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August 2017

**HIV, Stigma, and Faith: How African Faith  
Leaders Understand HIV in Scotland**

## Executive Summary

### Background:

This dissertation examines how African faith leaders understand HIV and HIV-related stigma. Waverley Care organized this project because of higher prevalence of HIV among Africans in Scotland and the need to tailor HIV awareness and prevention initiatives for Africans. In Scotland, 1 in 802 people has HIV, but 1 in 21 Africans has HIV (HPS.Scot 2017). Since 2004, Waverley Care's African Health Project has helped Africans in Scotland access HIV and sexual health resources. In 2010, Waverley Care developed the Faith and Health Agenda in recognition of the important role faith plays in the African community in Scotland. As treatment is free and readily accessible in Scotland, HIV stigma is often one of the most significant barriers to health within the African community in Scotland. Fear of stigma often prevents people from discussing risks and prevention, accessing services, testing, and disclosing their status. This project strives to gather information about why African faith leaders in Scotland choose to work with Waverley Care. The following questions guided the research:

- What contribution does partnership working with faith leaders make in reducing HIV stigma within African communities and HIV positive African's self-stigma?
- Why have faith leaders shifted from believing "HIV is nothing to do with me or my congregation" to "HIV is an important part of my work as an African faith leader and important for my congregation"?
- How do African faith leaders see themselves as contributing to reducing HIV stigma?
- What does Waverley Care do that allows African faith leaders to take ownership of challenging HIV stigma?

By better understanding what faith leaders see as their role in HIV awareness, Waverley Care can improve HIV can encourage other faith leaders to become involved in Waverley Care and promote better health for Africans in Scotland.

**Methodology:**

This is a qualitative study based on semi-structured interviews of six African faith leaders, two members of Waverley Care staff, and one Waverley Care service user in Edinburgh and Glasgow. The interviews were transcribed and organized by theme. The resulting information was then analyzed and compared to both external and internal documents.

**Results:**

- It is important to provide information in a culturally specific and sensitive way.
- Pastors in sample did not believe there was a conflict between faith and health and were receptive to working with Waverley Care. In fact, they saw HIV awareness and combatting HIV stigma within the church as consistent with Christian messages of acceptance and love. They see HIV stigmatization as an issue within other church congregations but not their own.
- Pastors in the sample emphasized the relationship with Waverley Care as key. It is important for Waverley Care to partner with faith leaders so they see Waverley Care's mission as consistent with the churches beliefs.
- African faith leaders need to feel responsible for HIV awareness and reducing HIV-related stigma.
- The shift towards increased faith leader involvement could be a result of building relationships over time or the result of increasing HIV engagement within the wider Pentecostal church.
- However, pastors may unintentionally stigmatize HIV, and it is important to remember that what pastors say and think is not always the message church-goers take away.
- Churches often approach HIV with ambivalence: Churches can be a positive force to fight HIV stigma but they can also be responsible for stigmatizing attitudes. It is important to understand the complex way that African Christians engage with HIV.
- Overall, Waverley Care's methods of engaging with African faith leaders appears to be effective, and with more time, many African faith leaders will likely work with Waverley Care Scotland.

## **Abstract**

This paper examines how the African faith community addresses HIV and HIV-related stigma in Scotland. HIV is a significant and often unacknowledged issue within the African community in Scotland, affecting Africans at a much higher rate than the general Scottish population. Churches and faith leaders are increasingly studied for their contributions to promoting HIV awareness and countering HIV-related stigma and may be especially important for the African community in Scotland. In the past, faith leaders have been reluctant to address issues of HIV but many faith leaders have since become open to working with Waverley Care Scotland, an HIV charity based in Edinburgh and Glasgow, Scotland. Drawing on semi-structured interviews of faith leaders and individuals working with Waverley Care, I examine reasons behind this shift and analyze the complex and often contradictory relationship between faith, stigma, and HIV.

*Keywords: HIV/AIDS; Africa; Scotland; Faith; Christianity; Pentecostal; Stigma; Advocacy*

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## Introduction

### Project Background

While many no longer believe HIV is a life or death issue in the UK, HIV diagnoses have risen yearly since 2001 (HPS.Scot 2017). Increased asylum seekers to the UK and redistribution to Scotland have contributed to this rise (Palattinyil and Sidhva 2011). HIV is specifically a problem for Africans in Scotland, and black Africans are the second highest risk group in the UK after men who have sex with men (MSM) (Zirra and Zimunya 2015). In Scotland, 1 in every 21 Africans is HIV+ compared to 1 in every 802 Scottish citizens (HPS.Scot 2017).

This dissertation is a study of how African faith leaders in Scotland address HIV in their churches and why they have collaborated with Waverley Care Scotland (WCS) – an HIV and Hepatitis Charity based in Edinburgh and Glasgow, Scotland. As a charitable organization, WCS promotes HIV awareness, encourages testing and treatment, offers support for people living with HIV (PLWH), and challenges stigma. WCS's African Health Project strives to understand the specific needs of Africans living in the UK and promotes a more individualized understanding of health care. Based on past studies (Kasengele and Baillie 2011; Ssentamu and Kamonji 2013; Zirra and Zimunya 2015; Lima, Jackson and Zimunya 2016), WCS believes the African church and faith leaders are key to promote HIV awareness and support HIV+ Africans in Scotland. Religious organizations often moralize HIV and isolate HIV+ individuals, and while aware of these barriers, WCS is examining the church as positive forces for HIV awareness.

In the past, many African faith leaders in Scotland resisted working with WCS, but recently have allowed WCS to speak about HIV and offer HIV tests after services. There is a shift from faith leaders saying "HIV has nothing to do with me or my congregation" to "HIV is an important part of my work as an African Faith leader and important for my congregation." This project examines why some faith leaders see HIV awareness as their responsibility while others deny HIV is an important issue. If faith communities address HIV in their community, they can support PLWH, raise awareness, and promote prevention at a local level (Kasengele and Baillie 2011). Understanding this shift could help WCS improve relations with the African faith community and improve health for Africans in Scotland.

## Methodology

For my dissertation, I did a Work-Based Placement with Waverley Care Scotland. Specifically, I worked with the Faith and Health Agenda, which developed out of the larger African Health Project in 2010. Unlike a library-based dissertation, I addressed the following research question set by WCS: “What contribution does partnership working with faith leaders make in reducing HIV stigma within African communities and HIV positive Africans’ self-stigma?” To address this question, I used a qualitative anthropological approach to study the lived experience and personal subjectivity of those in the African faith community in Scotland. Qualitative research that provides information on community norms is especially important when talking about marginal and neglected sub-groups within a larger community.

I conducted semi-structured interviews with six faith leaders, one service user, and two employees of the WCS’s African health team in Edinburgh and Glasgow, Scotland. All informants were born in Africa and immigrated to Scotland. To retain anonymity, the interviewees’ names have been changed:

- Jonas and Claire are part of WCS’s African Health Project
- Samuel, Ruth, Grace, Thomas, Malcolm, and Henry are pastors
- Sarah is a WCS service-user

WCS recruited the participants, and all but Malcolm had previously worked with WCS to have HIV-related programs at the church. The churches are Pentecostal, and I attended services at many of the churches before interviewing the pastors. The interviews lasted between thirty minutes and an hour and a half. They were audio recorded and manually transcribed. When quoting interviews, filler words such as ‘kind of,’ or ‘you know’ were removed for clarity, but grammar was otherwise left unedited. Participants were given the opportunity to follow up initial comments through email, and the dissertation was made available to interviewees. The Ethics Research Committee of the School of Social and Political Science at the University of Edinburgh formally approved this project.

I approached this project through the discipline of medical anthropology. Medical anthropologists maintain that medical interventions must make sense both biologically and socially. In keeping with the discipline, I consider larger social structures and the local lived reality of people. As Thomas (2008) observed, a strictly biomedical approach to HIV

intervention is insufficient and needs to address local understandings. To be effective, HIV prevention efforts should understand the political, historical, cultural, and social aspects of people's lives.

## **Limitations**

First, the number of interviews is small (9), and I cannot generalize to an entire community based on these limited interviews. While my informants helped elucidate how the African faith community in Scotland views HIV, their opinions and comments are ultimately their own. Second, while I chose to accept the truth of my informants' information, they could also be telling me what they think I want to hear as documented by the social desirability bias (Fischer 1993). This problem could be compounded as I am a young white female researcher. My informants may not expect me to share their opinions and therefore refrain from making potentially controversial comments. Thirdly, as WCS recruited the interviewees, they are predisposed to seeing HIV positively. Those who have decidedly negative opinions may opt not to be interviewed. Fourthly, my sample could be regionally biased as the pastors I interviewed are from Nigeria and Ghana, and the service user is from Zimbabwe. Church-goers are typically from the same country as the pastor. Due to time constraints, I was unable to interview pastors from Southern or East Africa, and these faith leaders may hold different views as HIV is more prevalent in Southern and East African.

I must also comment on issues of race. Talking about HIV within the African community and targeting interventions directly at this group risks being stigmatizing or racist by associating black Africans with HIV (Cree 2008). However, WCS staff emphasized that African-directed services are not only acceptable, but are necessary given the higher prevalence of HIV among black African immigrants in the UK and the fact that they are less likely to access mainstream medical and social services. While this study looks at black Africans, I acknowledge the problems of generalizing Africans given the diversity present throughout an entire continent. Furthermore, statistics for the African population in Scotland group Africans together, making minimal distinctions between regions, countries, or ethnicities. For clarity, however, I will refer to black African immigrants in Scotland simply as Africans within the dissertation. References to studies in the African continent will be noted and the country or region will be specified when possible.

## **HIV/AIDS in Anthropology**

Although anthropologists were initially late to address HIV/AIDS, since the late 1980s, HIV/AIDS has become a specific point of interest for medical anthropologists. The Annual Review of Anthropology has devoted six review articles to HIV/AIDS, starting with MacQueen (1994) and ending with Moyer (2015). In 2001 alone, four articles were published on the topic (Hutchinson 2001; Kane and Mason 2001; Parker 2001; Schoepf 2001). Anthropologists have used various frameworks to examine HIV. One school of thought relates the experience of HIV/AIDS to social and structural factors specifically emphasizing how poverty and inequality increase the risk of HIV and decrease access to treatment (Farmer 1992; Schoepf 1988; Treichler 1999; Fassin 2007). Anthropologists have also used Foucauldian (1978) theories of biopolitics and governmentality to discuss the regulation of sex and life in the context of HIV. Biopolitics – the politics of life – examines how governments regulate populations and physical bodies through measures such as demographics, birth rates, and death rates. And governmentality examines how people are made into governable citizens. Expanding on Foucault's concepts, HIV has also served as a case study for biological citizenship where AIDS activists are an example of biosociality (Rose and Novas 2005; Biehl 2007) and therapeutic citizenship (Nguyen 2005) which describes how HIV+ people in Burkina Faso become activists and lobby for access to treatment.

With the development and spread of antiretroviral therapy (ARTs), researchers increasingly focus on the biomedicalization of HIV (Hardon and Dilger 2011; Nguyen et al. 2011). Now, anthropologists talk about living with HIV instead of dying of AIDS, and the conceptual framework for HIV in the West has shifted from HIV as exceptional crisis and fatal disease to a manageable chronic condition (Rosenbrock et al. 2000; Smith and Whiteside 2010; Mattes 2014). In 1989, Susan Sontag argued AIDS would be normalized when it was better understood and treatable. Later, Castro and Farmer (2005) suggested structural violence and inequality were the main reasons for HIV stigma and expanding treatment would reduce stigma. However, despite the development of HIV treatment and expanding access to medications, social discrimination persists (Moyer 2015; Schoepf 2001). The social aspect of HIV/AIDS remains constant, and the risk of HIV and AIDS is as much socially as biologically determined.

My study overlaps with many existing themes in anthropology and HIV: religion, morality, sexuality, race, migration, socioeconomic class, identity, stigma, care, politics, and science. To narrow this scope, I focus on religion, stigma, and morality in relation to HIV in the African faith community in Scotland.

While HIV and AIDS are often used synonymously, it is important to remember that HIV is a virus whereas AIDS is an acquired condition that may develop from an HIV infection. While I discuss HIV and AIDS, I primarily focus on HIV because most PLWH in Scotland do not develop AIDS.

### **Christianity and HIV/AIDS**

Despite the centrality of religion to the lives of many PLWH, anthropologists were slow to examine the connection between HIV and religious faith. HIV in the context of African religion has only been researched since the late 1990s and was first examined as an impediment to HIV intervention. (Prince, Denis and Van Dijk 2009; Becker and Geissler 2009; Dilger 2010). In the past, researchers emphasized how cultural factors such as witchcraft or evil spirits influence the experience of HIV/AIDS in Africa and neglected faith (Yamba 1997; Wolf 2001; Ashforth 2002; Thomas 2008).

The religious response to HIV is complicated and both positively and negatively impacts PLWH (Dilger 2007; Dilger, Burchardt, and Van Dijk 2010; Campbell Skovdal, and Gibbs 2011). Because of theological traditions, religious groups may especially stigmatize HIV and moralize it as a punishment for sin (Van Dijk 2009; Mattes 2012). However, religious organizations – including Pentecostal churches – are increasingly involved in HIV education, prevention, counselling, care, and treatment (Garner 2000; Dilger 2001; Becker and Geissler 2009; Nguyen 2009; Paristau 2009). In Scotland (Palantinyil and Sidhva 2011) and the UK, (Anderson and Doyal 2004; Chinouya and O’Keefe 2005; Doyal and Anderson 2005; Ridge et al. 2007) Africans with HIV report that the church and faith provides spiritual, emotional, and psychological support and encouragement. Other research suggests the spiritual commitment, religious involvement, and socialization that take place within the church protect HIV/AIDS sufferers from social stigma and abandonment (Adogame 2007). Because of their potential to benefit PLWH, religious organizations could be one the main means to blocking or allowing HIV care and prevention (Dilger 2010; Moyer 2015).

Previous research suggests that the African faith community in Scotland is an important platform to address HIV-related stigma and discrimination. Religion may be especially important for Africans in the UK. About 70% of Africans in the UK self-identify as Christian compared to 59.5% of the general population (ons.gov.uk).<sup>1</sup> Qualitative studies show the importance of religion for Africans in the UK, especially for those with HIV (Anderson and Doyal 2004; Chinouya and O’Keefe 2005; Sadler et al.2005; Ridge et al. 2007). Kasengele and Baillie (2011) found Africans in Scotland see faith as paramount to their well-being and sense of identity. In Scottish studies, Cree (2008) found community organizations (Cree2008) – and more specifically churches (Zirra and Zimunya 2015) – are the most effective way to spread information to Africans in Scotland. As institutions, churches have well-established social networks, access to institutional and community resources, (Trinitapoli 2006; Campbell, Skovdal and Gibbs 2011; Zirra and Zimunya 2015) and especially help reach minority groups that may not use mainstream services (Chinouya&O’Keefe2005; Olivier&Smith2016).

Baker et al. (2015) and Zirra and Zimunya (2015) suggest that it is specifically important to engage with African faith leaders for HIV awareness as they act as gate-keepers for the African community in Scotland. Faith leaders are well-respected ‘father figures’ and may increase the message’s credibility (Waverley Care and NHS 2011). Faith leaders have also been shown to positively impact HIV stigma among minority and marginalized communities in the United States (For example: Bauer 2012; Frenk and Trinitapoli 2012; Adedoyin 2013; Olivier and Smith 2016; Kendrick 2017) and in Africa. Studies in Uganda (Liebowitz 2006), Senegal (Green 2013) and Madagascar (Rakotoniana et al. 2014) show the efficacy of engaging religious leaders in HIV advocacy and suggest this type of engagement would work in other settings. In England, Chinouya and O’Keefe (2005) found African faith leaders were generally receptive to HIV awareness despite ambivalence. Together, these studies suggest African faith leaders in Scotland can promote HIV awareness and decrease stigma.

While the social dimensions of HIV have been studied extensively, the social and cultural contexts of HIV among Africans in the UK is understudied compared to other contexts (e.g. Kesby, Fenton and Power 2003; Doyal and Anderson 2005). More specifically

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<sup>1</sup> Note: Statistics for African Christians in Scotland were not available

the role of religion among Africans in the UK is understudied (Chinouya and O'Keefe 2005). To my knowledge no studies have examined how African faith leaders in Scotland address HIV.

### **Structure of the Dissertation**

In Chapter 1, I examine HIV stigma in the context of Africans in Scotland and reasons for continual HIV-related stigma, focusing on the metaphorical associations of HIV. I end by suggesting the African Christian community may especially stigmatize HIV.

In Chapter 2, I address the ambivalence existing within the Christian response to HIV/AIDS and the need to understand how Christian beliefs frame the African faith community's response to HIV. I examine how religious beliefs can both counteract and exacerbate HIV stigma. I detail various barriers to HIV awareness but ultimately argue that HIV awareness aligns with the Christian worldview of pastors in my sample. Finally, I suggest that African Christians in Scotland may hold stigmatizing attitudes surrounding HIV despite outward acceptance of HIV awareness, emphasizing the messiness within the African faith community's response to HIV.

In Chapter 3, I examine the shift that has occurred within the African faith community in Scotland. First, I suggest presenting information as part of a relationship helps pastors see HIV as their responsibility. Then I look at changing views within the Pentecostal church generally and then specifically within the Pentecostal African church in Scotland. For a successful partnership, HIV charities should understand the complex and contradictory ways African Pentecostal Christians in Scotland understand HIV, and approach faith leaders by highlighting how HIV awareness aligns with their Christian worldview.

## Chapter 1: HIV and Stigma

In this chapter, I define stigma broadly, differentiating between enacted and felt stigma. Next, I examine stigma more specifically, looking at the harms of HIV-related stigma and instances of stigma in the African faith community in Scotland. Though HIV is highly treatable and people look to frame HIV in biomedical terms as a manageable chronic disease, it remains exceptional. I explore why HIV is continually stigmatized, arguing that misinformation and metaphorical associations are reasons for its continued stigmatization. In this chapter, I touch on themes of fear: fear of HIV itself and fear of stigma.

### What is HIV Stigma?

Goffman (1963) provides the seminal definition of stigma as “an undesirable difference” that isolates individuals from what is considered normal in a specific social context. Stigmatization creates a “spoiled identity” that implies social consequences such as discrimination and exclusion (Goffman 1963). People not only experience prejudice and exclusion, but are blamed for the stigmatizing trait. The trait can take on a “master status” that comes to define the individual (Goffman 1963).

It is also useful to differentiate between felt and enacted stigma. According to Jacoby (1994), felt stigma is how people feel about their condition and expect others to react, while enacted stigma is the actual experiences of unfair treatment or discrimination from others. Felt stigma is internal and can also be described as self-stigma while enacted stigma is external. HIV positive Africans in Scotland face both enacted and felt stigma.

HIV-related stigma is a major barrier to HIV awareness and prevention, threatens to affect long-term health, and may be one of the main drivers of the HIV/AIDS epidemic (Parker and Aggelton 2003; Campbell, Skovdal and Gibbs 2011). Stigma discourages people from discussing HIV risks and prevention, testing, disclosing status, seeking support, accessing health services, and adhering to treatment (Anderson et al. 2008; Lima, Jackson and Zimunya 2016). PLWH may struggle with issues of personal identity and social interaction and have poorer mental health (Flowers 2006; McGrath et al. 2014). As a result, HIV-related stigma often prevents people from enjoying the ‘normal’ life that ARTs provide (McGrath et al. 2014). In many instances, HIV stigma is “layered” with other stigmatized identities (Swendeman et al. 2006). For Africans in Scotland, stigma from ethnicity,

sexuality, migrant status or class can add to the stigma of poor health and HIV (Cree 2008). Because HIV treatment is free and readily accessible, stigma might be the most significant issue for PLWH in Scotland.

### **HIV Stigma in the African Community in Scotland**

Stigma was a major theme throughout my interviews and is described as something that inevitably comes alongside HIV. For example:

“Because of the stigmatization. They don’t want even to know [their status] ... because of fear.” – Henry

“They are not keen to open up on that aspect of their life [having HIV], because of fear of being labeled or stigmatized by society and possibly by the church itself.”  
– Thomas

While enacted stigma exists, fear of stigma was more frequently discussed as a barrier for testing or discussing HIV. In previous research, Green and Sobo (2000) suggest people overestimate enacted HIV/AIDS-related stigma, but experience high levels of self-stigma. According to the pastors, PLWH fear how others will respond, but church communities would support people who disclosed their status. For example, Thomas describes his experience with a woman who hid she had HIV, was deported to Africa, and passed away:

Maybe they looked at my body language or maybe...thought they should keep it to themselves as part of... the perception, the attitude from people around them, so they did not open up... Shortly after she died in Africa and that really broke my heart because if they had opened up in time,... they would not have been dealing with it by themselves. – Thomas

She did not reveal she had HIV because she was afraid of stigma. Thomas believes if she had not feared people’s reaction and sought the church’s help, he could have helped resolve her immigration issues, and she would still be alive. If this accepting attitude is the norm, then pastors and churches could help reduce self-stigma.

However, interviewees also mention instances of enacted stigma against PLWH. For example, Jonas tells how church-goers thought one service user was evil when they discovered she was taking HIV medication. Sarah similarly describes how church members judged people who revealed they had HIV and prevented them from performing duties in church. These examples from WCS staff and service users represent more obvious instances of enacted stigma but the pastors generally describe less intentional instances such as

avoiding physical contact with HIV+ individuals. These examples of enacted stigma, while perhaps less common, lead people to fear disclosure and self-stigmatize. They hide their status because they fear that having HIV will define their identity within the community and take on a “master status” (Goffman 1963).

The African community in the UK may especially fear stigma and avoid the topic of HIV though HIV affects them more than the general population (Doyal and Anderson 2004). In Jonas’ experience, African service users hide their HIV status. He only knows one African service user who has spoken openly about her lived experience of HIV, and other Africans perceive her as tremendously brave because Africans are not typically vocal about HIV. Sarah also mentions that Africans avoid discussing HIV because they believe simply talking about HIV brings suspicion and stigma upon the person. She comments, “The moment I start speaking about it [HIV], everyone’s gonna wonder why I am speaking about it so much and everyone’s gonna start thinking I have HIV, so I’m not gonna talk about it.” In other words, Africans in Scotland fear people associate HIV with the entire African continent, so they distance themselves from HIV just as they want to distance themselves from generalizations and stereotypes attributed to Africans in the UK. They associate HIV with a “spoiled identity” (Goffman 1963) and therefore avoid the topic of HIV altogether. Other informants describe similar fears. Grace says Africans are afraid people will “pick them out of the multitude” and identify them as infected. Regardless of whether stigma is felt or enacted, it is a significant problem for PLWH in the African community in Scotland.

### **Why Does HIV Remain Stigmatized?**

Despite arguments that biomedicalization would normalize HIV, a “persistent sociality” (Moyer 2015) surrounds HIV, and it remains stigmatized. While HIV can be framed as a chronic disease, its infectious nature differentiates it from other diseases and makes it exceptional (Moyer and Hardon 2014; McGrath et al. 2014). However, while HIV is infectious, the likelihood of contracting HIV is low. In Scotland ARTs are free and readily accessible, so most PLWH never develop AIDS and have a normal life expectancy (HIVScotland 2017). HIV is stigmatized because of its physical properties and perpetual misinformation. More importantly, it is stigmatized because of what it represents and the meaning people attach to it.

All interviewees cited misinformation as a main reason for HIV stigma and discrimination. WCS staff described how many people are misinformed about the basics of HIV transmission, available treatment, and the difference between HIV and AIDS. Pastors also discuss the persistent belief that HIV can be transmitted through everyday physical contact and Grace even admits that she used to avoid PLWH until WCS corrected this misconception.

While HIV is treatable, people may be unaware of treatment options and immediately associate HIV with AIDS and subsequently death. For example:

“People that are not taught well about this sickness think if you HIV, you have AIDS, so obviously you are going to die.” – Henry

“Back in Africa, it’s [HIV] like a death sentence... Once you hear HIV, the next thing you’re thinking about is death.” – Samuel

Because HIV/AIDS is more prevalent in Africa, Africans in Scotland may have stronger associations between HIV and death. According to Ruth, because HIV is incurable and linked to imminent death, “nobody will want to relate to such people so closely. They wouldn’t want any intimate relationship,” and “the moment people know, they might...move away from them... and not want to relate[e] to them as they were before.” Researchers such as Comaroff (2007) and Niehaus (2007) also argue that associating HIV with death creates HIV stigma. Death is often described as a process rather than a single event where biological and social death are separate (Hertz 1907). Biological death typically comes before social death, but with AIDS, social death comes first (Niehaus 2007; Hardon et al. 2011), and people may avoid relating to someone perceived as socially dead. For example, Mattes (2012) found that PLWH in Tanzania are afraid others will not invest in them because they are dying which further contributes to self-stigmatization and non-disclosure.

As these reasons for HIV stigma are tied to misinformation – especially surrounding biological transmission and treatment – showing people a less threatening picture of life with HIV may challenge this negative perception. However, stigma is also tied to social meanings attributed to a biological virus. These reasons for stigma may not be directly acknowledged and imbedded within the framework of society. HIV can be especially poignant as a disease of modernity, globalization, urbanization, and development (Setel1999;Schoepf2001;Barnett&Whiteside2002;Beckman2013). It is stigmatized because it

brings up fear of foreignness, counters the biomedical narrative of progress, and disrupts moral and social order.

HIV represents fears of otherness that exist within a globalized world. The HIV virus is a foreign invader that breaks through supposedly secure barriers, secretly lies in wait, and then AIDS violently destroys a person. HIV also appears to be insidious as it 'attacks' the immune system, the bodies' metaphorical defense against 'invading' pathogens. Especially in the West, this parallels fears of foreignness (Sontag 1989) and fears of terrorism (Comaroff 2007). The pathogen is not only foreign but those who have HIV may be perceived as foreigners, literally as people from other nations or as foreign social classes within mainstream society. In Scotland, Africans are foreign immigrants and are often depicted as an invading society that threatens the Scottish national identity. As many already fear immigrants, adding the fear of foreign pathogens to the fear of foreign people compounds stigma, both felt and enacted.

HIV is stigmatizing because it contradicts the idea that humans can eradicate infectious diseases through science. HIV emerged suddenly at a time when people believed biomedicine would eliminate all infectious disease. Because it is incurable, it threatens the narrative of modernity and progress, that people can control the environment, 'conquer' disease, and prevent death. HIV, perhaps more than other diseases, disrupts the biomedical narrative of continual progress and represents a return to a premodern era where illnesses were incurable and deadly (Sontag 1989; Rosenbrock 2000).

HIV is associated with recklessness, promiscuity, and corrupt society, and is discussed in terms of morality (Dilger 2003; Becker and Geissler 2007; Beckman 2013). Early 'risk groups' lead people to associate HIV/AIDS with marginalized groups, (MSM, intravenous drug users, sex workers, and immigrants from Haiti) and frame risk in moral terms involving blame and shame (Schoepf 2001; Smith 2003; Thomas 2008; Hardon et al. 2011). Most informants suggest moralizing HIV increases stigma. When speculating why some pastors may be biased, Henry says the "reason why HIV has more...stigmatization is the fact people always think that the person was promiscuous. That is why you know he was infected with the virus." This attitude leads people to see HIV as an individual problem that may be deserved, which increases self-stigma among Africans in Scotland.

More recently HIV is associated with the African continent and with marginal groups and ethnic minorities in the West (Parker and Aggelton 2003). As HIV is associated with

groups that already face discrimination, it reinforces and reflects social prejudice (Schoepf 2001; Moyer and Hardon 2014). Because of publicized high-risk categories, HIV+ Africans can be associated with poverty, homosexuality, drug use, and prostitution, thus causing HIV+ Africans in Scotland to fear “layered” stigma (Swendeman et al. 2006). Moralization and stigmatization of HIV may be more pronounced in religious groups because churches typically discourage behavior associated with increased HIV risk and may condemn groups such as MSM, sex workers or intravenous drug users (Adogame 2007).

HIV also has meaning as a disease that disrupts social order, especially in the context of an increasingly developed and urban world. First, chronic illnesses are generally stigmatized because they disrupt the order of normal life. In the West, life is typically a series of predictable linear events from birth to death, and chronic conditions threaten this order (Scandlyn 2000). Furthermore, HIV specifically highlights uncertainty present in the changing modern world (Hardon and Dilger 2011) and threatens traditional social values. HIV risk is tied to increased mobility, migration, and the degradation of traditional kinship systems (Dilger 2003). The metaphors of HIV might be greater among African Christians in the Scotland because AIDS has ravaged many African countries, and through the process of immigration, Africans in Scotland have experienced a disruption in social order and traditional kinship.

## **Chapter Summary**

HIV-related stigma is a well-documented phenomenon that negatively impacts HIV+ Africans in Scotland. The reasons for HIV-related stigma are complex and often hidden. HIV is stigmatized because of misinformation, its association with death, and because it represents a metaphorical disruption. It disrupts the idea of biomedical progress and threatens social and moral order. These stigmatizing attitudes affect all PLWH, but may be especially pronounced among Africans in Scotland. HIV+ Africans fear stigma because of their disease and their position in Scottish society. They fear stigma from outside their community but also fear stigma within their community, especially if they are Pentecostal Christians as HIV can be stigmatized within these communities. In Chapter 2, I specifically discuss stigmatizing attitudes within the African faith community in Scotland, examining how the church both exacerbates and counteracts HIV stigma.

## **Chapter 2: HIV Awareness within the African Christian Framework**

While Chapter 1 examined the reasons behind HIV-related stigma, Chapter 2 focuses on stigma and self-stigma in the African Pentecostal church in Scotland. I examine stigma and ambivalent responses to HIV in the African Christian community in Scotland, identifying two contradictory Christian responses: one blames PLWH and sees them as sinners and the other emphasizes love and acceptance towards PLWH. While churches moralize and stigmatize HIV, they are also important venues to support PLWH. I describe Pentecostalism and outline barriers to addressing HIV within African Pentecostal churches in Scotland. Next, I look at pastors who engage with HIV in church and examine how these programs support pastors' understanding of Christianity and their role as faith leaders. My research generally shows a side of Christianity that focuses on love rather than one that blames sinners. However, messages within the church are often complicated and contradictory, revealing a messiness within how the church views HIV. Even pastors who view HIV awareness positively, may unintentionally moralize and accidentally stigmatize HIV. For HIV awareness programs to be effective within the church, people need to understand the framework of the Christian response and the multiple ways that African Christians engage with HIV.

### **The African Christian community in Scotland**

The pastors I interviewed were Pentecostal, a branch of protestant Christianity that interprets the Bible literally. Pentecostalism is one of the fastest growing Christian denominations, and while there is no established link, the rise of Pentecostalism parallels the rise of HIV/AIDS and many suggest a connection (Garner 2000; Dilger 2007; Paristau 2009). Pentecostals focus on preaching morals, abstinence, and fidelity, and emphasize individual choice and a personal relationship with God (Pew 2006). They believe people are born into sin, but can be "born again" and achieve salvation (Dilger 2007; Gusman 2008). Pentecostals also believe in enigmatic spiritual forces that endow powers such as divine healing and speaking in tongues (Pew 2006; Adogame 2007). Aliments such as infertility, drunkenness and HIV/AIDS are attributed to demonic spirituals and various rituals are in place to deal with these spirits (Adogame 2007). The Pentecostal church is attractive in the context of HIV/AIDS because it promises to heal AIDS, but also helps people understand the changing modern world (Dilger 2007). Thus, Pentecostalism may specifically help people

understand HIV/AIDS given HIV is a powerful metaphor for disruptions to social and moral order. Pentecostalism is a strong force within the African community in Scotland, and it is important to understand how Pentecostal beliefs shape the African faith community's response to HIV.

### **Ambivalent Message within the Christian Community**

Christians generally – and perhaps Pentecostals specifically – respond to HIV with deep ambivalence, and religion both positively and negatively impacts Africans living with HIV/AIDS in the UK (Chinouya and O'Keefe 2005; Adogame 2007; Waverley Care and NHS 2011). On the one hand, the church may reinforce stigma and impede efforts to prevent and treat HIV. For example, based on her experience in Manchester, Sarah suggests that stigma against HIV is worse within the church:

In the African church stuff is very negative... It's not having an awareness of what the issues are and this reckless preaching that turns people that are not well or have chronic conditions into victims and being sidelined...I don't think there's room for me in church as a woman with HIV. I wouldn't walk into a church and say, "well hello this is me and I've got HIV... Or maybe the safest thing to do would be just turn up and pretend that everything's fine and when they do recklessly preach around promiscuity and HIV just sit there and pretend that that's not me that you're talking about.

Alternatively, faith is important for many individuals with HIV and Sarah also discusses how faith helps her cope with HIV:

[Faith] helps me ... have focus, have direction... I need to have something that I believe in because you do have crazy days sometimes when you have a chronic condition, and you do feel lost... And having sense of spirituality, having a sense of faith does bring you back to yourself because you've got something to hold on.

As institutions, churches can provide support beyond that of medicine. For example, Pentecostal healing churches in East and Southern Africa give meaning, hope, and support to those with HIV/AIDS (Dilger 2007; Klaitz 2010). And both Henry and Thomas stress that churches should provide psychological, emotional, and spiritual support for PLWH.

While the church is important to HIV+ Africans in Scotland, pastors may be key to the religious response and can either reduce or exacerbate stigma within the faith community. Pastors control which messages are heard in church and are in a social position that garners respect from their congregation (Zirra and Zimunya 2015). In Sarah's opinion, pastors should

educate the church community because they “are in a position of power because a lot of people look up to them.” She believes that engaging faith leaders to talk about HIV is “paramount,” and pastors need to understand how their preaching affects the congregation. However, according to Claire, Jonas, and Sarah, pastors often fail to support PLWH and counter stigma.

### **Barriers to Addressing HIV in the African Church**

Because religion can positively impact PLWH, examining why churches and faith leaders resist addressing HIV can help Africans living with HIV in Scotland. Based on interviews, the main barriers and stigmatizing factors are as follows: moral messages in the church that blame individuals; a belief in faith healing that suggests medical treatment is a sign of doubt; a reluctance to discuss sex among Africans; or the view that churches do not need to address HIV. Individuals may hold some or none of these beliefs and it is important to understand the multi-faceted way faith shapes perceptions of HIV.

HIV risk is often individualized within the church, leading to individual blame and guilt for PLWH. Since HIV is sexually transmitted, sexually active people may have a higher risk. Religious organizations also condemn other high-risk groups such as MSM and intravenous drug users. Moral aspects may be especially pronounced among Pentecostals because they emphasize abstinence, faithfulness, and individual choice (Adogame 2007; Burchardt 2009; Van Dijk 2009). PLWH are then blamed for their individual actions that exposed them to the virus. In Namibia, people are seen as ‘wanting AIDS,’ and HIV is seen as self-inflicted, the result of disregarding a moral code (Thomas 2008). While all pastors claim to support PLWH, Claire, Jonas, and Sarah describe how religious groups see HIV as a curse and associate it with immorality, ‘promiscuity,’ and ‘recklessness.’ For instance, Sarah comments:

[HIV is] something you get through committing sin...When church pastors do speak about HIV it’s more around condemning the action that then lead you to get HIV so even if you didn’t get HIV through being promiscuous or you weren’t a prostitute, you definitely don’t want to turn up to your pastor and tell them you have HIV because they’ve got these preconceived assumptions around how people get HIV.

The Pentecostal belief in faith healing also shapes perceptions of HIV in African churches. In the Evangelical tradition, born-again Christians are saved from numerous evils, including HIV/AIDS (Dilger 2007; Gusman 2009). Therefore, being a member of a

Pentecostal church implies immunity through religious faith and promises to heal members (Burchardt 2010). A belief in faith healing could prevent people from seeking treatment because PLWH risk being judged as not faithful or virtuous enough by members of the church. Jonas cites an instance where WCS service users stopped HIV treatment because pastors explicitly told people treatment was not consistent with their faith in God. Henry also mentions some pastors, especially in Africa, declare they cannot be sick because of their faith. As a result, people who are sick do not disclose their status for fear of judgement. Sarah also knows people in Manchester who stopped taking their medication because they believed faith and prayer would cure HIV. She believes pastors unintentionally imply people should not seek treatment. Because of how pastors speak, church-goers “go away thinking that if I pray hard and read my Bible hard and attend church hard enough I don’t actually need to take my medication, and I’ll be fine.” If faith leaders think true believers cannot get HIV or will be cured through faith, they will not encourage HIV awareness in their church. However, even pastors who referenced a personal belief in supernatural healing insist people with HIV seek treatment.

While HIV is transmitted in various ways, talking about HIV means discussing sexual health, a topic often avoided within the church. Sarah suggests Africans may not discuss sex because “culturally it’s taboo to talk about sex so openly.” It becomes “awkward” for pastors to address HIV, especially in church, and Jonas suggests discussing sex at church may be especially problematic if children are around. A religious “culture of silence” surrounds sex generally, and this attitude can prevent people from talking about HIV or disclosing their status (Kendrick 2017). This attitude is observed in Africa (Heald 1995) and among Africans in the UK (Kesby et al. 2003).

While the interviewees were open to talking about HIV, some are uncomfortable talking about condom use. Pfeiffer (2004) and Parsitau (2009) have found that even African pastors who openly discuss HIV feel uncomfortable discussing condoms for fear of promoting prostitution and sexual promiscuity. WCS staff reported a similar experience with African faith leaders in Scotland where some pastors believe condoms promote promiscuous behavior. Pastors Ruth and Malcom oppose discussing condom use in church and are vague about their sexual health programming. When asked about discussing safe sex and condoms in the church, Ruth replies, “we don’t encourage sex before marriage, you understand.” While not in favor of discussing condoms, Ruth did acknowledge the

importance of testing, especially with engaged couples. Similarly, Malcolm said his church addresses sexual health through “teach[ing] them everything that needs to be taught to live a holy life and a Christian life,” suggesting he promotes abstinence and fidelity as the main ways to avoid HIV.

Both Malcolm and Ruth are part of the Redeemed Christian Church of God (RCCG), suggesting they have similar views of how faith leaders should respond to HIV. RCCG – which was founded in Nigeria and has spread to over 60 countries – is typical of indigenous African Pentecostal and charismatic churches that promotes messages of abstinence before marriage (Adogame2007). While a belief in abstinence does not exclude HIV awareness, it generally precludes in-depth messages of sexual health. And a reluctance to talk openly about sexual health can contribute to self-stigma among African Christians (Adogame2007; Szaflarski2013).

Other pastors openly discuss safe sex and sexual health. Grace encourages using condoms to protect oneself against HIV, and both Henry and Samuel admit preaching abstinence does not guarantee people only have sex within marriage. Henry admits that “you can’t rule it [premarital sex] out,” and Samuel acknowledges that “you can’t tell completely whether people abstain.” However, while Samuel adamantly discussed the importance of more inclusive messages of sexual health, he stumbled around the word sex suggesting that while he intellectually recognizes the importance of openly discussing sex, he is not innately comfortable with the topic.

Pastors may not intentionally reject sexual health but avoid talking about HIV because they are uncomfortable with the topic. Jonas suggests pastors may want to promote HIV but do not know how. Claire, Samuel, and Sarah suggest pastors fear looking foolish, offending, or isolating people within the church. As Baker et al. (2015) observed, pastors feel pressure to vocally condemn what they see as immoral acts. They strive to be moral examples to their congregation, avoid hypocrisy, and gain respect. In WCS’s experience, this fear may be unfounded as church members generally want information surrounding HIV. If pastors realize their congregation wants to discuss HIV, perhaps they will initiate conversations about HIV in church.

Finally, some pastors may not believe HIV is a significant problem in the UK, something to prioritize, or churches’ responsibility. Thomas, Henry, and Grace describe HIV as specifically important to their work as faith leaders but Samuel, Ruth, and Malcolm do

not think HIV an issue in their church. For example, Malcolm comments, “In the time past when there was no information, people get scared. But I don’t think anyone is scared about HIV just now or worried about HIV. So, it’s not an issue.” Similarly, Ruth seems indifferent to HIV advocacy and does not feel “any particular way” about working with WCS. These pastors are open to working with WCS but are less enthusiastic than other pastors. From this perspective, HIV could simply be unimportant instead of something to morally condemn or avoid. These pastors may neglect HIV in the UK because with effective treatment, people with HIV often look healthy so pastors may not realize the extent it affects the African community in Scotland.

Pastors also may not see HIV awareness as their responsibility, something to address in church, or HIV may not be a priority compared to other issues. Malcolm comments, “I don’t even see HIV as a big problem concerning someone who went to prison and coming out and hasn’t got a place to go... HIV is something information is all over the world. Go to the network. Type this in and get information.” This attitude might be especially prevalent within the African community in Scotland as people often deal with other issues such as immigration. In Sarah’s experience in Manchester, pastors believe HIV is something for the health sector, “not for the church.” Grace notes a similar tendency among faith leaders suggesting pastors think “[HIV] is not part of my ministry.” For awareness programs to work in church, pastors need to see HIV as an issue for their congregation and the churches’ responsibility.

### **How HIV Awareness is Consistent with Christian Beliefs**

There are barriers to HIV awareness in churches, but they might be less significant than previously assumed. For one, pastors may willingly, or even enthusiastically, work with organizations to promote HIV. Pfeiffer (2004) found Pentecostal pastors in Mozambique responded positively to HIV awareness programs and wanted to participate in prevention efforts. He shows the potential of collaborating with churches on HIV intervention and the danger of ignoring churches. Similarly, Adedoyin (2013) found African-American churches’ desire to ‘do good deeds’ towards everyone, including PLWH, outweighs barriers to discussing HIV. These studies, along with my research, suggest that religion and religious leaders support HIV advocacy programs if it fits within their Christian worldview.

While Pentecostals believe in the healing power of faith or moralize HIV, churches may officially accept PLWH. For example, the Redeemed Christian Church of God (RCCG) – the parent church Ruth and Malcolm belong to – promotes slogans such as “Everybody is at risk for HIV infection,” and “Jesus cares for all. Care for people living with HIV and AIDS.” (Adogame 2007:481). These messages counter associations of sin and HIV, encourage acceptance, and may mitigate stigma for PLWH within Pentecostal churches. Despite ambivalent messages, within the church, pastors are increasingly willing to engage with HIV. For example, Malcolm resisted working with WCS in the past, but is now open to promoting HIV in his church. He comments, “If it’s a project that will bring awareness... to the church, there’s no way we will not be part of it.” There might be less conflict between the church and HIV awareness because it aligns with Christian messages of compassion, acceptance, and caring for the sick and disenfranchised.

Pastors may willingly discuss HIV but perhaps secular non-profit or government organizations are reluctant to work with faith-based organizations. Pfeiffer (2004) found that many expatriate workers in Mozambique dismiss, misunderstand or are skeptical of the church. Secularized public health and development initiatives neglect the faith community’s response to HIV (Olivier and Smith 2016) because they believe religion is contrary to modernization and development (Epstein 2007). Secular westerners may especially dislike or mistrust charismatic and Pentecostal Christians, (Epstein 2007) and members of WCS staff commented that non-religious people often mistrust religion and religious leaders.

While those working with WCS discussed impediments to HIV awareness within the church, the pastors did not mention personal issues with HIV programs. In fact, Samuel, Ruth, Grace, and Henry were visibly surprised to learn other pastors resisted working with WCS. Many pastors see HIV awareness as their responsibility because they feel compelled to look after their congregation. For instance, Henry discusses his “responsibility as a faith leader” and believes faith leaders have an “obligation” to their congregation to spread scientific information around HIV. While Malcolm has not worked with WCS, he, too, acknowledges the pastors’ responsibility towards their congregation’s health: “Your [a pastor’s] first duty is to look after the congregation. We call them sheep. You are the Shepherd... Every member who attends the church, their well-being is very important to us.” As part of their responsibility, pastors also mentioned the need to set an example for their congregation through openly discussing HIV. For instance:

“I did it [HIV test] first so that I can encourage them to come. ‘Oh, pastor has done it.’ So everyone come.” – Ruth

“If I become positive today, I won’t hide it. I will tell them also that as a leader that I’m doing that. And once they see you, the leader, taking a step... they all follow.” – Grace

Churches tend to moralize and individualize HIV. While it is not realistic to suggest churches forgo moralizing, churches may embrace HIV awareness if it fits within the Christian message of acceptance, non-judgement and forgiveness. As Malcolm insists, “Christianity is not a culture” but “a way of life.” For pastors and many church-goers, social actions must align with faith as it shapes their worldview. For example, Pentecostals may believe sexual intercourse has a moral dimension and is governed by individual obligation and responsibility. HIV advocacy organizations will not change the church’s views on sexual behavior, but can work within this framework by highlighting how HIV awareness fits within the African Christian worldview.

HIV awareness fits in the Bible and is consistent with Christian messages of love and acceptance. Multiple pastors emphasize that healing and medicine are in the Bible. The pastors believe Jesus would support PLWH as he cared for the sick and specifically showed compassion to lepers who were outcast from society. Since love and acceptance are central to Christianity, pastors suggest Christians should support PLWH:

“The Bible we preach is more centered on love so that... when one is going through this particular period [HIV], that is when he needs the other people the most to show him love and bring encouragement his way.” – Henry

“We need to give them psychological help on top of other medical efforts so that we don’t stigmatize them. We show them love. We believe they are part of the society. We empathize with them and that begins from the church.” – Thomas

“As far as HIV is concerned, we are supposed to embrace them,... love them,... [and] care for them. That is what my Bible says ... which means the person comes and says this [HIV] is my problem, I should see in the way of Christ. Simple.” – Malcolm

From this perspective, HIV is part of the church’s responsibility and commitment to a Christian ethic, and the church should not stigmatize HIV. Communities that encourage love and acceptance are shown to reduce HIV-related stigma, (Campbell, Skovdal and Gibb2011) so if the message is common in African churches in Scotland, stigma within the African community may decrease.

Furthermore, while Pastors Grace, Henry, Thomas, and Malcolm express a belief in faith healing, they emphasize that faith does not replace medical attention. They stress physical and spiritual healing are separate and lament that people refuse treatment because of faith. Thomas explains, “So many things that people spiritualize, has little or nothing to do with spirituality” and believes people should take advantage of treatment in Scotland. They hold faith should not prevent treatment and medicine:

“Faith works together with medicine... You can’t just say I bind the spirit of high blood pressure or HIV/AIDS without... getting any treatment. It will gradually destroy the person.” – Grace

“Our perspective is that people who are affected, because of the medication they are put on, they are still living really good, and they have a very long life span.” – Henry

“You have to approach things in a practical way, to let people know where to draw the line between... what I can prevent or what prayer can prevent... People need to understand the line between faith and health,... know where science is important and where faith comes in.” – Thomas

In short, they believe spirituality and biomedical treatment coexist and inhabit different realms. This belief exists in other contexts Dilger (2007) observes how Neo-Pentecostal Christians in urban Tanzania see no conflict between spiritual and biomedical healing. If this is the case, HIV charities could approach faith leaders by emphasizing the links between faith, health and HIV.

### **Unintentionally Moralizing Message**

While pastors openly talk about supporting PLWH, they may feel differently about people who get HIV through sex and those who contract HIV other ways. When considering correcting misinformation, some pastors emphasize it is not only through being promiscuous and highlight different ways people get HIV. This emphasis suggests a hierarchy of HIV stigma. It implies that some contracted HIV innocently, while others are responsible for their diagnosis and deserve blame. For example, when asked about Biblical responses to HIV, Ruth emphasizes that HIV is contracted in ways other than sex. She says: “Using scripture...when it comes to HIV anything could have caused it. Might not be totally intercourse. It could be through blood or whatever.” This statement suggests Christians might accept those who contract HIV through blood transfusions, for instance, but perhaps

negatively view those who get HIV through sex. Instead of removing stigma, it simply narrows the scope of who is blamed.

When describing stigma, Henry implies a similar distinction, suggesting people have a “misconception,” and think ““he was probably promiscuous that is why he contracted it [HIV].”” But he insists having HIV does not “make the person an evil person because it comes here so many ways.” He links stigma to information about transmission and suggests education helps people “identify themselves with those who have contracted [HIV]” and realize “maybe it did not come through sexual relations.” Later, he returns to the same idea, saying:

[The] reason why HIV has more of stigmatization is the fact people always think that the person was promiscuous. That is why you know he was infected with the virus. But... if people are conciensized about it, then they will know that maybe that person is innocent... People could be promiscuous [and HIV] probably came with that. And some are also born with it. They are innocent. Some probably got it from unsterilized instruments. So yes, there is a certain percentage of...HIV patients that got it through being promiscuous. You can't rule out that fact. But others are completely innocent.

Henry sees HIV awareness as part of his responsibility as a faith leader, emphasizes love within the church, and is adamantly against stigmatizing HIV. These views suggest the distinction is subconscious. When Sarah talked about stigmatizing attitudes from faith leaders she says, “I think there's a direct message there, and I don't think it's intentional.” Perhaps this is an example of an unintentional message. And even Sarah may differentiate between the ways people get HIV. She describes insensitivity and ignorance around how people think HIV is transmitted and comments, “A lot of pastors that don't understand that I could be born with disease, and it's not *necessarily* about committing sin” (my emphasis).

Alternatively, Thomas specifically emphasizes that churches should remain supportive even if someone did get HIV through sex. He insists having HIV “doesn't mean that they are morally loose or because they are promiscuous... and those that don't have it are smarter and more pious.” He also says: “I believe that people are getting more enlightened, and HIV/AIDS as an issue is finding its place of acceptance in the faith community. It is not just because of x-y-z reasons that people contact that, and even at that, the thing is not to condemn...It's just to offer support and help.” This openness to accepting PLWH even if communicated sexually is more progressive. Thomas was part of the Faith and Health Agenda since the beginning and is the most direct about supporting PLWH regardless of

how it was transmitted. He emphasizes the church's social role beyond solely promoting faith, suggesting a correlation between supporting PLWH and an expanded view of the church's role in society. While it is important to recognize different modes of HIV transmission, Jonas reminds pastors, "People don't make applications to get HIV. And even if they did, it's not a death sentence."

In contrast, Malcolm, says he would support PLWH, but also places the most importance on how people contract HIV. He says:

The Bible will definitely not be against anybody suffering HIV...What brought about this disease?... If you sin, there is consequences for sin... This thing is because of sin. Sin of promiscuity... We will not take the hammer to smash you but we will let you know that this is the reason why it happened... Every sin you committed, and you acknowledge it, you are forgiven, but the scar remains... If you come into the church, you have AIDS, you are welcome... We have treatment. It's not something anybody should be scared about as long as you don't go back to do the sins.

While Malcolm insists HIV is like other diseases and is something people should seek treatment for, he also supports a moralizing discourse which implies blame. Again, the idea of reckless, unintentional preaching is there. In a service at Malcolm's church, the sermon was about being a good father and the individual work needed to be a good parent. The sermon said people who put in individual work and pray will have positive outcomes, suggesting an individual responsibility to solve complex problems. While directly about parenting, the sermon could lead someone who is HIV+ and devoutly religious to blame themselves and attribute their disease to not praying or working hard enough. If those who get HIV from sexual intercourse remain stigmatized within the African church, all HIV+ Africans in Scotland may self-stigmatize and fear being blamed for the virus.

## **Chapter Summary**

In this chapter, I examine the multi-faceted and often contradictory ways African Pentecostal Christians address HIV in Scotland. My informants referenced pastors who reject HIV programming, but the pastors I spoke with either specifically support WCS or allow WCS to share information in their church. Currently, many African faith leaders in Scotland see HIV as their responsibility and want to counteract stigma within the community. Despite an outward openness to HIV advocacy, HIV may be unintentionally stigmatized. There may be a disconnect between what pastors think and how church-goers interpret the message.

However, despite barriers, African faith leaders in Scotland are more receptive to HIV awareness than in the past. This openness towards HIV is a relatively new phenomenon and may represent a shift in how the African Christian community views HIV, which I will further address in Chapter 3.

### Chapter 3: The Shift and Suggestions for Moving Forward

Recently, many pastors who WCS never thought they would work with are discussing HIV in church. Following my discussions of stigma and ambivalence within the African church in Scotland, I suggest reasons behind this shift. First, increased information and building a relationship with faith leaders may encourage pastors to work with WCS. Shifts within the African Pentecostal church generally, or specifically within the context of Scotland, may equally explain the change. While informants emphasize education, previous research suggests information alone is not enough to shape actions. For information to influence actions, it must align with existing worldviews, specifically Pentecostal Christianity which informs pastors in my study. I acknowledge the importance of working within the framework of Christianity and contend that the African Christian response to HIV in Scotland is often messy and non-straightforward.

#### Information and Education

My informants emphasize that education reduces HIV-related stigma, decreases fear of infection, and encourages people to empathize with PLWH. Both Jonas and Claire highlight the importance of education and find faith leaders work with WCS if they realize Africans have greater HIV-risk than the general Scottish population. The pastors similarly emphasize education. For example, Grace comments:

I keep saying that we need more information to enlighten people so that they can understand that what we were taught before was wrong. The picture that was shown to us before was a wrong picture about people with HIV/AIDS... This is what our people should know: that knowledge is power. – Grace

Furthermore, how information is presented may be as important as the message itself. When describing his interactions with pastors, Jonas emphasizes patience, trust, and developing relationships. While Jonas cannot know why pastors changed their minds, he suspects WCS's repeated messages and building relationships facilitated interactions with churches. And both Thomas and Malcolm – pastors who may represent outlying opinions – discuss the importance of a relationship with WCS. For example:

“As a church, we don't have an issue working with WCS... They genuinely want to help people... There isn't a hidden agenda... Over the years the partnership has been of mutual benefit, mutual respect.” – Thomas

“If there is relationship in place and if there is anything...concerning that area [HIV]... then Waverley can come in to help.” – Malcolm

Perhaps pastors needed time to build a trusting relationship and that is why WCS is seeing a shift after years of resistance. As a result, charity organizations should develop awareness programs as part of a conversation with churches instead of presenting information from the top down.

Working with Pentecostal churches to promote condom use in Mozambique, Pfeiffer (2004) suggesting that establishing long-term relationships with congregations is the most important factor to promote HIV advocacy. The organization succeeded in gaining support from pastors through “careful and patient engagement with the churches,” avoiding “pre-packed messages,” and collaborating with churches to understand what Christians sees as acceptable (Pfeiffer2004:93). As Feldman (2003) argues, how HIV awareness is presented is more important than the actual message. In the context of Namibia, Thomas (2008) argues that effective HIV prevention programs should avoid generalities and be locally relevant. In Scotland, HIV charities should establish trust and long-term communication with African faith communities instead of imposing pre-packed messages.

While education is important, it might be insufficient. Moyer and Hardon (2014) describe how HIV-related stigma persists even when stigma is challenged through education and awareness. Smith (2003) similarly notes a disparity between knowing about HIV and taking protective measures in Nigeria. I, like other anthropologists, (Smith2003;Burachardt 2009;Van Dijk2009) argue that education and medical facts are not enough to change people’s behaviors, which are tied to socioeconomic and cultural factors. Ultimately, African faith leaders in Scotland engage with HIV if it aligns with their faith. Organizations like WCS should work within the social frame of the church and address HIV specifically through faith.

### **Shift in Pentecostal Engagement with HIV**

Claire, Jonas and Thomas have noticed a shift in how African faith leaders in Scotland engage with HIV and suggest they are now more openly to HIV awareness. This shift among faith leaders in Scotland may reflect a general change in how churches engage with HIV. From the late 1980s through 1990s, Christian responses to HIV were generally negative and tied HIV to God’s judgement (Nicholson1996). But in the early 2000s, Pentecostal churches

began to revise their stand on HIV/AIDS (Dube 2003; Epstein 2007; Gusman 2008; Paristau 2009). Pentecostals initially associated HIV with sin and immorality, but churches re-evaluated their position when the pandemic began to affect those who were 'born-again' (Paristau 2009; Prince, Denis and Van Dijk 2009). As Robbins (2007) critiques, anthropologists often emphasize the continuities of Christianity and disregard the dynamic nature of religious organizations. In reality, religious organizations adjust to changing situations, and the HIV/AIDS pandemic has encouraged increased social engagement among Pentecostals (Gusman 2008; Paristau 2009). Paristau (2009) describes how forty Pentecostal church leaders meet in the African Rift Valley in 2002 and agreed to address the HIV/AIDS pandemic and associated stigma. This meeting perpetuated the shift from non-engagement to engagement. Since 2002, many large African Pentecostal churches have established HIV/AIDS ministries or departments, and church sermons increasingly address HIV (Paristau 2009; Prince, Denis and Van Dijk 2009). However, in keeping with Pentecostal traditions, morality, abstinence, and fidelity are discussed as the main ways to fight HIV (Gusman 2008; Paristau 2009). Overall, congregations are becoming less judgmental, more compassionate, and more willing to participate in programs to decrease HIV stigma (Paristau 2009).

Attanasi (2008) examined why some Pentecostal Christians prioritize AIDS-related ministry and how Pentecostal faith shapes the church's response to AIDS. She found Pentecostals who were exclusively concerned with the spiritual world and prioritized evangelism were not directly involved in HIV/AIDS efforts and linked HIV to individual morality. In contrast, Pentecostals who saw the physical world as crucial to their faith thought HIV/AIDS should be addressed in the church. These differing views of the churches' mission could explain why some African pastors in the UK discuss HIV while others do not. Sarah experienced negativity about HIV in church and repeatedly complained that African churches were not involved in the community. She comments:

The African church is about their own benefit... And that is a problem with the black church... It's a lack of understanding of what ministry is... You need to be out in the community doing stuff.

While some churches do not prioritize social agendas, others emphasize a responsibility towards social agendas even if they are not spiritual. The HIV/AIDS pandemic has perpetuated a theological shift where Pentecostal churches in East Africa increasingly engage with social issues as part of a general shift from "otherworldly" to "this-worldly"

(Gusman 2008; Paristau 2009). This change could help explain pastors' increasingly positive response to WCS. For example, Samuel emphasizes the churches' "social responsibility" and mentions that his church works with social organizations such as prison ministries and soup kitchens. When describing his church's relationship with WCS, he calls HIV awareness "a noble cause" and says, "From the perspective of the social aim of the church... we have a responsibility to the community and to congregants... We create that environment for people to learn and to know about social issues, even if they're not spiritual." Thomas also believes churches should engage with community and social issues beyond faith, commenting that faith leaders should acknowledge "that not everything's got to do with faith or that should be spiritualized. Some things are just social issues." He suggests community engagement may even be more important than social agendas, saying:

I've been able to learn a lot of things, to see ministry beyond the four walls of the church, to see that you can still do ministry in the community, the wider society, without people necessarily coming to sit on the bench in the church... The position that the church takes [is] that we should be visible in joining with people, rather than just quoting the Bible to them.

His view of the church's mission has expanded over time and may be a response to shifts within Pentecostal churches or living in Scotland. Perhaps Thomas worked with WCS since the beginning of the Faith and Health Agenda because he believes his church should be involved in wider society.

Malcolm, too, believes the church should have a social agenda and is "not just preaching and preaching," but prioritizes spirituality above all else. He emphasizes that social awareness agendas must directly align with faith and the Bible. While Thomas mentions engaging with the community in ways that are not spiritual, Malcolm stresses that community issues must enhance people's spiritual lives and is perhaps more skeptical of charity organizations' motivations. A willingness to engage with social issues beyond spirituality and how pastors see the churches' role might be a significant reason why some pastors address HIV while others do not.

Prioritizing social agendas may be a pragmatic response to living in an increasingly secularized Scotland. As Robbins (2007) argues, churches adapt and respond to changing contexts. As African pastors realize people in Scotland are less likely to attend church than in African countries, they may fear losing members. For example, Thomas talks about the difference between the church in Africa and in Scotland:

The people [in Africa] are already wired for faith. And faith has become a central part of their life... Not by choice but by default in the sense that there's a lot of poverty in Africa... There is no social infrastructure so people hang on to God, hang on to faith. So pastors don't have to do much to persuade people to come to faith. People [in Africa] are already looking towards faith.

Malcolm comments that religion is a choice, and many churches in Scotland are currently empty. Thus, pastors may be receptive to adapting their message. As churches are institutions, they often adapt to suit their self-interest, and if church-goers desire more community involvement, pastors may respond. Churches may shift their view to attract people and counteract the decreased predisposition to religion in the West.

WCS service users who consider themselves Christian have stopped going to church because they feel pastors and churches do not have social agendas or support PLWH. Sarah, for example, stopped going to church because she felt uncomfortable being HIV+ in church and wanted the church to be more involved in the community. She says:

It's [HIV] our problem and within the black community. And churches do need to do a lot more actually. And I do get that maybe it's an uncomfortable issue to talk about but maybe something you'd rather you pretend is not there, but that doesn't help the situation... It fuels the stigma, and it fuels ignorance, and it doesn't help when people pretend there isn't an issue and skirt around the issue or victimize [people with HIV] ...it does push people out of the church, it does push people far away from faith.

Jonas describes how one woman left Malcolm's church because she told him community involvement was important for her, and when he did not listen, she went to Henry's church instead. Perhaps Malcolm is more receptive to working with WCS because he fears losing members, especially in a more secular setting like Scotland. If members desire social agendas, especially focusing on HIV, and other pastors attract members through social agendas, pastors may adapt their message.

Churches might also discuss HIV more openly because of cultural shifts in the context of Scotland. Scotland is more secular than Africa and religious views of what is moral may differ. For example, pastors in Scotland may be more accepting of MSM and discussing sexual health. Jonas notes a shift towards pastors adapting their message, and he is having different conversations with people than in the past. Sarah also suggests that the African churches' perspective will change and believes people in Scotland will be more accepting of HIV:

It's that cultural mindset. But it's about breaking cultural mindsets as well... we're living in Europe. You need to open up your mind a bit, change things around. Not everything can revolve around culture because actually culture can be quite damaging. You're so stuck in culture you get left behind... and nobody wants to talk about it because it's taboo... People do need to be practical.

She suggests that people are changing their views in Scotland, and while people initially hesitate to discuss HIV, they may come to see talking about HIV as normal, especially if pastors take the initiative.

### **Chapter Summary**

Recently more faith leaders support WCS and promote HIV awareness. While pastors and WCS staff cite information as the main reason for this shift, the reality may be more complicated as people only respond to information that fits within their worldview. In other words, African faith leaders in Scotland engage with WCS if they see it as consistent with their theological beliefs. The change could be due to WCS's commitment to building relationships with churches, or to an increasingly social engagement with HIV/AIDS within Pentecostal churches. In Scotland, faith leaders may feel pressure to adapt their message as they are aware of decreasing church attendance. This shift may be a global shift, a local shift in response to living in an increasingly secular Scotland, or a combination. If WCS continues to build relationships with faith leaders and emphasizes how HIV awareness fits within Pentecostal beliefs, I believe they can work with faith leaders to reduce HIV-related stigma and self-stigma among Africans in Scotland.

## Conclusion

Through personal interviews, I examined why pastors partner with WCS to promote HIV awareness and reduce stigma. WCS has identified the church and faith leaders as significant forces to promote HIV awareness and reduce HIV stigma within the African community in Scotland. After meeting with initial resistance, many pastors now work with WCS to address HIV in church. By understanding this shift and how pastors see HIV as an issue to be addressed in church, WCS can improve their relationship with pastors, and, in turn, improve health for the African community in Scotland.

African churches and faith leaders can either reduce or increase HIV-related stigma and discrimination. As HIV is treatable, stigma may be the most significant issues for Africans living in Scotland. In Chapter 1, I argue stigma is due to misinformation and the continuing metaphorical associations of HIV, especially those tied to uncertainty and the changing modern world. In Chapter 2, I argue how African Christian response to HIV in Scotland is messy and contradictory. However, I, like other anthropologists, (e.g. Pfeiffer 2004; Dilger 2007; Burchardt 2009; Van Dijk 2009; Klaitz 2010) suggests religion, the church, and faith leaders can decrease HIV-related stigma. In Chapter 3, I specifically examine the shift in how African faith leaders in Scotland respond to WCS. I look at shifting views within the church and building relationships with faith leaders as key for the change. Following other anthropologists (Feldman 2003; Burchardt 2009; Van Dijk 2009; Moyer and Hardon 2014), I argue that HIV education, while important, is not sufficient. Instead, HIV awareness programs must make sense within their context and be embedded within larger social frameworks. In the context of the African faith community in Scotland, HIV awareness should fit within the framework of faith. If HIV awareness is thought to align with Christian beliefs and the churches' ethos of social awareness, churches will be open to working with WCS.

Overall, I am optimistic about the future success of WCS's Faith and Health Agenda. WCS's commitment to understanding how faith shapes people's view of HIV and to building relationships with churches enables faith leaders to advocate for HIV and combat HIV-related stigma. While my research developed a deeper understanding of how Africans faith leaders in Scotland understand HIV, further research could provide more information.

Interviewing pastors from Southern and Eastern Africa could explore possible differences in how African churches in Scotland engage with HIV. Future researchers could also talk to church-goers about their experiences with HIV in church. Seeing how church-goers (both HIV+ and HIV-) interpret pastors' views of HIV could establish if there is a disconnect between what pastors say and members hear. Understanding how people interpret sermons and church messages could help resolve unintentional stigmatization of HIV within the church. WCS's method of building a collaborative relationship with faith leaders and addressing HIV awareness in terms of faith has encouraged pastors to reduce HIV stigma, and I predict that more faith leaders will engage with WCS in the future.

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## **Appendix A: Interview Information**

### **Chronological Interviews:**

Jonas; 2, May, 2017, Personal interview. Waverley Care office.

Ruth; 9, May, 2017, Personal interview. Church office.

Samuel; 11, May, 2017, Personal interview. Church office.

Claire; 26, May, 2017, Personal interview. Waverley Care office

Henry; 30, May, 2017, Personal interview. Church office.

Grace; 4, June, 2017, Personal interview. Personal residence.

Sarah; 7, June, 2017, Personal interview. Personal residence.

Thomas; 16, June, 2017, Personal interview. Church office.

Malcolm; 22, June, 2017, Personal interview. Church office.

## Appendix B: Interview Questions

### Interview Format

The interview will be semi-structured. The following represents a list of potential questions for faith leaders that will guide the interview, but the actual interview will not necessarily follow this guide. I want the interview to be conversational and will not strictly adhering to the questions below.

### General questions

- How long have you been at X church?
- How did you decide to become a pastor? What were your motivations for becoming a pastor?
- What do you find rewarding about being a pastor? What do you find difficult?
- How do you see your role as a pastor? What are the responsibilities of a pastor?
- In your opinion, what is the most important function of the church?

### Relationship with Waverley Care

- What is your relationship with Waverley Care Scotland? How long have worked with Waverley Care?
- How did you find out about Waverley Care Scotland?
- What do you think of Waverley Care's work in general? The African Health Project? The Faith and Health Agenda?
- What is your perception of the organization? What do you think Waverley Care has done well? What could they improve?
- How did you think about HIV before Waverley Care approached you?
- What did you take away from your interaction with Waverley Care?

### Thoughts on HIV and sexual health

- What do you know about HIV/AIDS and other blood born viruses?
- How do you perceive HIV/AIDS?
- Do you think HIV is an issue for African people living in Scotland? Why? Why not?
- How important is HIV for your congregation?
- If you don't think HIV is an example of something important to talk about, what do you see as important?
- What do you think is the Biblical view on HIV? Does the Bible say anything about sexual health?
- How should African Christians respond to HIV?
- What is the responsibility of the church toward the health of its members?
- What is your role as a pastor and how would HIV awareness fit in with that perceived role?
- Should issues of HIV and sexual health be addressed in church? If yes, should they be addressed in front of the whole congregation or through individual conversations? Would you feel comfortable talking about HIV in church? About sexual health?
- Have members of your church talked to you about HIV or sexual health? If yes, how was that interaction?

- Is it appropriate to use condoms? Can you encourage your church members to use condoms?
- What ways do you think your church could promote sexual health and HIV awareness? How do you think this topic would be perceived?

### **Thoughts on Stigma**

- What makes HIV different than other illnesses?
- Do there is think HIV stigma is a problem?
- If yes, why do you think this stigma exists and persists? Where does it come from?
- Do you think the stigma exists within the African Christian community? The wider community in Scotland? Or does self-stigma exist on the part of the individual?
- To what extent, if any, does the church contribute to stigma? How do you think the church could help reduce stigma?
- Do you think church members would feel comfortable talking to you about HIV? Why or why not?
- If you knew someone was HIV positive, would you reach out to them, or would you wait for them to approach you?
- Do you think the church should take part in challenging HIV stigma? How?
- As a pastor, how much responsibility do you have to address issues of HIV and HIV stigma?
- To what extent is HIV an individual issue and to what extent is it a social/community responsibility?
- As a Pastor will you ordain an HIV positive person for any leadership position in your church?

## Appendix C: Project Information for Interviewees

Information about the Project:

My name is Caroline Gold, and I am a MSc student at the University of Edinburgh. For my dissertation, I am working with Waverley Care, which is a HIV/Hepatitis charity based in Scotland. Waverley Care promotes HIV awareness through encouraging testing as well as providing support and striving to reduce stigma for HIV positive individuals.

I am working on a project with the African Health team to look at the role faith leaders and the African Christian church in Scotland plays in HIV awareness and stigma reduction. I will research the following question: “What contribution does partnership working with faith leaders make in reducing HIV stigma within African communities and HIV positive Africans’ self-stigma?”

While many people do not see HIV as a major issue in the UK, HIV is on the rise in the UK, disproportionally affecting black Africans. HIV creates various physical, emotional, and social struggles, especially when the sufferer is already part of a marginalized group. Though HIV is less stigmatized than in the past, much stigma still surrounds HIV.

We believe HIV awareness through the church would be effective because churches are already spaces for social action, have access to a large community that may otherwise be hard to reach, and meet regularly. As people tend to put a lot of trust in their faith-leaders, we believe that faith-leaders can act as gate-keepers to their congregations. While some faith-leaders have been welcoming to a partnership with Waverley Care, others have been more resistant. By participating in this interview, I hope to learn more about how you see HIV as part of your work as a faith-leader, your relationship with Waverley Care, and how you and your church can help promote HIV awareness and reduce stigma.

Thank you for taking time to participate in this interview. If you have any questions or concerns, please do not hesitate to contact: [carolinegold@gmail.com](mailto:carolinegold@gmail.com)