the community communicated that it would be a safe place for

PLWHA.

Church Leaders

Church leaders highlighted a range of benefits to improving community outreach within

their own churches. Kevin stated,

So probably the best way is by meeting the needs of those people outside of the church.

That's what I think, because by saying that I'm meeting the needs of the people, it's

saying that I respect you as a person and so since I respect you as a person, I'm going to

meet your needs and I want to let you know that I'm not anti you.

Carolyn suggested that church members intentionally reach out to PLWHA through confession:

A confession to people on a one to one—"hey, I don't blame you at all for not wanting to

come to the church. I'm so sorry that we've lived in such a way that would make you feel

like that, that you're worse than others or that you're rejected."

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Overseas mission trips also were discussed in terms of outreach. Luke talked about the potential benefits of reaching out to PLWHA with HIV and AIDS in different countries. He believed that it would better prepare people for serving PLWHA in the United States:

I would think that, you know, AIDS or HIV, poverty, hunger, I would be surprised if you saw it somewhere else and you didn't become more aware, because it's here. It's just more hidden by our socioeconomic structures. You can ignore it if you want to. You can be completely oblivious to it here in the United States pretty easily.

Shelly described the benefits of serving overseas for increasing people's understanding of the virus:

I think the church does much about doing it in Africa, but I think the church's involvement in Africa has really helped the church understand that HIV is a disease. It's not a lifestyle. I think that when you look at the spread of HIV around the world, particularly as it goes into India, you start to see that this is a terrible public health threat, and it's no longer confined to any particular group that you can stigmatize. It crosses all kinds of boundaries the way that other diseases cross all kinds of boundaries, like race, religion, lifestyle.

Some participants shared about other groups that their churches were intentional about serving. As some of the participants with HIV or AIDS stated, when a church is serving its community, it increases a church's supportive identity, which can increase the likelihood that PLWHA will feel comfortable in these communities. Pam said,

We also outreach to those who have been battered, those who have been victim of domestic violence, those who live in shelters, and of course, it's always a stigma if you're

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poor. It always comes with the stigma of someone being poor, so we reach out to the poor also.

Dale shared an experience from when he and members of his church were serving at a coffee house that exists as a safe place for members of the LGBT community. He said,

When we were hosting at the coffee house a couple of years ago, there was a young man who came in there. You could tell he was there for the first time. I didn't even know if he was actually out, but he was anxious. He was nervous and no one else was talking to him. He was there all by himself. One of our students was standing at the counter with me. We just worked up a conversation with him. We were just nice to him. We were talking. Forty-five minutes into the conversation, he's telling us his whole life story, telling us about his family. We were connecting. We were laughing. We were really quiet when he was talking about some of the sensitive issues when he had gotten hurt, and then some nerd comes in and identifies me as a pastor. The kid's face goes white. He's like, "Oh my gosh!"

Sam talked about his church's involvement with a ministry that provided meals for homeless people. He said,

We've done a lot of the stuff with a homeless ministry…so we have a lot more homeless people coming to the church on a daily basis, so that's kind of balanced the atmosphere out nicely for us. We have people who may come to church drunk. We had one guy come to church whistling after every song, and we were worried at first because we had some visitors and we were worried about how she [one of the visitors] took everything in. Fortunately, when Ted followed up with her, she said it made her feel more comfortable

because she had struggled with it in her life. So to see a church that kind of allowed it to

happen, so to speak, made her feel a little bit better about her past and being there.

The church's intentionality with welcoming other marginalized communities made it a more

welcoming place for PLWHA.

<center>*Developing Health Ministries*</center>

In addition to general community outreach efforts, participants also suggested that

churches develop ministries that specifically serve people with health related issues or concerns.

Developing health ministries could be a great way for churches to improve their communities

because of a general need for accessible health services.

PLWHA

Many of the participants suggested that churches address HIV and AIDS alongside other

health issues. For example, Steven suggested that during a Sunday service,

> …they could say in service people with HIV or AIDS or have a drug problem or alcohol
>
> problems, "let's meet and get together and talk about it and maybe we can go from
>
> there." Other than shutting it down and saying "the Lord says this and the Lord says
>
> that." We understand what the Lord says, and we try to go by that, but embrace some of
>
> the people. The whole congregation is not clean and sober.

Steven's suggestion appears to be for PLWHA who also have a drug or alcohol problem, which

is the case for some PLWHA. Sheri suggested that churches take a broad approach to health

issues:

> By offering the different things like the health fairs and stuff and having different people
>
> come in to talk about different health issues. Not only HIV or AIDS because HIV or

AIDS is surrounded by so many other things [like] high blood pressure, obesity, diabetes, mental illness, substance abuse; all those things coming together. Doing those types of things just for the community. Substance abuse, HIV and mental health, we all know they all go together. They need to involve themselves more with people who are talking about those types of issues and bring them into the church.

Others expressed a desire for services specific to living with HIV or AIDS. Rick said,

I think that I would send fliers out to all the pastors and talk to them about the HIV or AIDS situation in the community and possibly talk to the congregation and get a support group at every church. You never know who might come forth and say okay, this is something that I need.

John talked about helping PLWHA to stay healthy because that is an important part of managing one's illness:

… [what] the church could do as a whole is when they find these individuals, put them in a fitness or health program. Make sure that they're eating the right foods and somebody is always being attentive to the reality of what they are facing. This is the duty of a church, to uplift the fallen and truly a sister or brother has fallen to a low depth on ones' noses and faces to face HIV or AIDS.

John points out that focusing on the dietary needs of PLWHA could be a way of communicating support.

Church Leaders

It became evident during the interviews that health ministries were not common among the churches in the Midwest. Although this point cannot be generalized to all churches, it may

reflect a trend among many evangelical churches. In regards to starting a health ministry, Allison suggested that churches take a broad approach:

I think opening up and beginning a ministry, but not just targeting that—I think health issues overall, because you don't want to stigmatize a group of people or you don't want to make them token. I think that's a good start, at least to acknowledge it, say this is what happens but we're here to support you.

Despite the scarcity of health-related ministries among these churches, some of the churches did have them. Pam described the health ministry that she ran in her church called TELA:

The focus and mission of TELA is to equip the body of Christ or to equip the saints with knowledge, resource, and skills that will enable them to make healthy choices and facilitate a healthy lifestyle. We look at different dimensions of wellness. I'm including physical and spiritual, emotional, intellectual, etcetera. We have different activities all throughout the year. We've had a health fair…We also have screenings—in the past, we've had Sunday screenings of your levels where we will have health screenings, blood pressure taking. We have glucose testing, cholesterol screens. We've also had events that focused on prostate cancer screening. We disseminate health information, and we were one of the churches that hosted the black awareness of AIDS for the Department of Health down here. Our aim is to allow people to live and to improve quality of life. That's what TELA's main purpose is, to educate, to make them health aware… and we use biblical principles because it's inside the church, so you use that context to help also

promote health…because a church looks at a holistic approach of holiness and healing of

body and mind and spirit….

Another participant shared that "there's a chronic condition support group [at my church]. Once

people who are already in have these problems, they're more likely to get in."

Some churches actually started their own health clinics. One participant was involved

with one at his previous church. He shared,

They have a health clinic that sees over 2,000 people a week. Being that you have a

health clinic with Christian doctors and it's a part of the church—you're instantly in

relationship with people that are marginalized, and so it's a lot easier for a doctor who

knows his patients and knows what they're going through to be like hey. If they're

already comfortable with the doctor, and the doctor's going to the church, it's a lot easier

for them to feel comfortable going to that kind of church

Participants who attended churches without a ministry specifically for health issues

highlighted other ministries within their church that focused on circumstances and events that

may have caused emotional distress or pain in a person's life. They felt that these ministries

would be safe places for PLWHA to seek emotional support. Stan said, "[our] emotional healing

class would be a great place to send them, I think, and I think the leadership of that would be

very sensitive." Keisha described a class she led based on a book about dealing with the pain of

one's past. She said,

I think those kinds of groups that could be a great way to minister to that community,

especially if some way it was—if they contracted it through rape or through a relationship

that they had with someone else…but, it's a very small group. It's super confidential.

You don't talk about each other or anything about the group outside of it. I feel like when

I led that group, there were not a whole lot of topics that were off limits. I tried to be as

vulnerable as I could so that people could feel the freedom to talk about whatever they

needed to talk about. I think something like that kind of group maybe could be beneficial.

Providing Access to Leadership for PLWHA within Churches

Providing access to leadership was mentioned in two previous sections of the results.

First, it was coded as a source of esteem support for the participants with HIV and AIDS.

Second, preventing PLWHA from leadership was coded as discrimination on the part of church

organizations. The issue of leadership also came up within the context of communicating

support.

PLWHA

One participant felt that allowing PLWHA to educate people within the church would be

a great way to both communicate support and educate church members. She said,

Yeah. Read up on it and learn more about what they can do and maybe sit down and talk

with some people that are HIV positive and let them give their insight and take that and

put it into a document on how they would want to pursue the issue or try to give out some

help to the community on that issue.

Church Leaders

Because many of the church leaders felt that PLWHA would not be given access to

leadership within their church community, they felt that changing this practice would send a

strong message of support. Leanne stated,

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Well, I'd say the single most effective thing you could do is if you had somebody in your church who was—for them to be in some position of leadership. Because that's saying not only—I mean, again, that's putting a lot of pressure on that person because when they screw up, it becomes—it just reinforces, but if they're willing to take that on—again, when people know actual individuals who don't fit their stereotypes, then there's little cracks in those stereotypes, and I think that's when little rays of light come in and start saying maybe I'm wrong. If you start with one person, especially if they're in a position of leadership…I think that to me is the best option, the most transformational.

Carolyn suggested that a person not affiliated with her church be invited to come and educate the congregation because she did not believe there was anyone within her church living with HIV or AIDS:

Yeah, I think inviting the AIDS community to educate us would be a humble step. To say "that we're not asking you to even become a part of our church or come to our church but gosh, we admit that we know so little, and that's our fault. We've messed up as a church of God, and we're so sorry. Would you please come teach this Sunday? This is so important that we want to invite you, not to speak at you, but to hear from you. God's shown us that we need to learn from this community." So rather than me saying "Gosh, you've been so blessed with this and inviting them in our lives to help teach us things unrelated to that disease," I think it's going to help that person to become more of who God's made them to be, not see this as a giant roadblock because it's an epidemic or because it's a chronic illness.

Lastly, Luke expressed his views on placing PLWHA in leadership roles:

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You could—something less overt might be just to—once you had some members who

might be living with HIV, you might put them in more prominent roles on the welcoming

team or doing announcements. You have to promote people who—if you want a diverse

church, you have to promote people who don't look and act the same. You have to do

that…Well, obviously, if there were any members that were proud and open about their

HIV—that you'd talk to them, bring them in, ask advice [and say], "I have a heart for

this. God's put this on my heart, but I don't understand it very well. I'm going to do some

reading myself, but I would like you to help me, help us, help the church understand how

we can be more welcoming."

Educating Church Members about HIV and AIDS

Offering educational materials or programs also were mentioned as effective ways to

communicate support. Addressing the misconceptions of HIV and AIDS can remove some of the

distractions that arise when these illnesses are discussed. This way, discussions about HIV and

AIDS can occur separate from the other issues.

PLWHA

Some of the participants preferred strategies that were more indirect so that the person

initiating the program would not experience courtesy stigma. John suggested that church leaders

put a sheet up and say "Is there anyone interested or who may have the knowledge of

HIV or AIDS that would like to start or create a class that could bring knowledge and

understanding would be something different?" Then the assumption won't be [that] this

individual is standing up and talking about this because this individual has this.

Annette talked about the type education to offer. She noted that it needed to be educational and made available to church members:

> I would like to see some kind of education program, even if it was just a half hour.
> Maybe it's just giving stats in a way that they doesn't seem boring. Maybe showing that
> at this rate, these are the people that are currently at highest risk of contracting. These are
> people with the highest risk of transmission. You can break it down to counties. In the
> last year, we went from X number of people diagnosed to X number of people diagnosed.
> It's not something just over in Africa. It's over here in the United States, too. And it's
> also not just—it's not in the big cities. It's here in little Champaign-Urbana. Education is
> very important.

> Others felt it was most important to educate the church staff. For example, Eric thought that

> …having their ministers and even their church boards trained, not just—because if you
> train the minister in HIV education and put him in a church that really isn't going to do
> anything with it, then you're kind of tying their hands because they've got their board and
> the church to answer to. If their deacons or deaconesses or whatever you want to call
> them don't want anything to do with it and want to remain in the background and in the
> dark, it's going to be that way. They can't really do anything without the board.

In addition to training church leaders to increase awareness about the needs of PLWHA, it also would help to reduce the stigma of these illnesses within churches. Sheri, an HIV and AIDS educator, advocate, and minister at her church said,

Everything has to do with education. They need to be educated and they need to realize

that it's not what they think it is. A lot of stuff is just ignorance. If they would recognize

people perish and if you don't know anything about it, shut up. You know how a fool

sounds when they don't really know what they're talking about, and this is a foolish

person. "Because I heard this and I heard that and duh, duh, duh," then you come in with

the facts and the spreadsheets and all the information, all the statistics, then what do you

have? Just a mouthful of "well, I heard." Education needs to take place. That's the level

we're at right now. Our first goal right now is to educate the people and to get a liaison

for people who are HIV positive. Right now I'm that liaison.

Sheri acknowledged the need for education and fulfilled the role of an educator within her

church and her community.

Church Leaders

There were a variety of approaches to education presented by the church leaders. Leanne

said it would be best to address the issue through a Sunday school class, which is a class that

allows congregants to explore issues on a deeper level each week:

…I would encourage him [the pastor] to…have an adult Sunday school class on the topic.

In our particular church, that is the one place where there is some give and receive,

because it's not a sermon, but often the leader will do some teaching, but there's an

opportunity to respond, and so it's more flexible than a sermon.

Phil also suggested that education take place through a class that would focus on training church

members to respond appropriately to PLWHA, as well as members of the LGBT community:

I feel like the best way to do it would be through relationships and building credibility

over time where maybe you start classes, but the classes are geared toward your

membership of how to be sensitive, how to be tolerant, how to love, how to reach out,

how to communicate and build relationships with people that are in those situations.

Then, as they build relationships, if a person feels safe with them, maybe they'll feel safe

going to the church. Then, maybe a group starts or something like that, or it just builds up

enough credibility among the LGBTQ community to where it's like "Hey, that's a church

that is really accepting and that you can come be ministered to, but also be challenged

and loved and all that." I think the first step of being intentional is educating whomever

you want to be intentional. And walking through those steps—"Okay, if you meet this

person and they join the church and everything's cool and then they want to serve in the

children's ministry, then what do you do and why is it okay for them to serve in it?"

Maybe having a doctor be like "Hey, this is totally okay for them to be here." You do

have to take certain precautions, but then again, it's not like if your kids give them a hug

they're going to get AIDS or something.

In addition to changing the behavior of church members, these classes also would focus on

changing their attitudes. Sam commented on the purpose of these classes, stating that they should

help others to

understand the disease, getting people to show at least some sympathy for people with

HIV or AIDS, trying to appeal to their current state and status as people who have a

chronic illness, and then really hit on that part of it and not trying to look at why they

have it, but trying to look at the fact that they do have it now and now what and really

taking that strong approach there.

Sam's focus is on showing compassion to PLWHA regardless of how they became infected,

rather than passing judgment.

<center>*Preaching about HIV and AIDS*</center>

Pastors or church leaders give a weekly sermon, or address, each week to the whole

congregation. Participants felt that this would be a great avenue through which to communicate

support, because the pastor has the ability to determine the content of these sermons.

PLWHA

Participants with HIV or AIDS expressed that pastors should preach more about HIV or

AIDS education, illness, and compassion. For example, Rick thought that pastors should educate

their members about the illness, as well as how to respond compassionately. He described this

process of education and skill building:

> I think the pastor could talk about it more instead of sticking it in every now and then.
>
> HIV or AIDS—this is not good. I think the pastor could educate the congregation about it
>
> and make them aware that it's not a sexual thing, but it can be contracted in many ways
>
> and that we're God's children, too, and we need to put our arms around these people and
>
> show them that we love them, and if there's something we can do for them, let's do it.
>
> Let's be Christ-like.

Sylvia thought that pastors should preach about illnesses more generally, stating that pastors

should

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…preach in their sermons and stuff like that to educate the people…When you

specifically talk about a disease, you need to specify all diseases that are among the earth

now, among the world, and you've got a lot of diseases here, just like the swine flu.

You've got a lot of stuff out here that people are not educated on and don't know what to

do to get themselves help.

Annette was more concerned about compassion and believed that pastors could "give more of the

parables where God helps those that can't help themselves, or—like the Good Samaritan." Jerry

expressed a similar desire:

Preach more about sex and healing and that there's deliverance for this and that they care.

They welcome these people in the church. They don't shun nobody. They welcome them

and want them to be in the church. They want them to come. They want them to have a

refuge, a place of escape.

Jerry wanted to hear intentional messages of hope about living with HIV or AIDS.

Church Leaders

Not only did church leaders feel that pastors could communicate support through their

sermons, they also felt that support could be communicated through public information platforms

like: announcements, which often are given verbally at the start of each church service; bulletins

or programs that are made available to each church attendee every Sunday; and bulletin boards,

where both church and community announcements may be displayed. Leanne spoke about this:

A lot of churches have bulletin boards with community events or church events, and they

could just make a point to have some things that are available for people with HIV or

AIDS. Maybe it's as simple as an agency that serves people with HIV or AIDS. Once

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again, you're not endorsing anything. You're just saying "here's some community

resources," but by seeing that one up there, people might say "oh, this might be a place

that would be open to me."

Tricia suggested that information be placed

in your bulletin or your announcements and have AIDS support groups or AIDS

whatever. I think even if it's—even if you think there are two people in your

congregation of 500, I think it'd be worth it not just to reach out to those two people

necessarily, but to make everybody else aware that there are hurting and suffering people

and that their own stuff, whatever it is, they can be welcomed and supported also.

Whereas the sermon suggestions made by PLWHA focused on providing education,

discussing illness, and encouraging compassion, suggestions made by church leaders focused on

de-stigmatizing the illness. Participants provided different communication strategies that would

de-stigmatize PLWHA as a way of communicating support. For example, Pam described how

pastors should introduce the topic to their congregations:

Well, one way to appeal to a church is help them see it impacts so many different

families, and families within their church. That's the major thing…So for instance, you

can do a poll in church. "How many of you all know someone that is impacted by

diabetes? How many hands are raised? Wow. How many people know of someone that's

been impacted by a heart disease?" Oh, so many hands would be raised. "How many

people do you know have been impacted by HIV or AIDS?"… So you have to build them

up to a point where they can open up and see who it is impacting their congregation

because everybody knows someone that's dealing with some type of chronic condition.

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The question is how many in your congregation are there? And you'd be surprised at how

many people have been impacted. And so once you see how many people have been

impacted by HIV or AIDS or any other type of chronic condition, you can see how that

can impact their service to that ministry.

Leanne described another strategy in which pastors included positive illustrations of PLWHA in

sermons that are not about anything health related:

…every sermon, pastors always use stories and always use examples, and so if some of

those stories and examples were people who had HIV or AIDS, but the story was them in

a positive way. That's not the message. That's not what you're focusing on. It just—it

seems like advertising. The idea isn't that you go out and buy that thing right now, but

that it's in your mind and when you do go buy, you think of that product. Oh, yeah,

there's that story and then I see this person and now I think—that might just be another

covert way.

Leanne's strategy provides a way to normalize the illness.

Other participants provided indirect ways of communicating support. For example, Tricia

argued that vulnerability would effectively communicate support:

I think something I really like in the church that we go to is that our leadership, at least,

tries to be really open about their problems and their struggles. If they can be open with

that and people are seeing that the church leadership and the congregation is supportive

of that and is loving and is open to working through those issues with people, I think to

me, that's probably the closest you can get to having the things that are even more taboo

than that to come out into the open and to be safe and to be supported.

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Shelly suggested that pastors should "acknowledge World AIDS Day and other things just as they acknowledge other things—Veteran's Day, Mother's Day, Father's Day." Finally, Leanne felt that it would be important for a pastor to interact with a person with HIV or AIDS publicly, if possible. She said, "But other things that can be done—something as simple as if there is somebody who has HIV that people kind of know, for the pastor to touch them. Not getting all crazy, but a pat on the back, handshake."

Although most of the participants did not feel that HIV and AIDS were addressed in their churches, some did feel that their pastors did other things that could create a welcoming environment for people, regardless of their serostatus. For instance, Keisha said,

> We do a sex talk every year, biblically where we stand as a church and what God says is okay. We've had one of our staffers, he actually struggled with homosexuality and was living in that sin for a while, and he did a talk about homosexuality and his struggle in that.

Sam's approach as a pastor is not to focus on behaviors considered sin. He stated that one must have

> a mentality that you can't force people to change no matter what the situation is and not treat them any …more or less than another. For instance, you'll never hear us globally try to preach about you need to stop doing this, this and this sin because the sins are numerous and immeasurable and you could do that for days and days. Our strategy is more so let's get you closer to Jesus and the reality is that whatever you are going through, seen or unseen, we trust in God and Jesus that if we pray for you and love you

like we ought to that whatever that path is, you'll eventually get there. It's that approach. It's a faith approach.

Summary

The results of this study were divided into four sections. Each section corresponded to the research questions, respectively. This is a brief summary of those findings.

PLWHA in this study believed churches were a source of social support for two reasons. First, they experienced God as a source of social support in their daily lives. Second, participants with the virus defined churches as sources of social support, welcoming communities, and as a refuge or hospital for the sick. The communication of HIV and AIDS stigma within churches, however, contributed to the discrepancy between their definitions of church and their experiences with churches. These stigmatizing messages decreased the likelihood that PLWHA would disclose their illness within these communities to receive support. Some participants did receive social support from churches after disclosing their status; however, this was not common due to the stigma. Both groups of participants recommended strategies for enacting support to improve the relationship between churches and people affected by this illness. A better relationship between these groups could increase the role of church organizations in providing support for PLWHA, especially for those individuals already attending these churches.

CHAPTER FIVE: DISCUSSION

This project explored the relationship between HIV or AIDS, stigma, disclosure, and social support within church communities. We know little about structural sources of stigma because much of the social science research has been concerned with stigmatization from the perspective of the stigmatized (Regnerus & Salinas, 2007). This study explores churches as a structural source of HIV and AIDS stigma using the perspectives of both PLWHA and church members. I believe this is the first study to include church member attitudes to understand HIV and AIDS stigma within churches. The results of this study extend what currently is known about HIV and AIDS stigma within these communities; the effect of this stigma on the disclosure patterns of PLWHA; and the types of support that these communities, as well as their belief systems, provide for PLWHA.

This chapter begins with a review of the study and summary of the findings, followed by a theory that explains the relationships within these findings. Next, I present the theoretical and practical implications of this research. Finally, the chapter ends with a discussion of the limitations of this project and suggestions for future research.

Review and Summary

The continued spread of HIV and AIDS requires that more be done to prevent HIV infection and to support those affected by the illness. The most effective way to address issues of this magnitude is to involve organizations with access to and influence among large groups of people. It also is strategic to involve organizations with an existing mission of supporting others (i.e., non-profits, social service organizations). The evangelical church qualifies as both for two reasons. First, Christianity is a religion with the expressed mission of compassion, service, and

love. Although the expression of these values may vary in both quality and effectiveness, the

foundation remains the same. Second, in a survey about church attendance in the United States,

47% of the population indicated that they regularly attended a church. Moreover, the church

attendance rate in the Midwest 54% (Barna, 2006). Additionally, there are high levels of

diversity among these churches with 52% of Blacks, 49% of Whites, and 29% of Asians

reporting that they regularly attend (Barna, 2006). This means that churches can have a great

influence in communities that are hard to reach through traditional public health methods

because of their abilities to influence people's attitudes and behaviors (Watt, Maman, Jacobsen,

Laiser, & John, 2009).

The stigma of HIV and AIDS unfortunately makes it difficult to increase social support

for people with these illnesses. Moreover, the evangelical church has been a source of HIV and

AIDS stigma (Genrich & Brathwaite, 2005). To understand the ways in which the evangelical

church can play a positive role in issues related to HIV and AIDS, I posed the following

questions:

RQ1: Why are churches perceived as having a supportive function?

RQ2: How are HIV and AIDS stigma communicated within church communities,

decreasing the likelihood of disclosure among PLWHA?

RQ3: What types of social support do PLWHA receive within their church communities?

RQ4: What changes need to be made so that churches can more effectively communicate

support to people affected by HIV or AIDS?

The answers to these questions accomplish four things: establish the church as a viable

organization for HIV or AIDS related work; acknowledge the challenges that exist in involving

churches in this type of work; highlight the positive experiences of PLWHA within church communities; and finally, identify what changes can be made to significantly improve the relationship between churches and PLWHA.

The themes that emerged during the analysis are presented below. Each section corresponds with a research question and contains a discussion of these themes within the context of the current literature. Following these sections, I present a theory developed from these findings to explain the relationships between the primary components of this project – stigma, disclosure, social support, and church communities.

Reasons Why Churches are Perceived to have a Supportive Function

Two primary themes emerged as reasons for why PLWHA perceive churches as having a supportive function. The first were experiences that they had with God as a source of social support. These experiences were the basis for their perceptions of church and fueled their expectations for church to be a source of support (more about this later). PLWHA in this study reported receiving tangible, emotional, informational, appraisal, and esteem support from God, which explains at least one role that faith in God plays in improving their quality of life.

This is not the first study to report a relationship between religious faith and improved quality of life for people living with HIV or AIDS (Cotton et al., 2006, Ironson, Stuetzle, & Fletcher, 2006; Maman, Cathcart, Burkhardt, Omba, & Behets, 2009; Mueller et al., 2001; Prado et al., 2003; Safiya, Marcia, Colleen, & Laderman, 2009; Yi et al., 2006). In a study about spiritual well-being and immune statuses of women living with HIV, the authors found a positive significant relationship between their immune status and spiritual well-being (Safiya et al., 2009). Another study concluded that incorporating spirituality into the care of PLWHA might

improve holistic treatment efforts, specifically as it relates to depression among PLWHA (Yi et al., 2006). Finally, in a study conducted with PLWHA in urban South Africa, some participants felt that they had been chosen by God to have the illness so that they could help others affected by the illness (Hlongwana & Mkhize, 2007).

Previous studies of religious faith and support have focused on outcomes and have included measures of church membership, church service attendance, and church community integration, but they have not included the actual beliefs associated with a particular religion (Adogame, 2007; Mueller et al., 2001). This study does, and according to the data, engaging in specific religious behaviors does not necessarily impact whether or not the participants experience God as a form of social support. It is similar to how some people may experience support from their family members. A person may not talk to certain family members regularly, but these members will offer their support to this person in a time of need because he or she is family. Similarly, a person may not engage in spiritual or religious behaviors regularly, but God is still experienced as supportive because a belief within the Christian religion is that all people are children of God and like a good parent, He is there to comfort His children, no matter what. Although not everyone may describe his or her relation to God in these terms, it is a belief expressed in the Bible, which is the foundational text of Christianity. The communication of comfort through social support from God may, in fact, be what is driving some of the benefits of religious faith because comfort improves emotional health, relieves pain and stress, and "signal[s] care, commitment, interest…[and] express[es] compassion and love" (Burleson, 1994, p. 5).

Attributing social support to something or someone that/who cannot directly be measured complicates research in the area of spirituality and religion; however, the purpose of reporting these data is not to argue the existence or nature of God, it is to provide a foundation for the identity of church organizations from the perspective of PLWHA. The description of the relationship that PLWHA have to God is significant because their experiences serve as the basis for the second theme that emerged—definitions of the church. The participants defined the church as a place that should be a community, welcoming place for all, and a refuge or hospital for the sick. These definitions combined reveal an underlying belief that the church should be a source of support for anyone who needs it, especially people living with an illness. This belief is consistent with the experiences of some PLWHA (Maman et al., 2009; Watt et al., 2009), but certainly not all.

Challenges of Creating a Welcoming Environment for PLWHA

The challenges of creating an environment conducive for prevention and support efforts within churches were described by both groups of participants. PLWHA highlighted issues that decreased the likelihood that they would seek support through disclosing their status in these communities. First, participants commented on how a lack of general community outreach and courtesy stigma among churches negatively affected the identity of a church as a source of support for PLWHA. Second, they shared negative personal experiences with congregation members concerning their illness or issues related to the illness. Lastly, they shared different stigmatizing messages conveyed by the pastor(s) that adversely affected the relationship between PLWHA and churches. Many of these themes related to a lack of education about the illness, which has been a deterrent to disclosing, resulting in nondisclosure (Gaskins, 2006).

Nondisclosure not only affects the ability of PLWHA to gain support within churches, it also limits their ability to fully engage in church-related events like church conferences, retreats, and mission trips because these often occur over extended periods of time. Concealing one's illness over an extended period may interfere with treatment adherence. For example, in a study about treatment adherence and disclosure, 20% of the participants ($N = 215$) reported not adhering to their treatment to conceal their illness, though most of them had disclosed to close family and friends (Stirrat et al., 2006). In fact, 49% of the participants said their non-adherence was because they were away from home. These negative experiences also can result in PLWHA not attending church at all. For example, in another study, PLWHA reported that they avoided churches because of the judgmental attitudes toward HIV, and instead, experienced the benefits of religious faith on their own, through their personal relationships with God and prayer (Watt et al., 2009). Given that these individuals avoided church because of stigma, it is possible that they would attend a church if these attitudes were addressed or did not exist. This, consequently, could increase their access to support networks and resources.

Church leaders identified barriers to creating the type of change necessary to improve this relationship. These barriers related to beliefs about homosexuality, communication about PLWHA and related issues, general community outreach, lack of education about HIV and AIDS, judgment against PLWHA, and problematic assumptions about them. These themes unfortunately contribute to HIV stigma by continuing to perpetuate inaccurate portrayals of PLWHA and beliefs about these illnesses (Alonzo & Reynolds, 1995; Aranda-Naranjo, 2004; Herek et al., 2002; Regnerus & Salinas, 2007).

The overall connection between HIV or AIDS and sexuality was a primary source of HIV and AIDS stigma within Christian churches (Hlongwana & Mkhize, 2007; Regnerus & Salinas, 2007). Church participants associated HIV with the most stigmatizing ways of being infected. For example, some of the members associated HIV and AIDS with sexual promiscuity and many associated these illnesses with homosexuality, which supports existing literature about the different levels of stigma attached to different behaviors (Elmore, 2006; Genrich & Brathwaite, 2005; Herek, 1999; Swendeman et al., 2006). Very few, if any, of the church participants related HIV or AIDS to drug-use, blood transfusions, or childbirth. This view of HIV and AIDS excludes PLWHA who do not fit into these stereotypes. For example, in a study about mother-child disclosure and stigma, many of the mothers had not disclosed to conceal the fact that their partners had infected them through unfaithfulness or drug use (Ostrom, Serovich, Lim, & Mason, 2006). Additionally, these messages make it harder for PLWHA who *were* infected through more stigmatizing ways to gain support (Chesney & Smith, 1999; Greene, 2000; R. S. Lee et al., 2002; Poku et al., 2005; Rintamaki et al., 2006).

The Types of Social Support PLWHA Receive within their Church Communities

Many participants received various types of illness-related social support within their church communities despite the barriers mentioned in the previous section. These included tangible, emotional, appraisal, and esteem support, which demonstrate that churches can be sources of various levels of support for PLWHA. For example, one participant reported that her pastor providing informational support in the form of advice on not accepting her illness as real. Another participant described how church music provided him emotional support by giving him hope. Some participants shared how they had discovered their life purpose through their illness

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(appraisal support), which lead them to help others living with HIV or AIDS. Public disclosure of a person's HIV status also provides esteem support (Paxton, 2002). Others experienced esteem support when they were given leadership opportunities within their churches because it communicated that they were valued regardless of their illness.

These experiences of PLWHA receiving social support within their church communities provide examples for church leaders unsure about how their church can provide support to this population. Because social support increases treatment adherence, strengthening the role of churches as sources of support for PLWHA could have a significant impact on the lives of those who lack support (Gardenier, Andrews, Thomas, Bookhardt-Murray, & Fitzpatrick, 2010). For example, in a study about the role of religion in the lives of women with HIV in the Democratic Republic of the Congo, pastors were an important source of support (Maman et al., 2009). The women often disclosed to their pastors and said that they received prayer, guidance on how to disclose to others, and encouragement in following their medical regimens from their pastors. This study provides promising examples of the types of illness-specific support that church communities can provide if they are willing to make HIV and AIDS a priority.

Strategies for Communicating Support as an Organization

Seven themes emerged concerning strategies that church organizations can employ to communicate support to PLWHA. These themes emerged from both sets of participants. A few participants shared strategies they actually had observed or experienced personally, but most shared their desires for change based on their needs and beliefs. The strategies suggested were to participate in advocacy work for PLWHA, partner with HIV or AIDS social service organizations, improve community outreach, develop health ministries, provide access to

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leadership within the church for PLWHA, educate church members about HIV and AIDS, and preach about HIV or AIDS and related issues. These strategies would improve both the churches' identity as a supportive organization, as well as the quality of support offered to people affected by HIV and AIDS. They also extend what currently is known about developing supportive messages within this context (Goldsmith, Brashers, Kosenko, & O'Keefe, 2008). These strategies are similar to the recommendations that Khosrovani and colleagues (2008) made in their study about how pastors in Texas communicate HIV and AIDS information to church members. They believed that church leaders could incorporate educational information about HIV into their sermons, allow health care professionals to address the congregation, provide counseling services and HIV or AIDS prevention materials to church members, and learn to communicate HIV and AIDS information effectively.

These strategies not only communicate support–many of them also provide support. For example, health fairs can provide testing, increase prevention, and reduce stigma within a setting designed to deal with health issues (Elmore, 2006). Partnering with ASO's to provide health services can be more cost effective for churches that cannot afford to develop a health ministry on their own (J. Smith, Simmons, & Mayer, 2005). Providing educational resources can reduce stigma (Bogart et al., 2008; Elmore, 2006; Estroff et al., 2004) and increase prevention (Khosrovani et al., 2008). Broadly speaking, the church is an untapped resource of support for PLWHA (Watt et al., 2009).

Theory of Organizational Identity Congruence

Although most churches provided access to some types of support for people within their communities, their ability to provide illness-related support to PLWHA depended on how they communicated messages about issues directly or indirectly related to HIV or AIDS. Because many churches have dealt with HIV or AIDS related issues poorly, PLWHA have sought support from God personally (Miller & Rubin, 2007; Watt et al., 2009), rather than from churches. As Regnerus and Salinas (2007) stated, "organized religion is regularly accused of being silent, even complicit, in the mistreatment of persons with AIDS (PWA), and of neglecting their imperative to love and care for the sick" (p. 36).

Previous research suggests that PLWHA separate the purpose of church from the people who operate the church (B. A. Hall, 1998). This study is no different. Although the participants with HIV or AIDS generally perceived the messages communicated by churches about HIV or AIDS as negative, the perceived identity of the church still was positive. This occurred because the PLWHA based the church's identity on their positive experiences with God as social support, as well as the expectation that churches should be sources of support because of their social service history and religious tenets to help those in need (Regnerus & Salinas, 2007; Slaughter, 2010). Thus, the historical identity of churches combined with the experiences of PLWHA with God as social support composed the perceived identity of church organizations.

The positive perception of churches influenced the evaluation of messages communicated about HIV or AIDS within churches. When messages about HIV or AIDS were consistent with the perceived positive identity of the church, the likelihood that PLWHA would seek support through disclosing their status increased. On the other hand, when these messages were negative,

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or inconsistent with the perceived positive identity of the church, the likelihood of disclosure

decreased, as well as the likelihood of church attendance. Put another way, when the perceived

identity of the church was congruent with the messages communicated about HIV or AIDS, the

likelihood of disclosure increased, which increased access to social support. When the perceived

identity of the church was incongruent with these messages, the likelihood of disclosure

decreased. Thus, the likelihood of a person disclosing his or her status to seek support within a

church depended on the church's ability to communicate about HIV or AIDS and related issues

in a way that was congruent with the church's perceived identity, as shown in Figure 5.1.
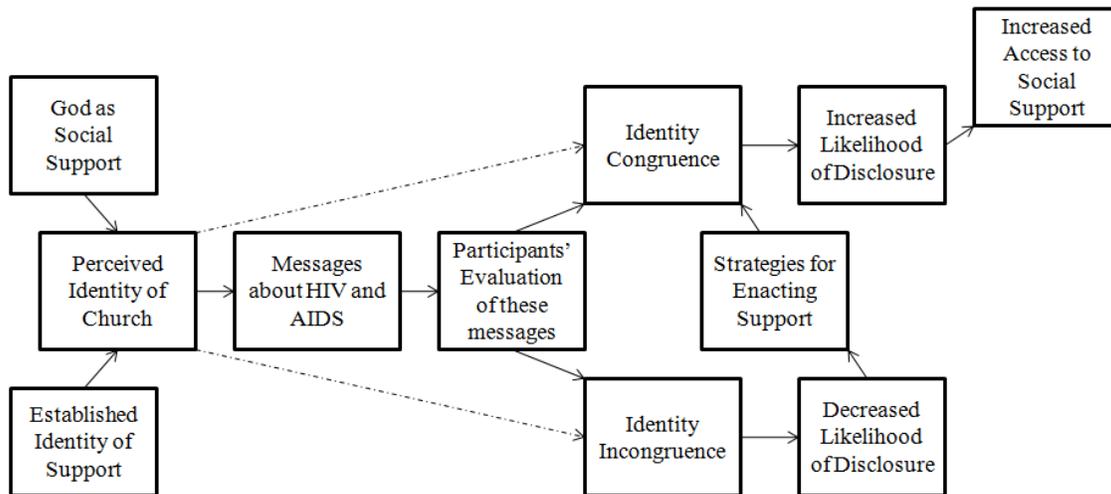
Figure 5.1 The theory of organizational identity congruence applied to disclosure.

Understanding how HIV and AIDS stigma affects illness disclosure and social support

within churches was the goal of this project. It became apparent during the analysis that these

relationships were dependent on the church's identity and communication about HIV and AIDS.

When church messages about the virus were congruent with the perceived positive identity of

church, the likelihood of disclosure increased. When church messages about the virus were

incongruent with the perceived positive identity of church, the likelihood of disclosure

decreased. I developed the theory of organizational identity congruence to explain these relationships, as well as strategies for achieving identity congruence. Three broad concepts make up this theory – organizational identity, organizational communication, and organizational impact. In this study, these concepts translate to perceived church identity, messages about HIV and AIDS, and the likelihood of disclosure.

Perceived Church Identity

The identity of the church was based on the definitions of church provided by the participants in this study living with HIV or AIDS. These definitions—a community of support, a welcoming place for all, a refuge or hospital—were extensions of their view of God as a source of social support. God provided tangible, emotional, informational, appraisal, and esteem support in relation to their illness; therefore, those same forms of support were expected from these churches and served as the basis for the perceived identity of church (see Figure 5.2).
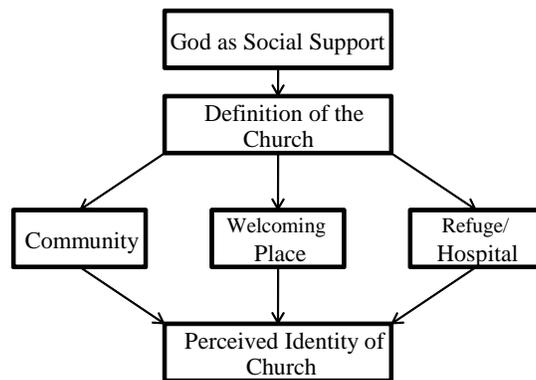
Figure 5.2 PLWHA definition of the church.

Additionally, the church, as an organization, has an established identity of generally being a source of support across many contexts. As Slaughter (2010) stated, "the church is the largest nongovernment/nonprofit social agency in the United States" (p. 17); however, there are

instances of identity incongruence in church communication about HIV and AIDS both

organizationally and interpersonally (B. A. Hall, 1998). Identity incongruence due to stigma

decreases disclosure and religious involvement among PLWHA (Watt et al., 2009).

Messages about HIV and AIDS

Messages about HIV or AIDS were delivered through three sources of communication.

The themes that emerged from each source are presented in Figure 5.3. Each of these themes was

developed from negative evaluations made by participants about messages communicated by

churches about the virus. These evaluations contributed to identity incongruence, which

decreased the likelihood of disclosure.
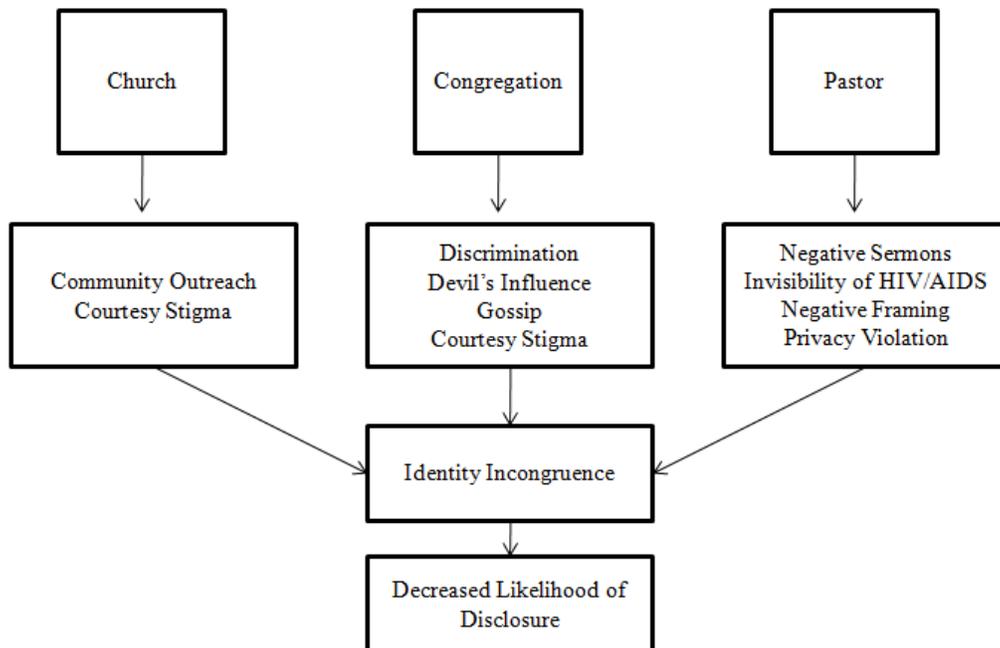
Figure 5.3 Decreased likelihood of disclosure among PLWHA.

The first source was through the church as an organization. At this level, participants

described how the absence of community outreach and the presence of courtesy stigma among or

within churches were incongruent with the perceived church identity. The second source was the

congregation. Participants provided interpersonal examples of negative experiences with congregation members that undermined the supportive identity of the church, resulting in identity incongruence. Participants reported experiences of discrimination and courtesy stigma among family members, as well as fear of discrimination due to the devil's influence on church members and gossip. These examples illustrate the type of environment that they felt existed within church communities, which is a stark contrast to the type of environment that should exist within these communities according to their definitions of church. The third source was the pastor, or other individuals given access to address the congregation. In many ways, they serve as the public face(s) of church organizations. Participants observed identity incongruence in how the pastor(s) preached about homosexuality, failed to include HIV or AIDS within sermons, framed HIV or AIDS negatively, and violated the privacy boundaries of PLWHA who disclosed their status. The concept of privacy boundary violations was developed by Petronio (2002) to describe when a person disclosed information that he or she did not have permission to disclose.

Church leaders discussed the barriers within churches that contribute to the poorly constructed messages about issues related to HIV and AIDS. As Dale, a youth pastor, stated, "We categorize people into certain groups, and what we do is we label them according to the way that we disagree with them, their hang-ups, their mistakes, or even what we would call sins. I don't think that's what Jesus did." Dale is describing the process of stigmatization, which occurs when people are labeled, categorized, and discriminated against because of a belief about that label (e.g., race, illness, socioeconomic status; Corrigan & O'Shaughnessy, 2007; Link & Phelan, 2001); thus, how church leaders and members discuss issues related to HIV or AIDS are incongruent with the perceived identity of the church. These themes included beliefs about

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homosexuality, communication about PLWHA and related issues, general outreach to the marginalized, lack of education about HIV or AIDS, blame placed on PLWHA for their illness, and assumptions about PLWHA (see Figure 5.4).
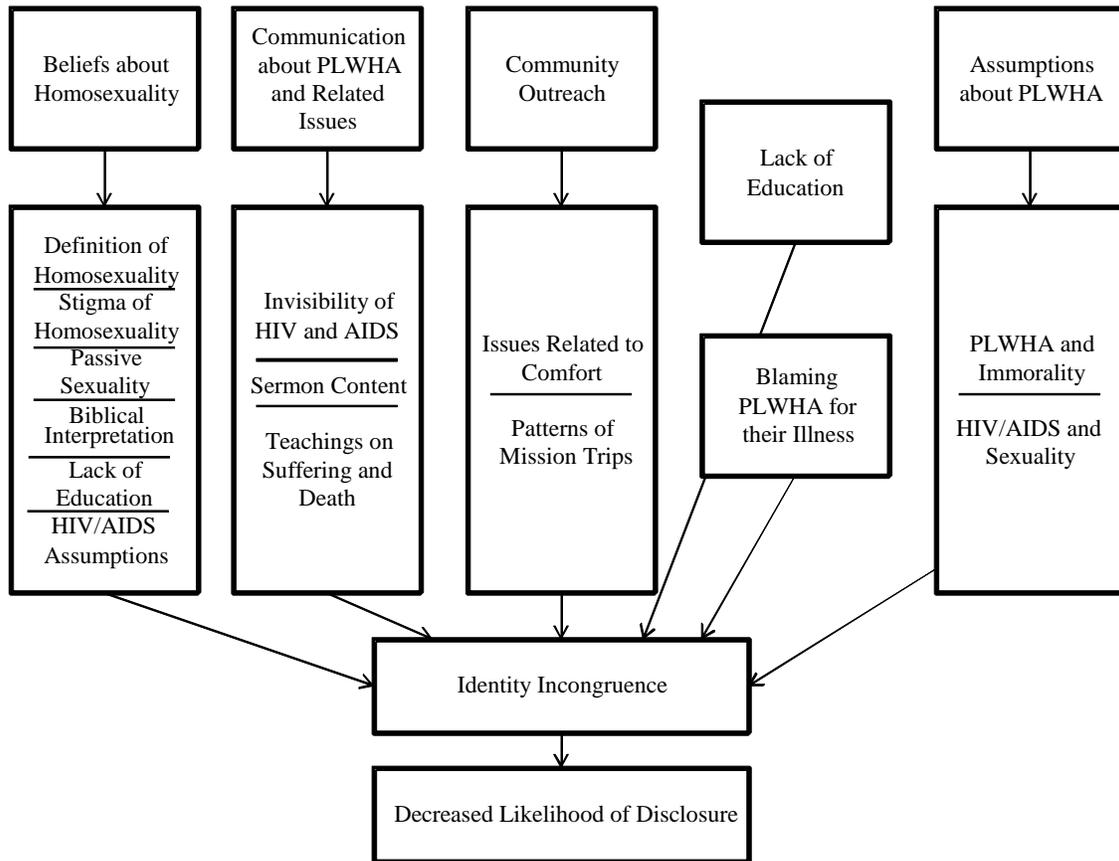
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┌─────────────┐  ┌─────────────┐  ┌─────────────┐                    ┌─────────────┐
│  Beliefs    │  │Communication│  │  Community  │                    │ Assumptions │
│  about      │  │about PLWHA  │  │  Outreach   │                    │ about PLWHA │
│Homosexuality│  │and Related  │  │             │    ┌─────────┐     │             │
└─────────────┘  │  Issues     │  └─────────────┘    │ Lack of │     └─────────────┘
                 └─────────────┘                     │Education│
┌─────────────┐  ┌─────────────┐  ┌─────────────┐    └─────────┘     ┌─────────────┐
│Definition of│  │             │  │             │                    │             │
│Homosexuality│  │Invisibility │  │Issues       │    ┌─────────┐     │  PLWHA and  │
│Stigma of    │  │of HIV and   │  │Related to   │    │Blaming  │     │  Immorality │
│Homosexuality│  │AIDS         │  │Comfort      │    │PLWHA for│     │             │
│Passive      │  │Sermon       │  │             │    │their    │     │  HIV/AIDS   │
│Sexuality    │  │Content      │  │Patterns of  │    │Illness  │     │  and        │
│Biblical     │  │Teachings on │  │Mission Trips│    └─────────┘     │  Sexuality  │
│Interpretation│ │Suffering and│  │             │                    │             │
│Lack of      │  │Death        │  └─────────────┘                    └─────────────┘
│Education    │  └─────────────┘
│HIV/AIDS     │
│Assumptions  │
└─────────────┘
                      ┌──────────────────────────────┐
                      │   Identity Incongruence       │
                      └──────────────────────────────┘
                      ┌──────────────────────────────┐
                      │Decreased Likelihood of        │
                      │       Disclosure              │
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Figure 5.4 Barriers to achieving congruence according to church leaders.

Likelihood of Disclosure

The likelihood of disclosure was dependent upon the evaluation of messages communicated about HIV, AIDS, and related issues. The participants evaluated these messages against the backdrop of the positive perceived identity of churches. Thus, any messages deviating from one of support for people affected by HIV or AIDS resulted in a negative evaluation of these messages resulting in decreased or nondisclosure of one's status and

ultimately, decreased access to support. It is as if these messages were correlated with risks, meaning that the greater the incongruence, the greater the perceived risk of disclosure, reducing the likelihood of disclosure. This is similar to Serovich's (2001) consequence theory of HIV disclosure, which suggests that HIV disclosures are determined by the perceived risk of disclosing. On the other hand, a positive evaluation could represent perceived benefits, resulting in what Black and Miles (2002) called the *calculus of disclosure*, which guides PLWHA through the decision-making process of how to disclose when the benefits outweigh the costs.

Because the likelihood of disclosure was dependent upon the evaluation of messages about HIV or AIDS, increasing the likelihood of disclosure requires that these messages change so that church organizations achieve identity congruence. Changing these messages to communicate support for PLWHA also is known as enacted support. Enacted support refers to how people communicate support in word and deed (Goldsmith, 2004). This project extends current applications of this interpersonal construct by applying it within an organizational context. I will revisit this point in the discussion of theoretical implications.

The themes that emerged regarding enacted support were the same for both groups of participants, adding credibility to the potential effectiveness of these changes. These strategies include: advocating for PLWHA, partnering with social service organizations, improving general community outreach, developing health ministries, providing access to leadership for PLWHA within the church, educating church members about HIV and AIDS, and preaching about HIV or AIDS and related issues (see Table 3). Table 3 contains direct quotes from the participants about communicating support. Incorporating these strategies for communicating support within church organizations will increase the likelihood of disclosure, increasing access

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to available support within these organizations. Moreover, employing these strategies will

increase HIV prevention efforts because of the increased education that naturally will occur by

implementing some of these strategies.

Table 3

Enacted Support as a Church Organization

Theme	PLWHA	Church Leaders
Partnering with Social Service Organizations	With the economy, we're not getting the grants and the money we need to support these people. We're not able to support them for food, the housing has— availability has gone down. Maybe you can help by if nothing else doing the AIDS walk or doing—supporting GCAP by attending their gala or donating food to the food bank.	…for the last three years, we have been working closely with the LGBT resources offices… It's just been a matter of building relationships and helping to break down the stigmas. It's been a challenge on both sides, because I know at the beginning, both sets of staffs—there was a lot of anxiety involved. I'm sure that there were times they wish we would have never come back.
General Community Outreach	I lived out in Scottswood, and there was a church that came on the property. They would bring a choir. On holidays, they'd give the kids Christmas toys. On Thanksgiving, they'd give the people turkeys. Any other needs that the people had out there at Scottswood apartments, they have volunteers that would go around and ask the people in that complex "what are your needs?" They would supply the needs of the people. I joined that church because I saw that it had the heart of the upliftment [*sic*] of humanity.	We've done a lot of the stuff with a homeless ministry…so we have a lot more homeless people coming to the church on a daily basis…. We have people who may come to church drunk. We had one guy come to church whistling after every song, and we were worried at first because we had some visitors and we were worried about how she took everything in. Fortunately, when Ted followed up with her, she said it made her feel more comfortable because she had struggled with it in her life. So to see a church that kind of allowed it to happen, so to speak, made her feel a little bit better about her past and being there.

Table 3 (continued)

Health Ministries	…they could say in service people with HIV or AIDS or have a drug problem or alcohol problems, let's meet and get together and talk about it and maybe we can go from there. Other than shutting it down and saying the Lord says this and the Lord says that. We understand what the Lord says, and we try to go by that, but embrace some of the people. The whole congregation is not clean and sober.	They have a health clinic that sees over 2,000 people a week. Being that you have a health clinic with Christian doctors and it's a part of the church—you're instantly in relationship with people that are marginalized, and so it's a lot easier for a doctor who knows his patients and knows what they're going through to be like hey. If they're already comfortable with the doctor, and the doctor's going to the church, it's a lot easier for them to feel comfortable going to that kind of church.
Access to Leadership	Read up on it and learn more about what they can do and maybe sit down and talk with some people that are HIV positive and let them give their insight and take that and put it into a document on how they would want to pursue the issue or try to give out some help to the community on that issue.	I think developing ministry, creating a ministry that targets that population—I feel like if there was a ministry that outreached to educate people and then brought some of those people in, people that were living with the disease to, even not be spokespeople or tokens…but just to encourage people like "yeah, I live with this disease. It could be a deadly disease, but I'm here and I'm alive." More to educate people about it.

(continued)

Table 3 (continued)

Education	Letting people know that it's not just gay people that have this disease. There is drug addicts, people shooting dope and stuff like that, and they're not just people that's out here being promiscuous or whatever. Basically, I think they should let people know that AIDS is not just a gay person's disease. It's for everybody and anybody that's not practicing safe sex	Understand the disease, getting people to show at least some sympathy for people with HIV or AIDS, trying to appeal to their current state and status as people who have a chronic illness, and then really hit on that part of it and not trying to look at why they have it, but trying to look at the fact that they do have it now and now what and really taking that strong approach there.
Sermon Content	Preach more about sex and healing and that there's a deliverance for this and that they care. They welcome these people in the church. They don't shun nobody [sic]. They welcome them and want them to be in the church. They want them to come. They want them to have a refuge, a place of escape.	…every sermon, pastors always use stories and always use examples, and so if some of those stories and examples were people who had HIV or AIDS, but the story was them in a positive way. That's not the message. That's not what you're focusing on. It just—it seems like advertising. The idea isn't that you go out and buy that thing right now, but that it's in your mind and when you do go buy, you think of that product. Oh, yeah, there's that story and then I see this person and now I think—that might just be another covert way.

To review, the theory of organizational identity congruence consists of three components – organizational identity, organizational communication, and organizational impact. Messages incongruent with the perceived identity of an organization can reduce its impact as an organization. Incongruent messages about HIV and AIDS hindered churches' abilities to support those affected by these illnesses. Employing strategies to achieve congruence could enable

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churches to have a positive impact on the lives of people affected by these illnesses, further strengthening the goal of many churches to reach out to their communities.

Theoretical Implications

The findings in this study contribute to three broader bodies of literature within the field of communication: social support, organizational communication, and disclosure. These implications relate to understanding the role of God in social support, enacted support and identity management, organizational identity and communication, and uncertainty management and disclosure. Following a discussion of the theoretical implications is a discussion of the practical ones.

Social Support

The theory of organizational identity congruence includes two broad themes related to social support. The first is the relationship between God and social support. The second is the use of enacted support as an identity management strategy.

God and Social Support

In a paper about metaphysical and physical aspects of social support, K. L. Ladd and McIntosh (2008) argued that

> Those who reduce religion to nothing more than social support, or who see social support in religious societies as identical to support outside such collections, are missing the distinctive gestalt of religious social support. We argue that researchers who do not consider what may be unique about religion are missing an opportunity to understand more fully the variety of social support that people experience. (p. 27)

One aspect of support unique to religion is the inclusion of the spirit realm and supernatural nature of God, or a higher power (K. L. Ladd & McIntosh, 2008). This study extends the literature on God and social support with its focus on specific types of support that people experience from God. The interviews allow us to see how people talk about God as a source of social support, as well as how they experience Him as such, and add to our understanding of the concept of having a relationship with God that is beneficial to one's quality of life.

The concept of having a relationship with God has emerged as a theme in previous studies about God and social support (Pollner, 1989). For example, in a study about HIV, spirituality, and culture among African American mothers, having a relationship with God was critical in managing their illness (Polzer Casarez & Miles, 2008). The benefits of this relationship were improved health, financial well-being, and management of stressors. The authors also concluded that these benefits depended upon whether or not the participants engaged in prayer and scripture reading. Similar results were found in this study; however, the data does not support the notion that there is a one-to-one ratio or causal relationship between participating in certain activities and experiencing social support from God. It appeared that the types of support they experienced had less to do with specific support-seeking behaviors, and more to do with their belief of having a relationship with God. That is, to have a relationship with God was to have a consistent source of social support, whether or not a person engaged in spiritual or religious support-seeking behaviors.

As stated earlier, all of the PLWHA had some type of faith background that was meaningful to them prior to their diagnosis. For them, these expressions of faith were not spiritual or religious; they were relational, which suggests that the idea of God is vast, intensely

personal, and interpersonal (Poindexter, Linsk, & Warner, 1999; Pollner, 1989). Whereas

previous research may have focused on positive religious coping behaviors or health outcomes

(i.e., prayer, scripture reading, church attendance; Trevino et al., 2007), this study focused on the

support behaviors attributed to God. The experiences of the participants illustrated the role that a

belief in God played in their lives and provided a foundation for their perceived identity of

churches.

Enacted Support

Enacted support is an action or message meant to assist someone with a stressor or

problem, designed by the person providing support (Albrecht & Goldsmith, 2003; Sarason,

Pierce, & Sarason, 1990). Goldsmith (2004) conceptualized enacted support as a form of

rhetorical communication. A rhetorical approach, also referred to as normative, incorporates the

setting in which the support is taking place to fully understand the performance of enacted

support. In this case, the setting would be churches. According to Goldsmith (2004), enacted

support occurs interpersonally. This project extends the use of this construct from an

interpersonal context to an organizational one. In the theory of organizational identity

congruence, enacted support is included as a way to manage a church's identity so that it can

achieve identity congruence, which will increase the likelihood of disclosure among PLWHA.

The strategies for enacting support emerged from participant responses about how

churches could more effectively communicate support. In this way, enacted support refers to the

rhetorical strategies used by church organizations to achieve identity, relational, and instrumental

goals. The theory of organizational identity congruence emphasizes identity goals, because

perceived identity emerged as a determining factor for how PLWHA interacted with church

organizations. Thus, the primary goal of these strategies is enable church organizations to achieve identity congruence, which will enable them to achieve relational and instrumental goals more effectively by improving their practice of the ideals of the Christian faith.

The strategies proposed by the participants will enable churches to achieve congruence by increasing social support for PLWHA, communication about HIV and AIDS, and leadership opportunities for PLWHA. Although the evaluation of these strategies is not included in the model, it would undoubtedly occur on a person-by-person basis as a part of the decision-making process of disclosure. What is different about enacted support in this context is that participants are not evaluating the enacted support strategies as recipients of the support, they are evaluating the support strategies as observers of it. Their evaluation of the support delivery determines whether they will seek support within a particular church. In other words, PLWHA will perform a risk-benefit analysis based on the performance of enacted support to determine if they will become recipients of that support.

The extension of enacted support can be useful for any social service organization or organization that seeks to manage a supportive identity. For example, a Veterans Administration Hospital began offering routine HIV testing, which destigmatized testing by normalizing it (Sobo et al., 2008). Offering routine testing created an environment in which patients felt free to be tested and eventually, they did. In the same way, implementing enacted support strategies will first change the church environment, which ideally will result in changed disclosure behaviors among PLWHA. In this way, the initial goal of enacted support is not to provide support, but to achieve identity congruence, which eventually will lead to participants taking advantage of the support because they first must know that the organization is safe before risking disclosure.

Organizational Identity

This study highlights the effects of identity incongruence on disclosure within an organization. Implicit in the theory of organizational identity congruence is a common organizational concept called organizational identity.

Organizational identity can be defined broadly as the perceived character of an organization according to its members (Dutton & Dukerich, 1991; see also Albert & Whetten, 1985). From the perspective of communication, organizational identity is defined by the messages communicated by an organization about its beliefs and values (Aust, 2004). For example, Christian churches seek to promote an identity that is consistent with the beliefs and values of the Bible; however, problems occur when their actions are inconsistent with the beliefs and values expressed in the Bible. Organizations are known through the things that they do and say and when there is tension between the two, the organizational identity likely will suffer.

Organizational identity research tends to focus on identity maintenance, adaptation, and recovery. For example, Dutton and Dukerich (1991) conducted a study about how the Port Authority of New York and New Jersey dealt with increased homelessness in the area. The authors found that actions taken by the organization that were perceived as negative had a negative impact on both the identity of the Port Authority, as well as the staff. The negative feedback that staff members received about their organization encouraged them to invest in strategies to repair its identity to regain the approval of others (Dutton & Dukerich, 1991).

Aust (2004) conducted a study of organizational identity by performing a content analysis of materials disseminated by a church to assess the primary components of their identity as it related to their values. Developing the identity of this particular church denomination was the

focus of his recommendations. His recommendations focused on identity maintenance, congruence, and refinement because the external communication of the church matched the internal values. If this were not the case, his recommendations would have focused on achieving consistency between the values and communication of the church.

The theory of organizational identity congruence differs from the above uses of organizational identity with its focus on evaluating messages communicated by organizations to determine how these messages affect the organization's ability to make an impact. This perspective adds to the existing organizational identity literature by extending its use beyond organizational identity management to organizational impact. That is, this theory examines the effect of organizational identity congruent and incongruent messages on the organization's ability to have an impact on a specific group of people or issue. I will illustrate these points using this study.

The desired impact of the churches in this study, according to the church member participants, was to offer support to PLWHA. Because the majority of PLWHA in this study had a perceived positive identity of churches, these churches needed to maintain congruent identities to achieve their desired impact. Both groups of participants, however, negatively evaluated the messages about HIV and AIDS communicated by these churches, which resulted in identity incongruence. To achieve the desired outcome, the churches needed to employ strategies for enacting support that would allow them to achieve identity congruence, which would better position them to make a positive impact in the lives of PLWHA.

There are two other scenarios to consider when applying this theory within the current context. The first is when churches have a perceived negative identity among PLWHA and

positively communicate about HIV and AIDS (identity incongruence). The second is when churches have a perceived negative identity and negatively communicate about HIV and AIDS (identity congruence). In the first scenario (negative identity; positive HIV or AIDS messages), churches would want to maintain identity incongruence by continuing to communicate positively about HIV or AIDS and related issues. This identity incongruence may result in PLWHA changing their perceived identity of churches, or viewing these churches as non-normative exemplars. Regardless of these two outcomes, the churches would be in a better position to achieve their desired outcome because they have distanced themselves from the negative identity. In the second scenario (negative identity; negative HIV or AIDS messages), churches would want to determine if their current identity was allowing them to achieve their goals. If churches wanted to improve their relationship with PLWHA, then they would need revisit their beliefs and values and employ strategies to change their identities. If they chose their identity over their goals, then remaining congruent would likely prevent them from improving their relationship with PLWHA.

To summarize, in the first scenario, incongruence was desirable because it allowed the churches to distance themselves from the perceived negative identity of church. In the second scenario, identity congruence was not desirable because the direction of the congruence was inversely related to the direction of the desired outcome. That is, congruence meant coupling a negative identity with negative messages about HIV and AIDS, which unlikely would result in a positive relationship between PLWHA and churches. Thus, the value of congruence or incongruence depends on the relationship between the organization's perceived identity and its goals. The goal of every church is not to help others; however, achieving whatever goals they

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have requires that they understand the impact of their messages in relation to their identities on the people or issues they wish to affect.

Disclosure and Uncertainty Management

Many PLWHA are uncertain about how others will respond to a disclosure of their status because of the stigma. Deciding to disclose one's status in his or her church community can be a difficult decision if the perceived risks do not outweigh the perceived benefits. PLWHA, therefore, may have high levels of uncertainty that they attempt to manage by evaluating messages about HIV and AIDS within their church communities.

Using the theory of organizational identity congruence as a reference, identity congruence or incongruence also could represent lower or higher levels of uncertainty by PLWHA, respectively (Brashers, 2001). This provides another interpretation of the strategies for enacting support. The decision to disclose one's status within his or her church community in this study depended on the perceived congruence or incongruence of the church's organizational identity. This means that the strategies for enacting support can achieve congruence for church leaders, as well as manage uncertainty about disclosing a person's status for people affected by these illnesses. Brashers (2001) stated that increased perceived support, and decreased stigmatization and rejection can reduce social uncertainty. Because many of the strategies for enacting support would have these effects, the social uncertainty would decrease, allowing PLWHA who desire to disclose their status to seek support more freely within a church community.

Although applying the theory within the context of uncertainty would mean that congruence is synonymous with decreased uncertainty and incongruence is synonymous with

increased uncertainty; these relationships do not mean that reduced uncertainty always is preferred. For example, if the perceived identity of churches were negative and PLWHA wanted to attend a supportive church, they would look for churches with identity incongruence, or churches that increased their uncertainty, because they would be looking for a church that does not fit within their definitions of church. Identity incongruent churches with negative identities would be churches that communicated positively about HIV and AIDS or engaged in strategies to enact support for PLWHA. PLWHA with negative perceptions of church may desire to increase their uncertainty by attending incongruent churches because it challenges their perceptions of church, giving them hope that they will find a church that exceeds their expectations.

Viewing identity congruence or incongruence as representations of uncertainty expands the utility of the theory in understanding the effects of identity on communication patterns and behavior. The key is to determine a person's orientation to the organization or group in question. The following section will focus on the practical implications of this research.

<center>Practical Implications</center>

This project was designed so that churches could become more welcoming environments for PLWHA and a launching site for HIV or AIDS interventions because of their prominent societal role, particularly in the Midwest. One of the aims of this project was to provide recommendations for churches who desire to address issues related to HIV and AIDS in the United States. This section contains suggestions that apply specifically to church organizations and people who will be leading the efforts to implementing these changes. Lastly, I discuss the

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cultural differences among the churches in this study, and how to utilize this information within the current context.

<p align="center">*Organizational Strategies*</p>

The results of this study suggest that churches can create a welcoming environment using strategies for enacting support. These strategies will communicate to PLWHA and others affected by the illness that evangelical churches are safe places to disclose their status, if they so desire. These strategies were developed by both groups of participants and are presented below.

External Strategies

External strategies refer to those strategies that require church leaders and members to work outside of their church organizations. Churches that do this can increase their visibility as an organization actively engaged in issues related to HIV and AIDS in the United States. Increasing positive visibility not only communicates support for PLWHA, it acknowledges the need for increased involvement in HIV and AIDS related issues, as well as demonstrates the importance of these issues to other churches. The four strategies suggested by the participants were to become involved with advocacy for PLWHA, partner with ASOs, improve general community outreach efforts, and develop health ministries for members of the community.

Advocating for PLWHA will send a clear message to them that churches are committed to improving the quality of their lives. Partnering with social service organizations sends the same message, while also strengthening community relationships between these organizations and churches. Improving general community outreach efforts will send a broader message to the community, as a whole, that churches are serious about serving members of their communities, and will strengthen the church culture of serving others that ideally already exists within church

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organizations. The most direct way to communicate support would be to develop health ministries. Whether these ministries address general health issues or HIV and AIDS specifically, an investment in health issues would send an undeniable message that churches care about the health and well-being of others.

These changes could help incongruent churches to achieve congruence, as well as churches with negative identities to achieve positive ones. The hope is that increased visibility of the involvement of some churches in HIV or AIDS related work will increase the involvement of other churches, normalizing the involvement of evangelical churches all together. Doing so will decrease the stigma of HIV and AIDS and increase the likelihood that people affected by the disease will seek support within these communities. Most importantly, these strategies will improve the quality of life for PLWHA by increasing social support resources and enhance efforts to reduce HIV transmission through increased education.

Internal Strategies

Internal strategies are ones that occur within church organizations. Whereas external strategies help define the public identity of church organizations, internal strategies improve the environment within the organization. It is crucial for churches that desire to get involved in this kind of work to change both internally and externally, so that when PLWHA decide to attend or disclose within a church because of its external changes, they truly are entering a welcoming environment. Additionally, a compassionate identity is not as effective without compassionate attitudes (Steffen & Masters, 2005), meaning that the external identity needs to match the internal one to achieve the desired outcome. The strategies for creating internal organizational change are to provide access to leadership opportunities for PLWHA who are already a part of a

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church, to educate church members about HIV and AIDS, and to preach about these illnesses and related issues (e.g. sexuality, discrimination).

Providing leadership opportunities for PLWHA will accomplish two important things. First, these opportunities communicate value and worth to PLWHA, as well as others who have experienced some type of stigmatization or discrimination. Leadership elevates marginalized individuals above stigmatizing messages designed to reduce their value and worth by providing them the opportunity to influence others. Second, allowing PLWHA to lead gives them the opportunity to explore and fulfill their own life purpose, particularly because many of the participants believed that their illness related to their life purpose.

Educating people about HIV and AIDS communicates support and prepares people to be supportive. Education will address some of the stigma that exists in churches related to contagion, infection rates and risks, and prevention. Education also can reduce transmission if those implementing the education incorporate health information into the content.

Lastly, preaching about HIV and AIDS adds credibility to any efforts enacted within churches because of the influence pastors have on church members. Sermons can help influence the environment of church organizations because they are delivered to the entire organization. There are a number of ways that pastors can incorporate messages about HIV or AIDS within their sermons. For instance, pastors can acknowledge World AIDS Day, share positive stories about PLWHA, or list HIV and AIDS as important issues to the church within their bulletin. An increasing number of pastors also post their sermons online, operate Twitter and Facebook accounts, as well as maintain blogs that can increase the potential impact of their increased involvement worldwide.

Change Agents

The previous section focused on *what* strategies to use within church organizations, this section will focus on *how* to implement them. Whether a person is an interventionist, advocate, or a concerned member of the community, creating change within established environments can be very challenging. When Dale, a pastor, first started doing this type of work in his church, he was met with a lot of resistance. He said,

> [They kept] reminding me that based on six or seven scriptures in the Old and New Testament that homosexuality's a sin, that we're to love the sinner and hate the sin, that God created Adam and Eve, not Adam and Steve, and I don't know how many more overused clichés that people can throw at me, like I just came on the scene yesterday.

Although there are a number of strategies for enacting support, church leaders and members will decide how to execute these strategies. For this reason, it is important that individuals attempting to initiate this type of work within church organizations understand how to work with church leaders to ensure that the implementation of these strategies are appropriate and effective.

According to the results, PLWHA receive messages from three primary sources–the church as an organization, the congregation members, and the pastor or church leaders. The communication about HIV and AIDS from these sources determined the perceived congruence or incongruence of a church. The church members in this study also identified five general barriers to improving the relationship between evangelical churches and PLWHA in the United States. These barriers were beliefs about homosexuality, communication about PLWHA and related issues, community outreach, lack of education about HIV or AIDS, and assumptions made about PLWHA. These issues are potential challenges to implementing strategies for

enacting support and provide a starting point for directing church leaders in how to create more

welcoming environments using the strategies described in the previous section.

I believe that these barriers can be overcome using three approaches when attempting to

involve a church organization in HIV or AIDS related issues using the strategies for enacting

support. First, present the suggestions for enacting support within the context of that church's

mission. Second, begin by educating those who will be involved with implementing and

maintaining the changes. Third, demonstrate the impact of how church leaders communicate

about HIV and AIDS on PLWHA and their loved ones. These three approaches will be the

foundation on which other efforts are established and developed.

Mission

The assumption is that most of the church missions will include something about

welcoming others into their community and offering support. For instance, the churches

represented in this study have mission statements that encourage church members to use their

skills to help others, focus on helping those outside of the church, and restore hope for people

who lack it. Presenting the strategies for enacting support within the context of a church's

mission increases the credibility of those strategies. For example, if one aspect of a church's

mission is to care for those in need, the strategies could be presented as additional opportunities

for church members to engage in the church's mission. In instances when the mission does not

focus on helping others, the person leading the adoption and implementation of these strategies

can appeal to the general foundations of that particular religion or denomination (e.g., love,

treating others as you want to be treated). By doing this, the individual can address the church's

incongruence as it relates to the foundational principles of the religion they represent to encourage the church to revisit their existing mission.

Most of the barriers to creating a welcoming environment for PLWHA identified by the participants in this study were incongruent with the missions of the churches. Some of the problematic behaviors that emerged within the data were stigma within and among churches towards those involved in HIV or AIDS work, discrimination against PLWHA, gossip about individuals within churches, privacy violations, and a lack of community outreach attributed to a desire for social distance from PLWHA and complacency. Reframing these behaviors within the context of the beliefs and values of Christian churches could be an effective way to change their behaviors. For example, in a survey of Black church members, participants indicated that they did not think negatively of PLWHA; however, many also indicated that they would feel uncomfortable if someone with HIV or AIDS touched them or something in their possession (Khosrovani et al., 2008). This disconnect could be addressed by situating their responses within the context of the church's mission, or the general mission of Christianity.

Education

Educating members and leaders about HIV and AIDS will address the misinformation that exists within communities, contribute to HIV prevention efforts, and prepare the organization to create a welcoming culture for people affected by these illnesses. A lack of education, according to the participants, contributed to unrealistic fears about contagion, inaccurate associations of PLWHA with immorality and sexuality, and generalized blame of PLWHA for their illness. Educational attempts should focus on detaching HIV and AIDS from these issues, so that they are addressed primarily as a chronic illness, rather than a social stigma.

Education also can prepare pastors to counsel PLWHA who come to them for guidance. Maman and colleagues (2009) interviewed 40 women with HIV in the Democratic Republic of the Congo to understand the relationship between their disclosure patterns and religion. They found that 12 of the 14 women who disclosed had consulted their pastors for guidance. Conversely, a questionnaire administered to 319 church members in Texas reported that 55% requested to receive guidance from their pastors about HIV or AIDS, but only 40% actually received any (Khosrovani et al., 2008). A similar finding emerged in the present study.

Information largely was absent in the types of support that PLWHA received within their churches due ignorance about the illnesses. This support type was most common in churches with ministries designed to support PLWHA (e.g., health clinics). This is disturbing considering that support networks can play a critical role in assisting PLWHA with managing their uncertainty, as well as their illness (e.g., illness progression, symptom ambiguity, risk of infection) through the provision of informational support (Brashers, Neidig, & Goldsmith, 2004). Brashers et al. (2004) found that support providers gathered and evaluated information, and protected PLWHA from information overload. Additionally, when a person's support network included others living with HIV and AIDS, these individuals also served as sources of information. The potential for peer support highlights a benefit for providing spaces in which people with similar illness may gather to provide or receive support. Prior to offering informational support, churches first must acknowledge the need to address HIV and AIDS related issues within their organizations. This acknowledgement can occur through education.

Communication

The previous two approaches concerned how to influence the behaviors and beliefs within church organizations. Communication addresses the messages about HIV and AIDS delivered by the organizations. Before changing how church leaders talk about HIV and AIDS, it is important that they understand the impact of the current ways they communicate about them. This ideally would motivate them to change how they communicate because their current approach would not be achieving their desired outcome, assuming that their goal is to achieve identity congruence to become more welcoming of PLWHA. Incorporating research about HIV or AIDS, sharing personal stories from PLWHA about the impact these messages have had on them, as well as inviting individuals with HIV or AIDS to sit down with these leaders to talk about these messages all are ways of helping church leaders to understand the impact of their communication strategies. This would provide an opportunity to discuss some of the issues identified by the participants, such as negative sermons about homosexuality, absence of HIV or AIDS within sermons, and negative framing of HIV and AIDS.

The goal would not be to change the beliefs or positions of church leaders about certain issues, but to encourage more sophisticated ways of discussing them. For example, instead of saying "it's Adam and Eve, not Adam and Steve" to express their beliefs about homosexuality, church leaders would be encouraged to talk about the issue with compassion. As Caughlin and his colleagues (2008) stated,

> Producers of rhetorical messages seek to foster a desirable interpersonal consensus about
>
> the social situation. Because such negotiations require consensus to be successful,

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rhetorical messages seek harmony; thus, they do not include conflict resolution

techniques like enforcing power relations or blaming the other. (p. 658)

Church leaders and members need to know that the stigmatizing experiences PLWHA have

within their organizations not only reduces the likelihood that they will seek support within these

churches, it also can decrease the likelihood that they will seek support from any place (Alvidrez

et al., 2008; Sirey et al., 2001; Weiss et al., 2006).

These three approaches prepare churches for adopting and implementing strategies for

enacting support. Because these strategies may result in increased disclosure by PLWHA to

acquire support, it also is important that PLWHA know how to connect with the supportive

resources. This is important for those seeking support, as well as those evaluating the delivery of

this support to determine if a church is, in fact, supportive. Connecting people affected by HIV

and AIDS with support could occur by including information about these services in church

bulletins, announcements, and sermons, as well as through other public media outlets (e.g.,

newspapers, television, the Internet). Each church could determine if it wanted to provide

specific information about these services, or to encourage people affected by these illnesses to

contact a specific person, who could connect them with these services. Other churches may

decide to designate a particular day of the week or month for people to receive support for

specific health issues. For example, one of the churches involved in this study dedicated one

night a week for people to receive social support for health and other issues (e.g., mental health,

chronic illness, grieving the loss of a loved one, addiction). This allowed them to advertise the

night as a place for people in need of support, regardless of the issue. A potential problem with

this approach is if the staff are not equipped to address a particular issue. Regardless of the

support structure, it is important that each organization has a plan for making their resources accessible to those who need them.

Cultural Differences

Despite the diversity within the sample in this study, the majority of the participants attended a church that was either predominately White ($n = 17$) or African-American ($n = 23$). Sunday is said to be the most segregated day of the week due to segregation among churches. This means that interventionists need to focus their partnerships strategically to ensure that churches of different cultural make-ups are included in their efforts.

The churches specifically addressing HIV and AIDS in this study were predominantly African American. It was common for these churches to have support groups, HIV testing, health fairs, as well as people with HIV or AIDS openly involved within these communities. This is surprising considering that African American churches usually are more reluctant to address these issues (Khosrovani e al., 2008). In fact, two of the churches ran health clinics. These services can make a huge impact in African American communities because churches are regarded as trusted organizations within these communities and are a large part of the culture. The other churches did not have health ministries, outside of one that recently began a chronic illness support group; however, it was not clear if this group was intended for PLWHA.

The data in this study cannot address adequately the cultural differences observed in this study; however, it is important to note that they can provide an incentive for cross-cultural partnerships. Additionally, it could be beneficial for churches with little to no experience in this work to partner with churches that are well-versed in it. Church partnerships could magnify the impact of these supportive resources because they would occur on a larger scale.

Limitations and Future Research

I will begin this section with my most surprising limitation. Of the 21 PLWHA I interviewed, only one shared that he had a negative view of God as a result of his diagnosis. I expected this to be a much more common theme. All of the others appeared to accept the reality of their diagnosis, and if they blamed anyone, it was the person who infected them. Thus, I concluded that my recruitment method may have attracted people with favorable views of God, despite the fact that my recruitment flyer stated that I was interested in both the positive and negative effects of religion and spirituality. It was not surprising that favorable views of God resulted in favorable definitions of church, which resulted in positive perceptions of church among the participants. A more diverse sample may have resulted in more diverse perceptions of God and church; however, I do not believe this would have significantly altered the relationships between church identity and communication.

Age also was a limitation, particularly among the participants with the virus. All of the participants with HIV or AIDS were 31 years of age or older. This may have been because young adults have a higher perception of stigma, which might discourage them from participating in a study. It also may have been because I did not recruit on campus for fear of interviewing former students. Finally, absence of young adults may be indicative of a larger trend within religious communities; that is, young adults with HIV or AIDS may not have participated because religion and spirituality are not significant in their lives.

Another limitation was the small sample size of both groups of participants ($n = 21$). Given the high rate of church attendance in the area, 42 participants does not account for a significant percentage of churchgoers. Additionally, some participants were from the same

church, resulting in a smaller number of churches represented in the study. Using smaller samples limits the applicability of the results for broader audiences. A broader sample may have added depth to the existing themes, contributing to the ideas already expressed. A broader sample also may have provided additional themes, increasing our understanding of the relationship between PLWHA, church organizations, and communication. Despite these limitations, the themes developed in this study extend what currently is known about this topic. Comparing the perspectives of church members and PLWHA also increased the applicability of the findings because they include input from both the recipients and deliverers of support, which makes it easier to determine the types of support to enact.

The use of only one religion, and a particular segment of that religion, also limited the study. Evangelical Christian churches were the focus of this study for two reasons. First, evangelical Christian churches are prominent in the Midwest (Barna, 2006; The Pew Forum, 2008). Second, focusing on a specific type of church increases the applicability of the findings, since there can be so much variation from church to church in religious doctrine and practice. Thus, these themes are limited to this sample of churches.

Conducting the study in an area with a small HIV and AIDS population also was another limitation. The views expressed in this study may have little to do with their church affiliations and more to do with the culture of the area (Regnerus & Salinas, 2007). Although there is no guarantee that church leaders in an area with higher infection rates would be better informed, the possibility that they had encountered the issue, at least once, is higher. This means that they would have formed some ideas about HIV and AIDS, as opposed to some of my participants who had not thought about HIV or AIDS since Magic Johnson's disclosure in 1991.

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Lastly, my familiarity with many of the church leaders in this area also may have limited the study. Our personal relationship or past interactions may have affected their communication about certain topics during the interview. This familiarity may have biased the sample, resulting in less variability among the church participants.

Future research should test the proposed theory of organizational identity congruence to see if the relationships between concepts are sustained. Because church leader positions, specifically pastors, are predominantly male within the evangelical church, future research should examine differences in messages about HIV or AIDS and related issues between male and female pastors. In a study about HIV disclosure and message design logics, women were more sophisticated in their message design (Caughlin et al., 2008), suggesting that female pastors may use more sophisticated messages when addressing their congregations, in comparison to men. Along those same lines, future research also should explore HIV or AIDS messages within church organizations to understand the types of messages most preferred by PLWHA in terms of sophistication (Caughlin et al., 2008).

The types of support currently enacted within church organizations should be evaluated for their effectiveness from the perspective of PLWHA. Although the majority of the churches in this study did not offer any health services, a few did. It would be important to know if PLWHA thought these services were effective before other churches are encouraged to adopt their strategies. It also would be important to know to whom these support efforts most appeal.

Confronting stigma is inherent in some of the strategies for enacting support in this study. Goldsmith and colleagues (2008) recommended that future HIV or AIDS interventions focus on equipping PLWHA to confront stigma, I would add to this that interventions also focus on

teaching community leaders to do the same. Churches have been criticized for not actively fighting the HIV or AIDS stigma (Regnerus & Salinas, 2007), which may be because they do not know how to confront it.

Lastly, in the conclusion of their literature review about religion and health, Mueller and colleagues (2001) suggested that researchers conduct studies to understand the negative effects of religious faith on PLWHA. One of the limitations in this study was that the participants with HIV or AIDS had a positive perceived identity of the church. Future research should explore what happens when participants have a negative view of the church or God, within the context of stigma, disclosure, and support.

<div align="center">Conclusion</div>

Involving churches in issues related to HIV and AIDS can significantly impact efforts to prevent HIV transmission and improve the quality of life of PLWHA. The themes that emerged during the analysis revealed that PLWHA generally perceived churches as sources of support. The decision to disclose one's status within a church depended on how the church communicated about HIV and AIDS. The theory of organizational identity congruence was developed to understand the impact of both positive and negative messages about HIV and AIDS on communication. Identity congruence increased the likelihood of disclosure by PLWHA, increasing their access to supportive resources. Identity incongruence decreased the likelihood of disclosure. Overcoming identity incongruence required that churches implement strategies to enact support for PLWHA. These strategies will enable churches to create a supportive environment for people affected by HIV and AIDS, increasing the likelihood that they will seek support within these communities.

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APPENDIX A: DEMOGRAPHICS QUESTIONNAIRE FOR PLWHA

The following questions are to provide me general information about the people who have participated in this study. I realize that some of these questions are of a sensitive nature. Please be assured that your answers will be kept confidential. You may omit any question that you are not comfortable answering.

1.   What is your age (in years)?   _____

2.   What is your sex?   _____

3.   What is your ethnic group/race?   _____

4.   What is your sexual orientation? (Check one.)

____gay   ____lesbian   ____bisexual   ____heterosexual   ____transgendered

5.   What religion do you identify with? _____

6.   Do you identify with a specific denomination? ___yes ___no

a.   If yes, which one? _____

7.   Are you currently employed?   ____yes   ____no

8.   Are you currently a student?   ____yes   ____no

9.   Are you currently on disability?   ____yes   ____no

10.   How would you classify your current yearly income? (Circle one.)

a. Less than $10,000 per year   d. $20,000-$29,999

b. $10,000-$14,999   e. $30,000-$49,999

c. $15,000-$19,999   f. $50,000 and above

11.   Where do you receive treatment? (Check all that apply.)

____a. private physician

____b. AIDS clinical trials unit

____c. hospital

____d. other clinic

____e. nontraditional source

      please specify _____

____f. other

      please specify _____

12.   Where do you receive most of your treatment? (Check one.)

____a. private physician

____b. AIDS clinical trials unit

____c. hospital

____d. other clinic

____e. nontraditional source

      please specify _____

____f. other

      please specify _____

13.   Do you have a partner with whom you are in a committed relationship?

____yes   ____no

14.   What year were you diagnosed with HIV?   _____

15.   Have you been diagnosed with AIDS?   ____yes   ____no

If yes, what year were you diagnosed?   _____

16.   Are you currently on medications for HIV?   ____yes   ____no

17.   Are you currently on medications for depression or anxiety?   ____yes   ____no

18.   Have you had a CD4 count?
     ____yes   ____no

If yes, what is your most recent count?   _____

19.   Have you had a viral load test?
     ____yes   ____no

If yes, what is your most recent count? _____

20. Do you currently attend a support group?
____yes   ____no

If yes:

Who sponsors it?   _____

How often do you attend?   _____

21. Do you currently receive services at ASO (for example, the Greater Community AIDS Project)?   ____yes   ____no

22. Do you currently volunteer at an ASO (for example, the Greater Community AIDS Project)?   ____yes   ____no

23. Do you currently have friends who are HIV positive?   ____yes   ____no

If yes, approximately how many?   _____

If yes, approximately what proportion of your friends are HIV positive? (Circle one.)

1-20%   21-40%   41-60%   61-80%   81-99%   All

24. Please circle the appropriate response for each item below:

a.   In general, how satisfied are you with the support you get from your friends?

Very satisfied   Satisfied   Neutral   Dissatisfied   Very Dissatisfied

b.   In general, how satisfied are you with the support you get from your family?

Very satisfied   Satisfied   Neutral   Dissatisfied   Very Dissatisfied

c.   In general, how satisfied are you with the support you get from others who are HIV positive?

Very satisfied   Satisfied   Neutral   Dissatisfied   Very Dissatisfied

d.   In general, how satisfied are you with the support you get from your physician?

Very satisfied   Satisfied   Neutral   Dissatisfied   Very Dissatisfied

e.   In general, how satisfied are you with the support you get from other health care providers?

Very satisfied   Satisfied   Neutral   Dissatisfied   Very Dissatisfied

f.   In general, how satisfied are you with the support you get from your church community?

Very satisfied   Satisfied   Neutral   Dissatisfied   Very Dissatisfied

APPENDIX B: DEMOGRAPHICS QUESTIONNAIRE FOR CHURCH MEMBERS

The following questions are to provide me general information about the people who have participated in this study. I realize that some of these questions are of a sensitive nature. Please be assured that your answers will be kept confidential. You may omit any question that you are not comfortable answering.

1. What is your age (in years)? _____

2. What is your sex? _____

3. What is your ethnic group/race? _____

4. Where did you grow up? (circle one) rural suburbs city other _____

5. Where have you spent the majority of your adult life? (circle one)

   rural suburbs city other _____

6. What is the highest form of education received? (circle one) GED high-school diploma some college college degree some graduate school graduate degree medical degree law degree other _____

7. Are you currently employed? ____yes ____no

8. Are you currently a student? ____yes ____no

9. How would you classify your current yearly income? (Circle one.)
   a. Less than $10,000 per year   d. $20,000-$29,999

   b. $10,000-$14,999   e. $30,000-$49,999

   c. $15,000-$19,999   f. $50,000 and above

10. Are you married? (circle one) Yes or No

11. Do you have any children? (circle one) Yes or No   If yes, how many? _____

12. With what Christian denomination do you identify? _____

13. What year did you become a Christian? _____

14. How long have you been a Christian? _____

15. Do you have a specific title or role within your church? Yes or No

    a. If so, what is it? _____

16. Are you a member of a smaller group, ministry, within your church community? Yes or No

    a. If yes, please list them_____
_____

17. On a scale of 1 to 10, how would you rate your church on its outreach to people who are marginalized, or stigmatized, according to teachings in the Bible?

                    (Poor) 1   2   3   4   5   6   7   8   9   10 (Great)

 18. Do you know anyone with HIV or AIDS?   Yes or No

    a. If so, how many? _____

    b. If yes, what is your relationship to them? _____

 19. Do you know anyone who identifies as lesbian, gay, bisexual, or transgendered? Yes or No

    a. If so, how many? _____

    b. What is your relationship to them? _____

APPENDIX C: INTERVIEW SCHEDULE FOR PLWHA

I would like to start by getting to know a little more about you.

1. Tell me a little about yourself (Where do you work? Where are you from?)

2. How long have you been diagnosed? What has life been like for you since you were diagnosed?

3. How did you feel when you were first diagnosed?

4. How do you feel about your diagnosis now?

5. What was difficult to accept about your diagnosis?

6. How have you come to accept your diagnosis?

7. Did you tell anyone about your diagnosis when you first learned of it? If so, who?

    a. How did these individuals respond to your diagnosis?

8. Do you have people in your life with whom you can discuss the illness? If so, who? (If not, skip to 7)

    a. Why did you decide to tell these individuals?

9. What advice would you give to other PLWHA about disclosing their diagnosis?

Sometimes people engage in spiritual activities such as prayer, meditation, spiritual reading to help them adjust to living with a chronic illness. Before I ask you more about this, I first want to ask:

10. What does spirituality mean to you?

11. Do you engage in any spiritual activities? If so, which ones?

12. Why (or why don't you) do you engage in spiritual activities?

13. How has the role of spirituality changed since your diagnosis?

14. Are your spiritual activities connected to any particular religion? If so, which one?

a. What do you like about this religion?

b. What do you dislike about this religion?

15. What does religion mean to you?

Some people who participate in a certain religion also attend church services.

16. What kinds of churches have you attended?

17. What church do you currently attend? Why do you attend it?

a. What church activities, if any, do you participate in outside of weekly services?

b. Why do you participate in them?

18. Have you disclosed your diagnosis to anyone in your church community?

a. If so, how did they respond?

b. If not, why not?

19. How do you think your church, or Christian churches if you do not attend one, is/are welcoming to people with HIV and AIDS?

20. What are some things that church people do to communicate that they are welcoming to PLWHA?

a. How do they communicate that they are unwelcoming?

21. What can churches do to appear more welcoming?

22. In your opinion, why does the church seem resistant to addressing issues of HIV and AIDS in the US?

23. Do you think it's possible to be a part of a church community that does not agree with or endorse LGBT relationships? How?

24. Tell me about a time when you have felt unwelcomed by a church.

25. Tell me about a time when you have felt welcomed by a church.

Some churches in the area provide support for people going through divorce, addicted to drugs, needing financial assistance, and dealing with death.

26. Are there any services that you currently receive from a church?

27. How could churches be more supportive of PLWHA?

28. In what ways could you use more support?

Thank you for your willingness to participate in this study. I learned a great deal from your responses. I would now like to close with a few final questions.

29. How have you grown as a person since your diagnosis?

30. What advice would you give to someone recently diagnosed with HIV?

31. What advice would you give to someone with HIV or AIDS who is looking for a church community?

32. Is there anything you would like to ask me?

Thank you again for your participation. I enjoyed our time together.

APPENDIX D: INTERVIEW SCHEDULE FOR CHURCH MEMBERS

I would like to start by getting to know a little more about you.

1. Tell me a little about yourself. (Where do you work? Where are you from?)

2. Are you a member of the Christian Mercy and Justice Network [insert organization they are involved with]? If so, how long have you been involved? (If no, skip to question 3)

   a. Why did you get involved in this network?

   b. What does the network do?

   c. What are some of the network's greatest accomplishments?

   d. What projects are you currently working on as a group?

3. What does mercy mean to you within the context of your faith? What about justice?

4. What does a church that embodies these concepts look like?

5. How do you feel that your church expresses mercy and justice within the community?

6. Can you give me an example of how your church has tried to serve the marginalized in this community such as the poor, minorities, or people with stigmatized health conditions?

7. What are some of the barriers that keep churches from reaching out to marginalized groups?

8. In your opinion, what groups does the church have the hardest time serving?

   a. Why do you think this is?

As I stated earlier, my dissertation is about the relationship between PLWHA and the church.

9. How would you describe the relationship between PLWHA and the church?

10. Why do you think the church is resistant to serving PLWHA in the US?

11. Do you think it's possible to be a part of a church community that does not agree with or endorse LGBT relationships? How?

12. What are some things that church people do to communicate that they are welcoming of PLWHA (confidential support groups, screenings, partner with public health)?

    a. How do they communicate that they are unwelcoming?

13. What can churches do to appear more welcoming to PLWHA?

    a. What are the challenges or barriers to doing this?

    b. How can churches overcome these challenges?

14. Tell me about a time when you felt a church was unwelcoming to PLWHA.

15. Tell me about a time when you felt a church was welcoming to PLWHA.

16. (moral area) Have you ever participated or observed a conversation about PLWHA among people in your church? Tell me about it.

17. What role does the leadership play in setting the tone for the relationship between PLHWA and the church?

Now, I would like to ask you questions about the role the church can play in the lives of PLWHA.

18. What does the church have to offer PLWHA?

19. What resources does the church currently provide for PLWHA in this area?

20. What resources could they provide?

21. How do you think people in your church would respond if a large number of PLWHA began attending your church? Explain.

22. Where can PLWHA go for support within your church community?

23. Why would you tell someone with HIV or AIDS to attend your church? How would they know it's open?

24. What reservations would you, or your church community, have about a person with HIV or AIDS attending your church?

25. Do you know anyone within your church community with HIV or AIDS?

    a.   How did you become aware of this?

26. How would you suggest that someone disclose their illness to others in your church?

It is quite common for people to turn to spirituality and /or religion when they are dealing

with a health issue.

27. Why do you think this is the case?

28. What is the difference between spirituality and religion?

29. What would you say to someone who said that PLWHA should steer clear of Christians?

Thank you for your willingness to participate in this study. I learned a great deal from your

responses. I would now like to close with a few final questions.

30. How have you grown as a person since becoming a Christian?

31. What advice would you give to someone wanting to create a ministry that supports

    PLWHA?

32. What advice would you give to someone with HIV or AIDS who is looking for a church?

33. Is there anything you would like to ask me?

Thank you again for your participation. I enjoyed our time together.

AUTHOR'S BIOGRAPHY

Erica D. Bauer earned a bachelor's degree in Communication from the University of Dayton in 2003. She also received a master's degree in Communication from the University of Dayton in 2005. She went on to complete a doctoral degree in Communication at the University of Illinois in Urbana-Champaign. In the fall of 2010, Bauer will begin her postdoctoral work at the Center for Management of Complex Chronic Care in Health Services Research at the Hines VA hospital near Chicago, Illinois.