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Examining Provider Perception of Loneliness in People Living with HIV (PLWH): An Emphasis  
on Social Environments Affecting Lived Experiences

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## ABSTRACT

Loneliness is a universal phenomenon; however, it is experienced differently based on one's identities and specific country context (Bekhet et al., 2008; Masi et al., 2011). Loneliness is relevant to the study of human immunodeficiency virus (HIV) because people living with HIV (PLWH) experience stigma-related social rejection, oftentimes associated with negative effects, including lowering adherence to treatment to control their infection (Ratanashevorn & Brown, 2021; Rokach, 2014). The purpose of this study is to present primary data collected through interviewing health professionals, accompanied by an in-depth literature review, to learn about provider perception of loneliness in PLWH in two different areas of the world: Dakar, Senegal and Central Pennsylvania (PA), United States. This insight will allow a greater understanding of reported and observed loneliness in PLWH by providers, specifically focusing on the subset of the population engaged in care. It will show how feelings of loneliness are perceived to still exist despite contact with the medical community, how stigma and different social environments are perceived to impact this experience, and what interventions exist. Through performing interviews in two different areas of the world, the differences in providers' perspectives on the lived experience of loneliness in this minoritized group will shine through. Examining this topic through a health professional's perspective, in a qualitative manner, allows a variety of lived experiences as explained by health professionals to be shared and provide greater depth than a survey.

The primary data collection involved conducting 11 semi-structured interviews with health professionals working with PLWH in Dakar and 12 throughout Central PA. After findings in Senegal indicated the importance of viewing these results through an intersectional lens, the

Central PA interviews dissected the lived experiences of two intersecting identities with HIV status: LGBTQ and people who inject drugs (PWID). Three major themes emerged from this data in Dakar: 1.) non-acceptance; 2.) cascade of care; 3.) fear of disclosing status. These findings both reflect the multidimensionality of loneliness, highlight its impact at the personal level, and show the influence of social and political factors. Four major themes emerged from this data in Central PA: 1.) internal processing; 2.) trauma; 3.) healthcare system; 4.) relationships. Here, the impact on the individual, as well as how health professionals respond, is emphasized, as well as how key population differences between LGBTQ and PWID affect this experience. Overall, the findings from this international comparative study show that social interaction, emotional support, societal stigma, and acceptance were commonly identified perceived factors by providers that impacted the lived experiences of their clients living with HIV. These findings ultimately show how policies exacerbate feelings of loneliness, but these interviews with providers point to how they are perceived to work in conjunction with the social environment.

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Although the organization was shut down in July of 2019 due to the public finding out about how the organization fights for rights for the LGBTQ community, and all my colleagues



have had to flee the country, their work was not done in vain. I saw every day for six weeks how their commitment to their clients, those living with HIV, the LGBTQ community, and sex workers, created connections and lifelong friendships within the community. It is important to highlight their work and bravery and share their story, as it further emphasizes the cultural context and mindset one must have when thinking about challenges that are faced on the ground when developing solutions to fighting loneliness. Fortunately, all of them are doing well and are safe where they have relocated, and I cannot wait to visit them upon graduation. If you, the reader, takes one thing away from this thesis, it is that emotional connections and support are important predictors of everyone's well-being and lifespan, but particularly those of stigmatized populations. If you know that you are part of someone's support network, please recognize this and understand the importance of maintaining such connections.

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## **Chapter 1**

### **Introduction**

#### **Loneliness in Stigmatized Groups**

Loneliness, or perceived social isolation, is defined as the experience of a difference between what is desired in social relationships and what is present, particularly emphasizing one's perception of isolation (Donovan et al., 2016; Masi et al., 2011; Peplau & Perlman, 1982). To further expand upon this, it is the idea that the relationships and connections one has do not meet their needs (De Jong Gierveld, 1998). As a result, individuals often experience psychological distress due to this perceived isolation, lack of satisfying relationships, and rejection (Rook, 1984; Young, 1982). Moreover, it is possible to be around others but still experience feelings of loneliness, as feeling loneliness is different than physically being alone and can be influenced by other factors outside of interpersonal relationships (Rokach & Brock, 1997; Rook, 1984). This points to the multidimensionality of loneliness: how someone perceives isolation and disconnection from others – in social, emotional, and/or existential manners – in their lives (De Jong Gierveld, 1998; Donovan et al., 2016; Masi et al., 2011; Rokach, 2004; Rokach, 2012; Rokach & Heather, 1997).

Branching off this subjective nature of loneliness, however, physically being alone could lead to loneliness if it is prolonged and not wanted, particularly if feelings of rejection or lack of belongingness start to develop (Ernst & Cacioppo, 1999; Peplau & Perlman, 1982; Wheeler et al., 1983). When these feelings of loneliness arise from such experiences – including societal rejection, lack of belongingness, or lack of meaning in life – they are associated with poor health

outcomes, including increased mortality rates (Cacioppo et al., 2015; Cornwell & Waite, 2009).

Although the study that will be discussed in this paper indirectly explored the impacts of loneliness in a stigmatized group (PLWH) through interviewing providers who work with the population, it is important to obtain a comprehensive understanding of loneliness in the population they are describing, since they are sharing their insight and perception of such experiences.

Social loneliness is defined as whether one feels welcomed by a group of people and belongs to a social group (Larsson et al., 2019; Rook & Peplau, 1982). This really touches on the belonging aspect mentioned above and is particularly relevant to the study of socially stigmatized groups both in terms of how one experiences feelings of loneliness as well as how stigma affects such experiences (Rokach, 2014). According to Rokach (2014), when studying minoritized or stigmatized groups, the emotional or interpersonal side of loneliness as well as the existential side of loneliness are common dimensions of how these groups experience loneliness. These types of loneliness include people feeling that they do not have someone close to them with whom they can share thoughts and build trust, feeling a lack of meaning in life, feeling uncertainty as to where they fit in the world, or feeling a lack of purpose (Larsson et al., 2019; Rook & Peplau, 1982).

The reason why this topic of study is so important is because of how feelings of loneliness are linked to negative health outcomes. On a biological level, loneliness is associated with negative health concerns including increased cortisol levels, blood pressure, and inflammation, all of which increase the risk of developing chronic illnesses and are associated with early mortality (Hawkey et al., 2009; Holt-Lunstad et al., 2015; Russell et al., 1984; Steptoe et al., 2013). Loneliness is also connected to biophysical processes, including decreased

immune regulation (low CD4 cell count) which is directly linked to worsening of the human immunodeficiency virus (HIV) condition (Rendina et al., 2019). These are potential mechanisms that link the potential risks associated with loneliness to other health concerns in this target sample of people living with HIV (PLWH).

When looking at how these feelings of loneliness impact stigmatized groups (i.e., PLWH) on a behavioral level, there is an increase in poorer relationships with others, increase in reported levels of depression, decreased quality of life, increased substance use, and overall increased rates of mortality (Greene et al., 2018; Hawkey et al., 2009; Holt-Lunstad et al., 2015; Russell et al., 1984; Steptoe et al., 2013). To further expand on the depression aspect, Ypsilanti et al. (2019) found that those who were lonely and expressed depressive symptoms more often reported feelings of self-disgust and poor emotional regulation. Moreover, loneliness and depressive symptoms influence each other in a reciprocal fashion, so loneliness can influence one's depressive symptoms and vice versa (Vanhalst et al., 2012). A biological explanation for this is that the same genes involved in loneliness are also involved in depression (Matthews et al., 2016).

In order to become competent in understanding the extent to which these factors impact loneliness within PLWH, it is important to discuss loneliness by exploring its connection to internalized stigma and psychological outcomes. Although PLWH were not the subject group of study, but rather their providers, it is important to develop an understanding of how PLWH generally experience this themselves so that what the providers explain can be better interpreted. HIV-related stigma occurs when individuals feel as if they are of less value in society due to possessing the identity of living with HIV (Fekete et al., 2018). Many PLWH report experiencing HIV-related stigma, and that ranges from being related to how PLWH perceive

societal perceptions towards PLWH, the self-stigma (or internalized stigma) where PLWH personally believe that there is a stigma around living with HIV and internalize it, and anticipated stigma where PLWH believe that they will experience stigma when they disclose their status to others (Fekete et al., 2018). Since PLWH anticipate being stigmatized by others, it often impacts their willingness to freely share their status (Fekete et al., 2018). It has also been found that self-stigma and loneliness are linked to the development of depressive symptoms, increased anxiety, a decrease in medication adherence, and poorer sleep quality (Douek et al., 2002; Hubach et al., 2015; Rivera-Rivera et al., 2016). Individuals in stigmatized groups, including PLWH, are more likely to experience chronic forms of loneliness through persistent stigma and rejection that increases the likelihood that they face isolation and are thus at greater risk of experiencing subjective loneliness over extended periods of time (Cacioppo & Hawkey, 2005; Fekete et al., 2018).

Having established the importance of studying loneliness in stigmatized groups, the relevance of focusing on provider perspectives of loneliness in their clients can now be explained. Given the nature of this study, and desire to hear in-depth explanations, it is necessary to have provider opinion to allow for a comprehensive overview of what they have seen in their clients. It is also important to learn about their understanding of how policies and the environment impact the experience of their clients. HIV is their field of expertise, and they have extensive training and background knowledge on the topic to inform their insights. These providers include medical practitioners (physicians and nurses) as well as community-based workers (community health workers, health mediators, case managers, mental health therapists, and social workers). These providers have direct contact with PLWH, specifically in the context

of their care related to overall well-being and a holistic approach to treating HIV, making them the most relevant providers to study (HIV.gov, 2021a; Kitahata et al., 2002).

## **Introduction to HIV**

Although PLWH are one of the most protected groups in human subject research, making it difficult to access them directly, speaking to the people who interact with them on a regular basis to treat their condition provides indirect insight into what PLWH experience. HIV is a chronic illness involving a weakening of the immune system through the destruction of white blood cells (Cowley, 2001). The third and final stage of HIV is when it is medically classified as acquired immunodeficiency syndrome (AIDS); however, the first two stages are classified as acute HIV infection and chronic HIV infection and now make up the majority of PLWH in the U.S. (U.S. Department of Health and Human Services, 2019). June 2021 marked the 40<sup>th</sup> anniversary of the first diagnosed case of AIDS (HIV.gov, 2021b). There are currently almost 38 million people around the world living with HIV or AIDS, with just over 500,000 people dying of AIDS-related deaths per year (UNAIDS, 2021). Moreover, only about 1.7 million of the global burden of HIV are under the age of 15, showing that the overall burden is among adults (UNAIDS, 2021). Certain populations are more vulnerable to contracting the virus, and these individuals are part of what is termed the key populations. The internationally agreed upon key populations include the following: men who have sex with men (MSM), transgender people, people who inject drugs (PWID), and sex workers (UNAIDS, 2021).

Although HIV is no longer a death sentence as it was before the development of antiretroviral therapy (ART) – a weekly oral or (very recently) monthly injectable medication

that promotes viral suppression – it remains a chronic condition (UNAIDS, 2020b). Moreover, just under three quarters of PLWH (73%) are currently receiving treatment, showing the treatment gap that persists (UNAIDS, 2021). According to Kharsahy & Karim (2016), this is particularly the case in sub-Saharan Africa which now accounts for two thirds of the global burden of HIV. In addition to the geographical divide, there is also a gender divide, with over 50% of PLWH worldwide being women; in sub-Saharan Africa, women comprise 63% of new infections (Kharsany & Karim, 2016). As stated by UNAIDS (2021), for all regions outside of sub-Saharan Africa, 93% of infections occur in individuals within the key populations; however, in sub-Saharan Africa, this accounts for only 39% of the incidence.

The fact that drugs exist to treat HIV and prevent people from contracting the virus shows the extent of progress that has been made in the past 40 years. Still, there are challenges being faced globally, since there is still no cure, a 10-million-person treatment gap (people who have HIV but are not receiving treatment), increases in HIV in some parts of the world, and general neglect and discrimination toward PLWH (Kaiser Family Foundation, 2021; UNAIDS, 2018). PLWH often report feeling marginalized due to governments criminalizing behavior associated with HIV (e.g., homosexuality, sex work), making them feel like outcasts and more vulnerable, and facing difficulties in accessing services (UNAIDS, 2018). In addition to these inequities, individualized, community, family, and faith-based stigma around the disease prevent many from getting tested to determine status, start treatment, and attain undetectable viral loads (UNAIDS, 2018).

HIV is a retrovirus, and it works on a biological level to either harm or destroy CD4 cells (white blood cells), threatening the body's immune system response and ability to properly fight infection (Cowley, 2001; Kirchhoff, 2013). The virus attaches itself to the CD4 cell, fuses with

the cell, and then overpowers the DNA to begin replicating and releasing more HIV into the blood (Kirchhoff, 2013). ART targets the HIV at different stages of its lifecycle in efforts to achieve an undetectable viral load of fewer than 200 copies per milliliter (Avert, 2020). Once this load is achieved, a patient is considered virally suppressed and no longer at risk to pass the virus to someone else (Avert, 2020).

The Joint United Nations Programme on HIV/AIDS (UNAIDS) (2018) has explained that reaching their 2030 goals, which include zero new HIV infections, will not be successful unless stigma surrounding HIV is addressed. Stigma is a noted barrier to good treatment, and the COVID-19 pandemic is adding to this (United Nations, 2021). At United Nations (UN) high-level meetings, there have been reinvested commitments to HIV domestically and globally, particularly through decentralizing treatment and encouraging community implementation of pre-exposure prophylaxis (PrEP), which is medication individuals can take to prevent HIV (Kaiser Family Foundation, 2021). Still, the need to achieve equitable access, promote human rights, and reduce stigma and discrimination are worldwide issues and need to be global priorities (United Nations, 2021).

### **Loneliness and HIV: An Emphasis on Contextual Factors**

Mental health, and loneliness in general, is of particular interest to PLWH because HIV is most common among groups who are already marginalized and stigmatized, including LGBTQ-identifying individuals, PWID, and sex workers (Rokach, 2014). Loneliness has been shown to be experienced in these groups due to their intersecting identities, which are associated with increased stigma-related social rejection and exclusion as the identities are layered



(Ratanashevorn & Brown, 2021, Rokach, 2014). This, in addition to internalized stigma that many PLWH report, oftentimes results in negative effects such as lower adherence to treatment (Ratanashevorn & Brown, 2021; Rokach, 2014; Turan et al., 2016). PLWH suffer stigmatization at the level of affecting personal relationships in their lives, and a general fear of disclosure of status due to concerns that they might be rejected by society results in them oftentimes hiding their status, leading to added psychological burden (Laryea & Gien, 1993).

It is important to note that the social, cultural, economic, legal, and physical environments in which people live play an important role in mental health (UNAIDS, 2018). This is because much of the social inequality, discrimination, and human rights violations minority groups experience – in their specific country’s context – are associated with an increased risk of negative mental health experiences (UNAIDS, 2018). Studies performed in Western countries have shown that PLWH experiencing feelings of loneliness are also more likely to be depressed, misuse alcohol and tobacco, report a lower number of emotional connections, report lower levels of self-worth, and have significantly lower CD4 cell counts (Greene et al., 2018; Grov et al., 2010; Stanton et al., 2015; Straits-Troster et al., 1994). Moreover, there is significant evidence of individuals independently working to combat their loneliness through activities such as drug use and sex, simultaneously increasing the rates of HIV transmission and the presence of negative self-image (Hubach et al., 2012).

To further expand on the study of loneliness amongst PLWH around the world, Henry et al. (2015) explored the topic of loneliness in the Global South, emphasizing how disclosing one’s HIV status impacts mental health. Almost a quarter of the sample Henry et al. (2015) recruited (which included PLWH from Mali, Morocco, Democratic Republic of the Congo, Ecuador, and Romania) reported that it was a mistake to disclose their HIV status. In these specific contexts,

Henry et al. (2015) found that, even when people predicted they would have a positive experience with disclosure, it was emotionally taxing. Moreover, there was a fear about stigma by others, but higher levels of internalized stigma caused greater regret in such individuals (Henry et al., 2015). These high levels of regret due to disclosure resulted in lower self-esteem and higher levels of loneliness (Henry et al., 2015). Other systematic reviews of PLWH in the Global South have shown how poor mental health in this group is correlated with low socioeconomic status, unemployment, and low levels of education (Brandt, 2009; Breuer et al., 2011).

Person-level interventions used to reduce loneliness must be considered to understand what providers who will be interviewed might already be familiar with. Samhkaniyan et al. (2015) found that mindfulness led to a reduction in levels of stress, depression, and anxiety and an overall improvement in factors like executive function and attention. Loneliness was often accompanied by feelings of loss or apathy, such as through a lack of commitment to relationships, and mindfulness exercises reduced these feelings (Samhkanyian et al., 2015). Samhkaniyan et al. (2015) also found that the practice changed the perception of the self, which is important when addressing self-stigma. The mindfulness increased physical quality of life that had been disrupted by negative mental health experiences (e.g., loneliness) as it promoted adherence to medication (Samhkaniyan et al., 2015). Other interventions have discussed the importance of involving community organizations in tasks of educating the community, creating spaces of empowerment for PLWH, and hosting support groups (Lyons et al., 2017; Pantelic et al., 2019).

Although there is a wealth of research showing the importance of combating feelings of loneliness at the societal level through education and policy that raises awareness about HIV,

testing, and disclosing status, removing laws particularly at individual country government levels that harm PLWH and are discriminatory around key populations (e.g., criminalizing homosexual behavior and sex work and requiring evidence of residency in order to access treatment), are vital, too (Grossman & Stangl, 2013; Mahajan et al., 2008). Overall, it has been found that a comprehensive approach to mental health interventions around loneliness at individual, policy, and interpersonal levels is crucial (Mall et al., 2013; Nuwaha et al., 2012).

Taking all of this into account, this paper will explore two different studies. The first study will examine provider perception of loneliness in PLWH in one city in a country in the Global South: Dakar, Senegal. The second study will examine provider perception of loneliness in PLWH in the US: Central PA. However, part of this particular study will involve exploring the topic through the lens of key populations, given that the layering of different identities has been found to result in different lived experiences among PLWH (Ratanshevorn & Brown, 2021, Rokach, 2014). The intersecting identities that will be explored in combination with HIV status will be LGBTQ-identifying individuals and PWID. This will present a cross-cultural approach as well as an intersectional approach through a framework that examines how providers perceive that these broader issues (including loneliness, cultural context, stigma, and intersecting identities) are impacted based on intricate social, political, and cultural contexts.

### **Qualitative Studies: Dakar, Senegal and Central PA, United States**

Due to the opportunity of Laura Guay's study abroad experience in Dakar, Senegal and given that she is an employee at AIDS Resource in State College, PA, the trust and credibility in these two contexts made it most appropriate for this international comparative study on provider

opinion of loneliness in their clients living with HIV to be conducted. What makes Senegal particularly interesting, however, is that Senegal has the lowest HIV rates in all of West Africa (0.4%); however, there are still key populations to treat. HIV prevalence among key populations, particularly among MSM and female sex workers, is still quite high at approximately 30% and 5%, respectively (Mukandavire et al., 2018; UNAIDS, 2020a). The difference between these rates and key populations as compared to the general population is largely due to the factor described above: stigma (USAID, 2019). The fact that this is the case leads to the need to focus on mental health, as key populations possess not only the stigma of the disease, but also their sexuality, occupation, or lifestyle. The LGBTQ community, one of the key populations in Senegal, often faces these inequalities, discrimination, and human rights violations based on the context of Senegal (Human Dignity Trust, n.d.). In Senegal, homosexuality is considered a crime punishable by time in prison (up to 5 years) and a hefty fine (the equivalent of 5,000 USD), ultimately affecting living conditions (Human Dignity Trust, n.d.). Action to improve living conditions across the lifespan has been shown to offer opportunities to improve population mental health and reduce the risk of mental health problems associated with social inequalities, such as discrimination and human rights violations (UNAIDS, 2018).

Central Pennsylvania presents its own challenges. First, Central PA is a region faced by the opioid epidemic and has a high concentration of methamphetamine use (Drug Enforcement Administration, 2018). Because PWID are one of the key populations of PLWH and the key population that is most at risk for contracting the disease, this is a very appealing and attractive point of study (UNAIDS, 2021). Moreover, according to Giano et al. (2020), people who are members of the LGBTQ community are typically more highly stigmatized in rural areas in the US, like Central PA, due to smaller communities of support and fewer people with whom they

can identify. The stigma around the virus leads to many PLWH refusing to reach out for help or even get tested (Giano et al., 2020). There is also a noted lack of available mental health resources, and the healthcare system in the US, which does not provide universal access to care, places the burden of insurance coverage on PLWH (Mongelli et al., 2020; Patel & Saxena, 2019).

These two studies are phenomenological in nature, as they focus on descriptions of provider perception of the experience of loneliness in their clients living with HIV (Patton, 2015). The phenomenological approach provides the opportunity to engage in both observational and interview pieces, with the Senegal study particularly emphasizing the observation component (Patton, 2015). However, since both regions are looking at the contextual situation and trying to understand how society got to a place where they treat a certain group of people in a particular way, this style of interview allows a discussion of how history informs the present situation (Patton, 2015). Although this study was certainly qualitative, there was a component that truly made it a critical ethnography, whereby the research was trying to explain loneliness and how it is experienced by a certain population in two different regions of the world (Reeves et al., 2013).

Data analysis involved uploading interview transcripts to MAXQDA to both organize data and create a codebook for the interview transcripts. The analysis team only consisted of one individual: Laura Guay. This individual approached the transcripts in the following way to properly analyze them, using the Framework Analysis method: (1) designated a first round of codes to text based on meaning; (2) organized these codes into broader, more common, categories; (3) reviewed categories to further notice where overlap across codes existed and charted these; (4) classified identified themes to connect them to the collected data and map

them; and (5) created a coherent narrative that included quotes from interviewees that supported these recurring themes to explain the broader contextual connections (Gale et al., 2013; Ritchie & Lewis, 2013). Note-taking also occurred during the analysis to develop ideas around how to present the data (Gale et al., 2013). Although this detailed process was followed, only one person was involved in coding the data and identifying themes for both datasets. It is acknowledged that it would have been better for someone else or a team to also code these two datasets to see if they would arrive at similar themes and subthemes. This will be discussed further in Chapters 2 and 3.

### **Positionality Statement**

For the context of this study, it is important to recognize that I (the researcher, Laura Guay) am situated as a young, white, upper-middle class, college-educated, HIV-negative American woman who has spent most of my life in Central PA. Although I have been trained in HIV education, have been a certified Peer Educator at AIDS Resource, in State College, PA for three years, and have also been studying loneliness in the Stress, Health, and Daily Experiences Lab for three years, this is my vantage point. Therefore, even though I may have a trained background in these intersecting fields, my identities are related to biases that undoubtedly impact my ability to interpret data.

### **Objectives of the Research**

Objectives of this qualitative research include understanding provider opinions and perceptions of 1.) how their clients living with HIV experience loneliness; 2.) how policies and the environment (e.g., stigma, cultural norms) impact loneliness in their clients; 3.) available

support and/or interventions; 4.) different experiences of key populations living with HIV. By nature of this being qualitative research, there is an ability to study how and why provider perception of their clients are shaped by the unique circumstances in which they occur (Maxwell, 2013). This specific and non-specific (qualitative and literature review) comparative qualitative analysis will work to further emphasize this through analyzing interviews performed with health professionals in Dakar, Senegal and Central PA, United States. Additionally, through findings in Dakar that made it clear that more effort is needed to differentiate between key population groups, there was a decision to go a step further in Central PA and look at intersecting identities with HIV status, namely sexual orientation and injection drug use.

## Chapter 2

### Loneliness and HIV in Dakar, Senegal

#### Introduction

In Senegal, PLWH, a highly stigmatized group, show higher rates of mental health-related concerns; little previous research has explored these issues in-depth (Brandt, 2009; Breuer et al., 2011). This presents an opportunity to explore provider perceptions of loneliness in an urban group of PLWH in a country in the Global South that is deeply religious and has punitive laws in place against groups commonly affected by HIV (Human Dignity Trust, n.d.; M'Baye, 2013). This qualitative study explores opinions of health professionals specialized with working with PLWH on loneliness experienced by their clients. Eligible participants were recruited from community organizations (largely NGOs) and local health centers in Dakar, Senegal. They included healthcare mediators, community healthcare workers, and physicians who all had specialized experience working with PLWH. A total of 11 participants responded to a semi-structured interview about loneliness, stigma, and medication adherence in their clients.

Mental health, including loneliness, is largely understudied, and often not addressed in policy or treatment options in many countries of the Global South, including Senegal (Soltani et al., 2004). Few studies have assessed loneliness in populations living in the Global South, even though mental health morbidities are increasing in both Western countries and countries in the Global South (Soltani et al., 2004; WHO, 2001). The limited findings, however, indicate that



lack of knowledge around the importance of training individuals to respond to mental health needs are concerns in Senegal (Monteiro et al., 2014).

Although PLWH in sub-Saharan Africa account for over 2/3 of the global HIV burden, the emphasis around a holistic approach to treating HIV, including mental healthcare, is not present (Collins et al., 2006). In addition to the lack of psychiatric care in the region, a systematic review of the literature on HIV and mental health in countries in the Global South identified a need for research on the mental health of PLWH (Collins et al., 2006). A recent meta-analysis of studies conducted in sub-Saharan Africa found a 24% prevalence rate of depression among PLWH; they may experience depression and anxiety as they adjust to living with a chronic illness, experience or anticipate stigma, or manage ongoing stressors (UNAIDS, 2018).

Perceived HIV-related stigma in the community can cause PLWH to internalize stigma and anticipate these experiences, which is associated with adverse mental health effects because PLWH isolate themselves from friends or experiences, and isolation is correlated with loneliness (Turan et al., 2017). Additionally, previous research has shown that perceived stigma in the environments of PLWH can lead to self-stigma, meaning that there are multiple levels of stigma in the lives of PLWH that need to be examined (Katz et al., 2013). Any HIV-related stigma compromises the ability of PLWH to successfully adhere to ART treatment (Katz et al., 2013). Moreover, understanding health professional perception of such cases in their clients is important to see whether implementation of services and screenings will be effective and possible when working to combat such feelings of loneliness (Parcesepe et al., 2018).

HIV is highly stigmatized in Senegal, especially among marriages where women who have contracted HIV omit telling their husband out of fear that their husband will accuse them of

cheating (Bott & Obermeyer, 2013). In most cases, the wife keeps her condition a secret, but if she is in a polygamous marriage, which is 40% of marriages in Senegal, there is a risk that HIV then gets passed on to the other wives, as well as their children (Sow, 2013). According to Sow (2013), it is a burden on Senegalese women and has serious implications on the family because she hides such a grave secret from her husband. Although there might be a push for disclosure of status, it is not always safe because of this social risk (Sow, 2013). Therefore, even though there are plenty of national awareness campaigns and organizations that promote the importance of testing and treatment for HIV, it is generally not commonly present in public discourse because of the stigma (Bott & Obermeyer, 2013; Sow, 2013).

Before one can effectively study loneliness in PLWH, it is important to obtain information from health professionals (e.g., clinicians and community health workers) who are experts in the field of HIV. This is because stigma behind the disease is very high in sub-Saharan Africa, and there is a history of PLWH being subjected to human rights violations (Mbonu et al., 2009; Williamson et al., 2017). As a result, there are many research protections in place to protect this population (Williamson et al., 2017). Moreover, it has been found that when providers share the same race and cultural background as patients, which was the case in all instances in this setting, there is more overlap in similarities between patients and providers in how the illness impacts the patient's life (Kennedy et al., 2017). For Laura Guay to present herself as a culturally competent and informed researcher, it was determined that it would be most helpful to conduct research on health professionals who work directly with PLWH. This style of interview allowed health professionals themselves to learn more about the ways they notice HIV affecting their clients' mental health, particularly regarding perceived levels of loneliness. By capturing perspectives of health professionals who have clients living with HIV,

these perspectives have the potential to shape behavior and be reflective of a range of client experiences; however, the responses may also reflect biases of health professionals. Moreover, they may reflect a subset of non-representative clients, given that they can only speak to loneliness in clients who have accessed the care site or community center at some point in time. This preliminary data will inform next research steps where it would be possible to extend these studies to additional samples (such as PLWH themselves) that also have more of a focus on studying and testing loneliness interventions.

This study will provide qualitative data that will further emphasize the findings of previous (albeit limited) research about loneliness, stigma, and the general mental health status of PLWH in Senegal through considering provider opinion on these topic areas. The overall goal of this research is to better understand how providers perceive their clients living with HIV to experience loneliness, how providers perceive loneliness to impact their clients' lives, and how providers perceive the stigma of the disease and cultural norms to affect this experience and the overall mental health of their clients. Qualitative data on the following was collected through interviews with healthcare mediators, community health workers, and physicians to understand their perception of the following: levels of loneliness in PLWH and how this relates to living with HIV, individual experiences of PLWH, moods of PLWH, access to healthcare for PLWH, how PLWH might experience stigma surrounding the disease, caregiver involvement with PLWH, and treatment adherence among PLWH.

The following three research questions were investigated through this research: 1.) How do providers believe PLWH experience loneliness, and how does it impact the lives of their clients? 2.) How do providers believe stigma and Senegalese cultural norms impact the

loneliness experienced by PLWH? 3.) What available support or interventions do providers believe are in place to respond to loneliness experienced by PLWH?

**Table 1: Research Questions Dakar, Senegal**

Research questions	Items in Instrument That Connect to Research Question	Analysis Method (software), Deductive/Inductive	Identified Themes
RQ1.) Provider perspectives//beliefs about how PLWH experience loneliness/impact on their lives	2a, 2b, 2c, 2d, 2e, 2f, 2g, 2k	MAXQDA, inductive	<ul style="list-style-type: none"> <li>• Non-acceptance</li> <li>• Fear of disclosing status</li> </ul>
RQ2.) Provider perspectives//beliefs about how stigma and Senegalese cultural norms affect loneliness in PLWH	2h, 2i, 2j, 3, 5, 6, 7, 11, 12, 14, 15, 16,	MAXQDA, inductive	<ul style="list-style-type: none"> <li>• Non-acceptance</li> <li>• Cascade of care</li> <li>• Fear of disclosing status</li> </ul>
RQ3.) Provider perspectives//beliefs about available support/interventions	4, 8, 9, 10, 13	MAXQDA, inductive	<ul style="list-style-type: none"> <li>• Cascade of Care</li> </ul>

Outline of research questions as well as the corresponding items in the instrument, the listed analysis method, and the identified themes linked to the research question

## Methods

A total of 11 participants were recruited to participate in this semi-structured interview. Given that Laura Guay, the researcher, was interning at AIDES Senegal, participants were either recruited by Laura Guay directly from AIDES Senegal or AIDES Senegal partner organizations and health centers. Participants were 18 years or older, French-speaking, and either a physician, a healthcare mediator, or a community healthcare worker who specialized in working with PLWH. Ethical approval was obtained through the West African Research Center in Dakar, Senegal, which partners with the University of Minnesota's Studies in International Development program. As this research involved speaking to providers, and not the direct population, this

study was classified as exempt regarding risk to participants. Nonetheless, informed consent was obtained from participants. The process involved verbal consent whereby, at the beginning of the interview, participants were informed of the details of the research and where the findings would be disseminated. All participants were then asked if they had any questions and gave their verbal consent before agreeing to complete the interview.

The interviews lasted between 20 and 25 minutes (one interviewee spoke for 40 minutes) and were all conducted at the interviewee's place of work by Laura Guay, a researcher who was trained in the Stress, Health, and Daily Experiences Lab at the Pennsylvania State University. During these interviews, the researcher used a script to introduce herself to the interviewee and explained the reasons and motivations for the research before obtaining verbal informed consent. After this, a digital recording began. Then, basic demographic information was collected; participants were asked about their perceptions and beliefs regarding stigma, isolation, and loneliness seen in their clients; participants were asked about medication adherence in their clients; participants were asked about social support their clients receive; and participants were asked about lived experiences of their clients (Fekete, 2018; Rokach, 2014). The questions on loneliness were adapted from a portion of the UCLA Loneliness Scale which identifies factors of loneliness such as lack of social, spiritual, and cultural connections (Russell et al., 1978). The specific questions can be seen listed under "*Interview Script*" in the Appendix. Although it is a long list of questions, the interviews were semi-structured. Therefore, in some interviews, questions were skipped because they had already been answered in different questions. In some interviews, additional follow up questions were added, mainly using the guide as shown in the Appendix under "*Helpful Follow-up Questions.*" Moreover, the critical ethnographic portion of the research described in Chapter 1 was particularly emphasized in this study in Senegal, as there

was a descriptive and focused observation of the setting where 7 of the 11 interviews occurred (Reeves et al., 2013).

Analysis of the data involved transcribing and translating (from French to English) to provide a verbatim transcript (in both French and English) of what was discussed. All identifying information, such as the names of the individuals interviewed, was removed. Instead, their study participant number was the sole identifying piece of information. They were labeled as “DS\_01,” for example, interpreted as “Dakar, Senegal\_Participant 1.” Transcripts were uploaded into MAXQDA, as mentioned in Chapter 1, and analyzed using the Framework Analysis method. The organizations that were represented in the interviews included all the employees of AIDES Senegal, as well as several partners. The first partner contacted was the Dominique Health Center in Pikine. Two interviews were performed at Fann Hospital and a third at the office of a prominent physician who works specifically with MSM in Senegal.

## Results

**Table 2: Interviewee Characteristics Dakar, Senegal**

Characteristics		Dakar, Senegal Study		
		Mean/Percent (%)	SD	Range
Age		37.64	11.10	26-63
Sex	Male	82%	-	-
	Female	18%	-	-
Race	Black	100%	-	-
Subregion	Grand Yoff	55%	-	-
	SICAP Liberte	9%	-	-
	Pikine	9%	-	-
	Fann Point	27%	-	-
Education	High School	9%	-	-
	Bachelor's	82%	-	-
	Doctor	9%	-	-
Employment	Healthcare mediator (specializing in HIV)	36%	-	-
	Community health worker (specializing in HIV)	55%	-	-
	Physician (specializing in treatment of MSM living with HIV)	9%	-	-
Years spent working in HIV		7.73	5.76	1-16

Table outlining demographics of all participants, since all 11 interviewees provided responses for all items above

Participants, all of whom were Black Senegalese individuals, ranged from 26 to 63 years old with an average age of about 38 years old. Most people (82%) had a Bachelor's degree. One person had a high school degree, and one person had a Doctorate degree. People had been working in the field of HIV for about 7.73 years, on average. Their positions included either healthcare mediator, community health worker, or physician, and they all specialized in HIV-related care. Two community centers were represented, and three health centers were represented. Within the city of Dakar, departments (neighborhoods) represented included Grand-Yoff, Sicap-Liberté, and Fann Point. Within the region of Dakar at large, Pikine was also represented.

### Three Themes: Non-acceptance, Cascade of Care, Fear of Disclosing Status

Three major themes were identified from this data. From these three major themes, they were divided by subtheme (a total of 9) to answer the research questions outlined in Table 1 above.

**Table 3: Identified Themes Dakar, Senegal**

Theme	Sub-theme and Corresponding Research Question
Non-acceptance	<ul style="list-style-type: none"> <li>• Existential dread – RQ1</li> <li>• Inner loneliness – RQ1</li> <li>• Religious attitudes – RQ2</li> <li>• Intersecting identities – RQ2</li> </ul>
Cascade of Care	<ul style="list-style-type: none"> <li>• Medical care – RQ2</li> <li>• Equitable access – RQ2</li> <li>• Community organizations – RQ3</li> </ul>
Fear of Disclosing Status	<ul style="list-style-type: none"> <li>• Social rejection fear – RQ1</li> <li>• Confidentiality fear – RQ2</li> </ul>

Representation of themes and sub-themes identified through framework analysis of interview transcripts from Dakar, Senegal

#### Non-acceptance

##### *Existential Dread*

Many participants indicated that one of the main challenges that social workers, healthcare mediators, and peer educators often face is tackling the existential dread they perceive their clients to be experiencing. They perceive this to particularly be present in their clients at the beginning of the diagnosis. Interviewees reported that clients will call several times a day because they are so distraught, and the workers at these community organizations and health centers guide them through this phase when clients are expressing sentiments such as their life being meaningless and completely over:



*“There are other diseases that are more serious than AIDS. It's just to raise awareness after they express this [sentiment], but they oftentimes still say: ‘No, it's the end for me because society will reject me no matter what.’ They will cry because even though they now have this knowledge [about how to manage the disease], society rejects them anyway.” (SN\_05)*

Other participants reported that they believed this experience highlights the importance of raising awareness to change the misconception around HIV and death. Even though interviewees explained that they perceive there to be more awareness around the topic than in the past, they believe that many Senegalese still associate HIV with death and with being a cursed person. Because of this, participants explained that many do not even want to know their status, while others feel that everything is hopeless because they have lost their chance at a normal life:

*“For them, when they have HIV, it's over. They can't have a spouse, they can't get married, they can't have children [because of society's perception of HIV].” (SN\_01)*

The fact that there is no cure for HIV is really what still leads to the lack of acceptance and apprehension here, participants explain. Community health workers and healthcare mediators, specifically, noted this was a real concern with loss to follow-up treatment. This is because people leave the country to pretend that the diagnosis does not exist, and then they stop taking the medication:

*“They are going to leave the country or go to other countries. Just flee and avoid the situation and their fear of being exposed as PLWH, and this will cause problems for them.” (SN\_05)*

That's why, according to community health workers, providers push the importance of clients following their medication regimen. This is because, according to providers, when PLWH

start to see visible physical results that the medication is helping them, it tends to change their perception of meaning in their lives.

### *Inner Loneliness*

One of the findings that was mentioned by every participant is that PLWH do not always experience loneliness, or at least a change in social connection, when they keep their status to themselves. So, although providers think the risk of being ostracized is when people find out their clients' status, participants explained that, due to this lack of sharing, it can lead to other problems such as avoiding society and withdrawing. This is because providers believe PLWH self-stigmatize, asking themselves why they did this to themselves and starting to question whether they are a good person, all while living isolated in fear:

*“Most of the people that I see, their status keeps them away from others, apart from us at [community] organizations who are the people who accompany them so that they can have good health.” (SN\_02)*

Providers explain that these patients, oftentimes not taking advantage of community organizations, are dropping out of care, going underground to take medication, or going to the hospital without someone to support them (e.g., a peer educator, a health mediator, a community health worker). As a result, participants believe that because it is only people at these organizations who are the confidants of PLWH and know their status, their clients experience emotional loneliness:

*“In the context of our country, if someone has the virus...everyone ignores them, everyone condemns them as a bad person, gives them a low rank in society. That's why many [PLWH], sometimes if they don't have a good [community] organization that*

*accompanies them in taking the drugs, they can totally give up and leave the care structure.” (SN\_02)*

*“They feel loneliness because loneliness is something that you feel when you have different problems or you need support, but you don't know who to talk to or who to share it with.” (SN\_07)*

### *Religious Attitudes*

Religion is deeply rooted in Senegalese culture and customs. However, participants noted that PLWH often exclude themselves from religious groups and gatherings, and this is particularly true for MSM. In fact, that was the key population that was highlighted in virtually every response relating to religion. Providers explained that it is difficult for many Senegalese to accept LGBTQ-identifying individuals because although Senegal is generally a secular society, it is very Muslim. Society associates being a bad person with being HIV positive because Senegalese automatically associate it with a disease in gay men or in sex workers, and Senegalese believe that PLWH deserve the consequences of the disease:

*“When [Senegalese] see that a person has HIV, they say...that one is a bad person because [they] got it because [they were] having sex with everyone, things like that. [They were] living like a bad person, that's why people don't always continue practicing their religion.” (SN\_03)*

*“We are in a society where people are too fatalistic towards everything that happens. It's God who wanted this, people are very fatalistic...but now [that you're infected], what you have to do is to follow the treatment...this problem can be solved...follow your treatment. If not, in fact you are responsible for the situation.” (SN\_11)*

Therefore, interviewees explained that physicians have also taken this as a way to convince patients to accept responsibility and have autonomy over their situation. However, not all physicians are created equal, and interviewees explained that they believe the religious attitudes of some physicians impact the way PLWH experience rejection:

*“An MSM, they go to the physician. Maybe the physician says, I'm not going to touch you because you're MSM. My religious beliefs don't allow me to touch an MSM. So, I'm not going to diagnose you. I'm not going to touch you. That's the reality of care.” (SN\_01)*

This is concerning, as there are no health structures dedicated to specifically treating LGBTQ populations, and this experience leads to further self-stigma and humiliation. Although there are some MSM friendly physicians, they operate on their own and not within a formal health structure specifically dedicated to LGBTQ care. That being said, providers explain that this lack of touching tied to religious beliefs is more related to sexual preference than living with HIV.

### *Intersecting Identities*

As noted above, many participants specifically mentioned how MSM are often the target of religious non-acceptance in Senegal. However, MSM, and those of other intersecting identities, including sex workers (though only two interviewees mentioned sex workers in their responses), experience a double stigma because of their work, sexual preference, and HIV status. That being said, there is likely some other clustering occurring here as well, given that PLWH at large are more likely to be of lower socioeconomic status and social class (Benzekri et al., 2015; Breuer et al., 2011). People who then possess these subsequent intersecting identities, particularly MSM, face this to even greater degrees (Scheibe et al., 2014). With this context,

participants explained that Senegalese think key populations are the source of this disease, so discrimination is more frequent and violent towards these groups. Violence may occur on a physical level, but appears generally to be rare, as providers believe that PLWH solely experience verbal abuse, unless otherwise identified specifically as MSM or a sex worker:

*“With the key population, they have a double stigma...if they come out and identify as that, too, for example, MSM or sex worker or lesbian, and are HIV-positive, then it's a double stigma...Society thinks that the key populations are the source of this disease, so the stigmatization is more frequent there and more violent, and right now can still be stigmatized on a more physical level, with the violence.” (SN\_04)*

*“When I give the examples of the key population, an MSM who is known as an MSM in the family, who is well known, and that they live with HIV, it is doubly stigmatized, and often it makes...the family rejection even more intense.” (SN\_10)*

Participants also believed that those with intersecting identities are more likely to be impacted economically (such as by losing a job) because of that other identity, not because of their HIV-positive status:

*“Recently, there was one who tested positive for HIV, but her work card to be registered as a sex worker was taken away. And this increases the precariousness of the person, because then she's without a job and without income.” (SN\_04)*

*“If they [colleagues] know that a person is living with HIV or a sexual minority, they [PLWH] might leave their job because of the stigma.” (SN\_07)*

However, providers believed that if people know their client is a member of a key population, people automatically assume that their client has HIV. Providers explained that their clients lose jobs if they identify as a key population. On the flipside, however:

*“When we know that this person, for example, is not part of the key population groups, when we don't know your HIV status or it's less likely to automatically assume you are PLWH since you're not in that key population group, they don't stigmatize you.” (SN\_07)*

This is particularly important to note, because, as mentioned above, only 39% of HIV infections occur in members of the key populations in sub-Saharan Africa (UNAIDS, 2021).

### Cascade of Care

#### *Medical care*

At another level, the interviews assessing provider perception revealed that often the only individual who is aware of one's status is the health professional who treats them. Healthcare mediators, peer educators, and community health workers might know, too. This is because they typically accompany PLWH to appointments, rather than someone who is close to them, like their partner, family member, or a friend; however, there was a stated need by these professionals for help in addressing mental health needs:

*“We, the healthcare mediators, need that [wider availability of mental health services]. Sometimes, we are so tired because we're working so hard to meet these mental needs; however, we need psychiatrists. It's not an easy job.” (SN\_07)*

*“Sometimes people need to talk, to exchange, to find other solutions to their problems, but their care management is limited to just everything that is medication, treatment, prevention, but not all those aspects that make it more comprehensive.” (SN\_08)*

*“It's true that we don't have [many] psychiatrists...you're physicians, but you wear the psychiatrist's hat...in addition to medical care, [you provide] spiritual guidance, you do everything at once.” (SN\_11)*

Despite the prevalence of depression and isolation in PLWH, the available psychiatrists are rare, which means that, if visits do occur, they are infrequent:

*“It's a problem because we have clients with depression related to their HIV status and we treat that with the psychiatrists, and they set the appointments so far apart that the patient has much more to say than they can with that limited frequency because they are not numerous.” (SN\_09)*

Providers explained that there is limited available support and psychiatric intervention for PLWH, and the professionals who take on this task are overwhelmed. For example, although healthcare mediators accompany PLWH psychologically, there is a stated need for more support. Considering that providers believe there are other concerns accompanying HIV that health structures do not consider, the following statement is concerning:

*“Well, a lot of times when you experience stigma it can actually make the person depressed. Often, it is the case. The person is not well, and in fact, it is this part of stigmatization that creates more problems for the patient than even the pathology [of HIV].” (SN\_10)*

### *Equitable Access*

When participants spoke to what makes medication adherence (e.g., ART) difficult for their clients, the majority (9 out of 11) cited reasons related to societal stigma, rather than reasons related to healthcare infrastructure; however, many participants still noted that, in

addition to the lack of comprehensive healthcare (treating physical health symptoms more often than mental), there was a lack of healthcare infrastructure and challenges with the cost of appointment visits. Ultimately, all these concerns of equity related back to the idea of dropping out of care, being alone, and no longer adhering to medication. Providers explained that if clients do not go to the structures, they are not really connected to community organizations. Even though the community organizations were based in Dakar, as there is minimal support available outside of the city proper, providers reported that some clients travel hundreds of kilometers to seek support. Moreover, even though ART is free in Senegal, and has been since 2003, there are sometimes shortages when the state's supply is not high enough to distribute to everyone, and there are other costs involved (WHO, 2005):

*“There are patients who do not have the means to pay for their [check-ups] ...to measure the progress...what we have to do next for treatment...ARTs are free, viral load checking is free, but follow-up check-ups are not free.” (SN\_11)*

### *Community Organizations*

All interviewees explained that interaction with other PLWH and organizations supporting PLWH and key populations, mostly those with shared identities, are the main actors who provide PLWH with social and emotional support. Providers believed that community-based organizations are in place to guide and accompany PLWH through services and create a support network:

*“We, [the community organizations], are in contact with all the people, without discrimination, without judgement. When others say, ‘How did you get that?’ we say, ‘You are welcome here.’ We are here for all, no matter how you got it.” (SN\_06)*



Participants explained that community organizations often have the same goals as PLWH, because they want everyone to be detected and treated. The importance of organizational support for PLWH with stigmatizing intersecting identities was noted by providers; however, providers also explained that even in communities like LGBTQ groups or women's groups hosted by such organizations, there are members who do not disclose their HIV status to other members. Interviewees also noted that activities and advocacy efforts led by such organizations, such as workshops, support groups, and activities to build the capacities of LGBTQ community leaders, can help people feel more connected. This is because providers perceived it to be community building, but also an effort to reduce stigma surrounding key populations, working to fight self-stigma that clients might be experiencing. Providers believe that when PLWH go to community organizations, they generally feel comfortable because they know they will not be discriminated against or stigmatized. Interviewees explained that clients often feel free and relieved in these spaces where they can safely share their status and be heard:

*“I can say that it's the organizations [that provide support] because...they are there for that and offer that, activities like capacity building workshops...we do workshops to let people know the prevention techniques as well, the methods of contamination, all the things that are related to HIV so that people can be more at ease and familiarize themselves with the disease.” (SN\_02)*

At the same time, though, providers noted that individuals working in these spaces encourage their clients to share status with someone in their everyday life as well. Providers perceive this as a way for their clients to share the pain and have someone to listen to them and comfort them as they encounter new experiences with their illness. According to providers, in the care structure and even within community organizations, it is oftentimes just one person with

whom the client wishes to share. These professionals are relied upon to talk with every patient and go out into the field to see how they are being treated:

*“Sometimes the PLWH, their only confidante or friend who takes into account their interests, are the peer educators, that community...the healthcare mediators, psychosocial health workers, that's it.” (SN\_01)*

Outside of these spaces, providers believe that PLWH cannot share what they are feeling, and it consumes them. Providers think that community organizations become like family to their clients and their emotional support:

*“At AIDES Senegal, people are very comfortable when they come here because there is a very good atmosphere, and there is also care and a family atmosphere between us and the people with whom we help to treat their illness.” (SN\_08)*

### Fear of Disclosing Status

#### *Social Rejection Fear*

Providers believe that the marginalization and stigmatization by the family can result in a lot of pain for PLWH. Due to the strong stigma that exists around HIV, providers noted that families often do not allow PLWH to eat with them or share a home with them. If Senegalese discover one's HIV-positive status, participants explained that greetings change, and they risk losing emotional support from family members. Providers perceive all of this to be associated with people leaving the country:

*“It happens sometimes, especially when young people have HIV, when their family finds out that they have HIV, they are totally shunned. They can't eat together around the bowl with the family, they are totally marginalized...it's humiliation, it's insults.” (SN\_06)*

*“In the homes...they are treated differently than others. There is simply the rejection, so there is no support in the family. So, there is the struggle, there are several difficulties, there are some who have beliefs...and refuse to shake hands. Sometimes it hurts, because you are like all the others, but they refuse to shake hands because you...[have] HIV.”*  
(SN\_11)

The noted familial fear by providers is neighbors learning a family member has HIV, which would then bring shame to the entire family. Providers believe that this is a motivating factor for PLWH to keep their status to themselves:

*“Out of ten people, only two can share, but the eight can't...People are afraid. When you have HIV, you are stigmatized. Out of ten people, there are nine who are stigmatized when [Senegalese] know that [the individual] is living with HIV.”* (SN\_09)

Participants said that their clients who ended up sharing their status, which would occur either with their partner, family, and maybe (rarely) friends, oftentimes had an experience where friends were afraid to associate with them. Participants explained that it was not so much that they are living with an infectious disease, but more because of their assumed sexual orientation. Providers, again, believed that those who did not share their status with friends had continued support and relationships with them. Overall, familial rejection was emphasized in provider responses much more often than that of friends or partners. It was repeatedly noted by providers to have a strong effect on driving feelings of loneliness or refusing to disclose status, ultimately living in a state of inner loneliness because of the possibility of rejection:

*“In fact, it's problematic to share. It's not actually all patients who share their HIV-positive status...because the first information about HIV that was disseminated, it lied about the disease. Anyone who was infected with the virus was considered a lesser*

*person or a person who injects drugs and stuff like that. So as soon as the first information was disseminated, people had a negative perception of HIV infection.”*

*(SN\_10)*

### *Confidentiality Fear*

Another realm of fear was related to confidentiality. Providers perceived a general fear in their clients about going to the hospital regularly or going to the hospital where someone knows them because PLWH do not want others to discover that they are living with HIV. Providers believe that the reasoning behind this is because people in Senegal talk, since there is a culture of gossip, and they might know someone at the hospital:

*“PLWH, they say...in the hospital I have family members, or an uncle or a neighbor who goes there. So, if they see, they're going to find out that I have HIV. They're going to tell everybody...Sometimes, PLWH prefer not to go to the care sites and that's troubling.”*

*(SN\_01)*

*“Most people, they prefer, when you live in Pikine, for example, you prefer to get treatment in another department (neighborhood).... because the people you know go there all the time, and you don't want to be identified as living with HIV.” (SN\_02)*

With the providers' description of this worried cascade effect of one person finding out, everyone will find out, there is a lack of sharing outside of care sites. However, some participants, particularly the community health workers at community organizations, noted that before they even start a conversation with their clients about their care, they assure their client that the result will remain confidential. Despite this, however:

*“Sometimes, clients, they're afraid to share status. Some people have a difficult time, sometimes even between us. They don't trust us. Here they always go to the same person...to share, to relieve themselves from the suffering.” (SN\_05)*

Now, outside of the care structure, participants noted their clients’ desire to not bring medication home out of fear that people will see them take it. This often results in them hiding the medication and ensuring they are alone when they take their medication:

*“There are some who don't want to keep the medicines at home because they share their room with their brother. Sometimes it is difficult to keep the medicines secret... [if the medicine is not at home], they don't have to answer the questions about what medicine it is.” (SN\_11)*

*“When they take their medication, they usually try to hide it. Or they are not in close proximity to others who don't know their status when they take their medication. You might consider sharing [your status] with your brothers and sisters, as it's difficult to take your medication properly when being so secretive, and that's a problem. It's all about the lack of trust.” (SN\_07)*

## **Discussion**

Findings of this study of provider perception of loneliness in their clients living with HIV meaningfully contribute to the limited previously existing research on mental health of PLWH in Dakar. The results show that a common thread throughout all themes includes concerns around disclosing status, due to the potential result of a lack of support. This shows how providers perceive that sharing status is impacted by stigma, which affects loneliness, particularly

emotional loneliness. Providers believed that if PLWH did not share their status, they would not experience the rejection from society that others who share their status oftentimes experience.

This idea of hesitation around sharing status, most heavily emphasized by the rejection that would occur at the level of the family, aligns with previous studies. It has been found that PLWH who are socially excluded after they share their status, those who have been discriminated against in personal and professional settings, and those who report physical isolation – oftentimes associated with experiencing feelings of loneliness – are less likely to disclose status to others (Henry et al., 2015).

Now, in this scenario, the impact of what it means to engage culturally is significantly altered, too. According to provider opinion, if clients share their status, they no longer experience Senegalese culture in the same way. For example, providers believe that Senegalese who know you are living with HIV likely will not greet you the same way or practice the same eating patterns with you (e.g., the traditional technique of gathering with your family around a communal bowl and using either spoons or hands to eat the shared meal). Therefore, this shows that despite the awareness campaigns that have occurred, the power of the education has only gone so far. Potential reasons could be the result of most effective programs involving peer educators, rather than a mass media campaign that goes to the public (Faust & Yaya, 2018). Peer educators typically work with small groups at risk for HIV, try to access more difficult to reach populations (e.g., MSM, sex workers), rather than the general population, and are often HIV-positive themselves (Faust & Yaya, 2018; Leonard et al., 2000). However, people being unaware of the modes of transmission might not be the only reason; it could also be due to the deep cultural connection with religion that was heavily emphasized throughout interviews. This is particularly because of society's assumption that once the HIV-positive status is discovered, it is

automatically assumed that the HIV was either contracted through culturally taboo or immoral means, such as through sexual activities involving MSM or sex work.

The double-stigma of sexual orientation and living with HIV arose in every theme. Providers perceived LGBTQ were more often rejected or even forced to leave the house or have physicians refuse to touch them because of their sexual orientation. This stigma surrounding sexual orientation also explained why it is so difficult to take medication. Providers believe that social factors, before medical factors, are more likely to make ART care effective, due to how social factors lead to people hiding their medication and refusing to return to physicians who display homophobic tendencies. However, given the culture of gossip, providers believe PLWH often feel conflicted about seeking treatment, and the added burden of keeping this status secret weighs heavily on them.

Despite providers believing that religion impacts HIV-related stigma, religious leaders have historically played a large role in the success of low rates of HIV in Senegal, particularly through the promotion of prevention techniques (Ansari & Gaestel, 2010). HIV is currently a topic openly talked about in mosques, particularly amongst women, which is an admirable step toward its de-stigmatization (Ansari & Gaestel, 2010). A popular conservative figure, Abdoulatife Gueye, created a religious-affiliated organization that is now famous for its work to implement programming around combatting HIV (Population Reference Bureau, 2001). Although Gueye's efforts do not go as far as work of NGOs with more secular values, these discussions have helped convince followers of Islam that HIV exists (Population Reference Bureau, 2001). This is not an easy task in a society where there are ideas that HIV is created by the West and specifically targets non-believers and sexual minorities (Population Reference Bureau, 2001). According to Niang et al. (2010), Western Africa has faced issues around

effective HIV programming due to many refusing to not only believe that HIV is something brought over from the West, but also the idea that homosexuality is a false identity from the West. This, in turn, results in a lot of violence and rejection exhibited toward MSM, in particular, as was similarly reflected in the interviews (Niang et al., 2010). Still, despite efforts to engage religious leaders, there are many biases that remain in this community (Ansari & Gaestel, 2010). Therefore, organizations try to explain the lived experience of PLWH and the important role of religious leaders in supporting the spiritual health of PLWH (Ansari & Gaestel, 2010). This may help with existential feelings of loneliness and feelings of worthiness, an important step to treating loneliness, as discussed in Chapter 1 and throughout these interviews.

Another aspect that was highlighted throughout interviews and specifically used as evidence to support the “Existential Dread” subtheme was that providers saw several pressures within the lives of PLWH that ultimately resulted in their clients fleeing the country. Providers mentioned that sometimes they noticed this was motivated through a constant overhanging fear that someone would find out or the fact that someone did find out (HIV-positive status or presumed sexual preference because of HIV-positive status). This was similarly presented under the subtheme of “Confidentiality Fear” where providers explained that PLWH would hide their ART or at least ensure they did not take their medication in front of others to avoid feeling stigmatized. This is supported by findings in a study by Kalichman et al. (2019) that showed that PLWH who hide their medication show less adherence to their ART regimen. These behaviors, specifically motivated by internalized stigma, were found to negatively impact adherence to medication more significantly than high reported levels of depression (Kalichman et al., 2019).

To further touch upon the feelings of lack of worthiness, the lack of sharing is highlighted again. Providers reported not only an association between lack of sharing status and a decrease in



social and emotional support outside of care settings for their clients, but also an association with an increase in self-stigma. Participants noted that this self-stigma had a very strong effect on the existential loneliness that their clients experienced. At the beginning of diagnosis, providers believed that PLWH thought that their life was over. Providers perceived community groups to be vital during this stage to help with this existential loneliness and provide medical facts about the disease. In addition to general health knowledge regarding staying safe and transmission, providers believed that the education through such organizations show clients that they can have a family, and that they are not a bad person or cursed. Their culture might tell PLWH this, and these feelings were identified by providers to be associated with a lack of self-worth. However, when PLWH do not share, providers believed that everything builds up inside of PLWH, leading to not just this existential loneliness, but also the emotional and social loneliness. Providers perceived this to be since PLWH automatically self-stigmatize themselves by self-isolating and thinking that they do not belong in any group. After all, participants who reported clients sharing status said that their client felt more comfortable and relieved, stressing the importance of sharing status as part of treatment.

It was also noted by providers, however, that even though sharing in some environments – such as in LGBTQ spaces, with other PLWH, or in community organizations supporting individuals with such identities – can create connection, PLWH can still experience feelings of loneliness and rejection because of experiences with sharing with families and friends. Previous research has found that the loneliness gay men experience is not only associated with a lack of intimate relationships in their lives once status is shared, but also an unsupportive community and environment around them at broader levels (Rokach, 2014). This lack of social support can lead to many psychosocial concerns, particularly when considering that many LGBTQ express

lack of familial support due to their sexual orientation, and if support is desired, sexual orientation is oftentimes hidden, resulting in further psychological anguish (Rokach, 2014). The idea that lack of connection in one group (such as family) may contribute to feelings of loneliness for the individual, despite connection with a community organization, is supported by previous research focusing on the multidimensionality of loneliness (Rokach, 2014; Rokach & Heather, 1997).

Some suggestions by participants about how to combat loneliness in the context of Dakar and intervention-related work was to integrate respect for LGBTQ and care for key populations into the training of hospital and health center staff. Moreover, with the general lack of psychiatric care, there was a big push for treatment to both include physical and mental health aspects. Currently there is a heavy burden on all health professionals working with this population, given that PLWH cannot receive the care they need in this regard. This high burden, as shown in the responses and exasperation of many interviewees, is concerning, especially given the close connection to burnout with healthcare workers who are over-worked (Dubale et al., 2019). Additionally, attention is needed in relation to the poverty that affects the ability of PLWH to access care. Given that many services must be paid for, it is an added burden and can quickly result in PLWH dropping out of care. This is concerning because it has been found that poor ratings of quality of life amongst PLWH has been linked to depression and lack of social support, in particular (Adewuya et al., 2008).

All of the aforementioned points are relevant to loneliness because, as participants explained, these health centers often connect PLWH with community organizations who can help them process the experience of being newly diagnosed. Community organizations were reported to provide psychiatric services to treat mental well-being in the interviewees, since there

is a lack of psychiatric care country wide. These organizations can offer workshops and support groups by a specific identity within the population (e.g., women, LGBTQ), as described in these interviews, as well as that emotional and social support PLWH are seeking and lacking at the family level. Previous literature has found that intervention at the community level that is peer-based and provides peer-led group sessions to reduce perceived stigma and individual stigma helps to prevent the spread of HIV, increases adherence to ART, and decreases the overall community viral load (Lyons et al., 2017).

Although there was minimal distinction in responses between community health workers, health mediators, and physicians, the health mediators were more likely to mention the psychological effects of HIV and their clients' need for support. Moreover, those in higher profile positions (community health workers who were the presidents of organizations, the physician, and the health mediators) were much more likely to directly reference the key population, particularly MSM, in their responses. Others only had their responses address PLWH at large. Given the context of the situation, where the community health workers at AIDES Senegal ensured that the door to the building was always locked and that the building was unidentified (in an attempt to remove the stigma for clients, but also for the safety of the organization's employees), this is no surprise. These are blatant examples that show the fear of employees, and it was certainly valid since AIDES Senegal was shut down just three months after these interviews were conducted.

Finally, the other key population in Senegal associated with HIV, sex workers, was virtually entirely left out of interviewee responses, other than a couple of brief references by two participants. The literature shows, however, that even though sex work is legal (people can legally register as sex workers in Senegal), if someone contracts HIV, they are often without a

source of income. As one participant explained, this puts them in a situation where care is more difficult. This example, as well as many others with MSM, shows that although Senegal has made much progress in fighting HIV, there is a lack of a human rights-based approach, particularly around protecting key populations (Foley & Nguer, 2010). Therefore, even though the policy might be in place, the way providers perceive it to play out in society, within which religion and morality is engrained, impacts the way that PLWH are ultimately treated and the stigma and loneliness they will experience.

### *Limitations*

During the course of the interviews and data collection, there were many obstacles that limited the ability to collect quality data and conduct the research. First, the goal was to get at least 12 interviews, as it has been found that for qualitative studies to reach saturation, only about 6-7 interviews are typically needed to encompass approximately 80% of the themes (Crouch & McKenzie, 2006). In order to reach higher levels of saturation, 11-12 interviews are needed, which was the approach of this specific study (Crouch & McKenzie, 2006; Guest et al., 2006). Fortunately, 11 interviews were ultimately obtained, meaning that it is likely that very high levels of saturation were reached; however, the method of sampling was entirely convenience sampling. This limited the extent to which the full population of individuals employed in HIV-related care was represented. In this scenario, there was clearly an over-representation of community healthcare workers from community organizations and a lack of medical providers in health centers. Moreover, only one person who was interviewed at the level of community organizations worked with sex workers living with HIV; everyone else worked with MSM living with HIV. This was also a cross-sectional interview, meaning there was no follow-up with health

professionals. Longitudinal studies investigating perceptions of PLWH, not just professional opinions, would likely provide an even more comprehensive overview of this topic.

Other limitations include the fact that some interviews (3/11) ended early because the interviewees expressed the need to shorten the interview, due to other obligations they had that day. Also, there were many interruptions during interviews, such as phone calls, someone entering the office looking for something, or taking a break to share a meal together. Moreover, interview questions were very general and not specifically probing for information about other identities of key populations. Interview questions probed for information about the mental health of all PLWH – without any specific questions about intersectionality; therefore, the responses of interviewees were very closely linked to the intersection between sexual orientation and HIV. That is likely because, again, most interviewees worked with the LGBTQ population. As a result, it is difficult to expand findings beyond those with the intersecting identity of LGBTQ and an HIV-positive status in Dakar. More research is needed to further dissect different intersecting identities with HIV status. Finally, since these findings are from a qualitative research design, they lack generalizability. The entire population of this study was recruited via AIDES Senegal and their partner clinics. Therefore, the experiences these participants shared about their clients living with HIV might have been different from PLWH seeking support from other clinics. This does not allow results to be generalized to the entire population of PLWH in Senegal.

### *Future Directions*

The main future direction alluded to above, but clearly summarized by one interviewee, is as follows:

*“You have to focus on the key populations...When you talk about HIV in general, you won't have a lot of information because [Senegal] is very advanced in terms of treatment or management of HIV. The drugs are free, there is a lot of testing, we are doing well, but there are certain segments of the population that benefit less. So, I think that while all PLWH are important, the focus should always be on the key population.” (SN\_08)*

Since AIDES Senegal has now been shut down for the safety of its clients and employees after being outed by a local newspaper as an organization that fights for human rights for the LGBTQ community, it is unlikely for this level of research to occur in Senegal in the near future. Still, it informs areas for future research in countries and cultures where distinguishing between certain populations and having open conversations is not a safety concern.

### *Conclusion*

This research was useful in showing how providers perceive PLWH to experience loneliness and stigma and how it affects their disease management. In particular, it was found that providers believed that hesitation for PLWH to share status was motivated by the culture of gossip, the role of religion (particularly in relation to how intersecting identities are perceived), and lack of emotional support (particularly from the level of family). This rejection, fear, and stigma that encompassed their clients was perceived by providers to contribute to feelings of loneliness in PLWH. Moreover, providers explained that the societal stigma was oftentimes internalized by their clients and was reported as a contributing factor to lack of adherence to ART. Providers also noted there was minimal support outside of community organizations, and the feelings of worthlessness and meaninglessness were noted barriers to PLWH becoming connected with community resources to tackle their emotional loneliness. However, this research in Senegal was so closely linked to the identity of being a sexual minority and the key population

of MSM that it was exceedingly difficult to compare the opinions of health professionals on the experience of loneliness in PLWH with different intersecting identities (e.g., sex workers) (UNAIDS, 2018). Because of this, to better understand opinions of health professionals on loneliness in PLWH with different intersecting identities, there is a need to continue studying this topic. Since populations vary widely across countries, particularly in relation to cultural and social norms, a new sample outside of the Global South should be studied so that a country comparison of HIV provider perception of loneliness can occur (Kreuter et al., 2003).

## Chapter 3

### Loneliness and HIV in Central Pennsylvania, United States

#### Introduction

Dakar, Senegal presented its own set of circumstances in an urban setting in sub-Saharan Africa. It is equally important to determine whether cultural context plays a role in provider perception of these factors around loneliness, stigma, and available interventions for PLWH by exploring the topic in a completely different region of the world. In Central PA, there is an ability to both explore a different context (a Western country versus a country in the Global South) and a different geographical setting (a rural region, rather than an urban area like Dakar). This qualitative study explores opinions of health professionals on loneliness experienced in their clients living with HIV. Eligible participants were recruited from community organizations (non-profits) and local health centers throughout PA in the towns and cities of State College, Williamsport, and Harrisburg. They included physicians, nurses, mental health therapists, social workers, and case managers who all had experience working with people living with HIV. These individuals offer valuable insight into this study given their training and expertise in different biopsychosocial aspects of HIV. A total of 12 of these providers specializing in HIV-related care responded to a semi-structured interview about their perceptions and beliefs regarding loneliness, stigma, available support or interventions, and the lived experiences of LGBTQ-identifying individuals and PWID to explore different intersecting identities with HIV status.



There are 1.2 million PLWH in the US, a country where PLWH are disproportionately living at or below the poverty line, more likely to be a racial minority, and more likely to be experiencing homelessness than the average American adult who is HIV-negative (CDC, 2021). In Central PA, representing the counties from which interviewees in this study were recruited, there are between 1500-2000 PLWH out of a statewide total of approximately 36,000 (Pennsylvania Department of Health, 2019). In the US, 75% of PLWH are men, just over 50% identify as LGBTQ, just under 50% are Black, and almost 75% are 40 or older (CDC, 2021). In Central PA, key populations that are of interest because of their higher rates of HIV include LGBTQ-identifying individuals (largely gay men and trans women) and PWID (Pennsylvania Department of Health, 2021). According to the Pennsylvania Department of Health (2021), in 2018, MSM made up 47.7% of new infections throughout the state, while injection drug use accounted for 9.9%. Given that less than 3% of cases were transmitted through both MSM contact and injection drug use, this will not be explored for the purposes of this study (Pennsylvania Department of Health, 2021).

Again, since members of the LGBTQ community are more highly stigmatized in rural areas, because of lack of community connections, there are concerns about how stigma impacts their ability to seek consistent treatment and connection with other community care networks (Giano et al., 2020). In terms of PWID, the rural setting is shown to increase feelings of social and emotional loneliness, which is in turn associated with increased IV drug use (Hosseini et al., 2014; Hsieh & Liu, 2021). Although there is quite a large presence of PWID in rural settings of the US, specific services for PWID populations, outside of traditional Narcotics Anonymous (NA) or Alcoholics Anonymous (AA) groups that take in people battling addiction, is both understudied and underrepresented (Paquette & Pollini, 2018). These findings show that the

setting of rural America impacts mental health of PLWH, but particularly those of key populations.

Although the CDC (2021) projects that 98% of PLWH have health insurance to cover their care and ART, it is quite a complicated system. For example, although about 50% of PLWH are eligible for coverage through Medicaid, there are still 12 states that did not expand Medicaid under the Affordable Care Act (ACA), making it very difficult for PLWH without healthcare to access services (CDC, 2021; Graydon, 2000). Although the ACA resulted in no individual being denied coverage due to a pre-existing health condition, including HIV, it is still an option for states to expand Medicaid to include those at 138% below the Federal Poverty Line (HIV.gov, 2021c). Without this option, oftentimes PLWH are not eligible for Medicaid until an official diagnosis of AIDS (HIV.gov, 2021c).

Fortunately, the Commonwealth of Pennsylvania expanded Medicaid in 2015, so PLWH in PA can benefit from such services (Kaiser Family Foundation, 2015). Moreover, according to Kaiser Family Foundation (2019), about 50% of PLWH have coverage through the Ryan White HIV/AIDS Program, a program through the federal government that supports PLWH in obtaining and connecting to comprehensive care that uses a wraparound of services model (a one-stop shop for physical, psychiatric, and pharmaceutical needs, etc.). There is also an AIDS Drug Assistance Program that specifically helps those without insurance access ART (Kaiser Family Foundation, 2019). In addition to providing assistance in paying for drugs, according to the Pennsylvania Department of Health (n.d.), this funding will also cover CD4 and viral load tests. The Special Pharmaceutical Benefits Program (SPBP) through the PA Department of Health is another avenue of support; however, the state encourages people to use this as a last

resort, and only individuals who have gross annual incomes below or equaling 500% of the Federal Poverty Line are eligible (Pennsylvania Department of Health, n.d.).

Although the US government has explicitly voiced their commitment to ending HIV in the US and around the world and partners with global actors such as UNAIDS, the Global Fund, WHO, private and public sector institutions, other governments, civil society, and PLWH, there are challenges that remain (HIV.gov, 2021b). In addition to the barriers stated above that restrict eligibility for insurance to cover both care and treatment, there are challenges in strengthening community organizations, state and local governments, and networks of PLWH to address inequities including transportation, affordable housing, and other social determinants of health (Gant et al., 2012; Zeglin & Stein, 2015).

Again, as seen in the interviews in Senegal, the same method was adopted to obtain all information from health professionals (e.g., clinicians and case managers) who are experts in the field of HIV and regularly interact with PLWH. In this context, it was important to do so given the sensitive nature of research directly on PLWH. This population has been historically threatened through research, making them one of the most protected vulnerable groups in human subject research (Shivayogi, 2013). Moreover, provider perception of this experience is valuable information on its own given that previous research has shown that providers report a similar understanding as their patients of how the condition affects their patients (Street & Haidet, 2011). That being said, this has typically only been the case when there is active participation between the provider and the client and when they were of the same race and ethnic background (Street & Haidet, 2011). Other literature also points to how providers overestimate negative impacts of disease on clients (Hall et al., 1999). Still, taking all this into account, these providers were encouraged to provide examples and recount stories of instances with their clients.

Therefore, although there are noted limitations with this approach, a recount of experiences by providers presents a relatively complete picture of their perception of PLWH in the region who are engaged in care.

The following four research questions were investigated through this research: 1.) How do providers believe PLWH experience loneliness, and how does it impact the lives of their clients? 2.) How do providers believe stigma and the social environment of Central PA impact the loneliness experienced by PLWH? 3.) What available support or interventions do providers believe are in place to respond to loneliness experienced by PLWH? 4.) What are provider perspectives/beliefs about how the different intersecting identities of LGBTQ or PWID impact the experiences of loneliness in PLWH?

**Table 4: Research Questions Central Pennsylvania, United States**

Research questions	Items in Instrument That Connect to Research Question	Analysis Method (software), Deductive/Inductive	Identified Themes
RQ1.) Provider perspectives//beliefs about how PLWH experience loneliness/impact on their lives	6a, 6d, 7a, 8a	MAXQDA, inductive	<ul style="list-style-type: none"> <li>• Internal Processing</li> <li>• Trauma</li> </ul>
RQ2.) Provider perspectives//beliefs about how stigma and the socio-cultural context of Central PA affect loneliness in PLWH	6c, 7a, 7b,	MAXQDA, inductive	<ul style="list-style-type: none"> <li>• Internal Processing</li> <li>• Healthcare System</li> </ul>
RQ3.) Provider perspectives//beliefs about available support/interventions	7a, 9a, 10a	MAXQDA, inductive	<ul style="list-style-type: none"> <li>• Trauma</li> <li>• Healthcare System</li> </ul>
RQ4.) Provider perspectives//beliefs about how different intersecting identities (LGBTQ versus PWID) impact the experiences of loneliness in PLWH	6b, 7c, 8b, 9b, 10b	MAXQDA, inductive	<ul style="list-style-type: none"> <li>• Relationships</li> </ul>

Outline of research questions as well as the corresponding items in the instrument, the listed analysis method, and the identified themes linked to the research question

## Methods

A total of 12 participants were recruited to participate in a semi-structured interview. Participants were recruited through word of mouth amongst colleagues at AIDS Resource, a local non-profit in State College, and through word of mouth from colleagues and partners of Penn State Hershey. Participants were asked about their professional opinion about loneliness in their clients living with HIV who were part of either two key population groups: LGBTQ or a PWID. Participants were 18 years or older, English speaking, and either a provider, case manager, or mental health therapist who works with PLWH. Ethical approval was obtained through the Institutional Review Board at Penn State University. Since the research involved speaking to health professionals and not the direct population, it was classified as exempt. Still, informed consent was obtained and accounted for verbally before each interview began. The details of the research and where the findings would be disseminated were shared, and participants were asked if they had any questions before agreeing to complete the interview.

The interviews lasted between 30 and 40 minutes and were all conducted via Zoom in English. Before the recording began, participants were renamed with their corresponding participant ID number by Laura Guay, a researcher who was trained in the Stress, Health, and Daily Experiences Lab at the Pennsylvania State University. During these interviews, Laura Guay used a script to introduce herself to the interviewee and explained the reasons and motivations for the research before obtaining verbal informed consent. After this, a digital recording began. Then, basic demographic information was collected, and participants were asked questions about their clients feeling withdrawn and isolated from people and experiences in their lives, from themselves, and existentially. Probing around stigma, adherence to treatment, lifestyle behaviors, and loneliness interventions was also performed, considering the desire to

differentiate between the experiences of PLWH who also either identify as LGBTQ or PWID. The format involved an interpersonal interview, as open-ended questions were asked, and there was probing for in-depth responses about providers' opinions, experiences, and background knowledge (Creswell & Plano Clark, 2018). The specific questions can be seen listed under "*Interview Script Central PA*" in the Appendix. Since the interview was semi-structured, in some interviews, questions were skipped because they had already been answered in different questions. In other interviews, additional follow-up questions were added to probe more into some of the new ideas that participants were sharing.

Analysis of the data first involved transcribing the interviews to provide a verbatim transcript. All identifying information, such as the names of the individuals interviewed, was removed. Instead, their study participant number was the sole identifying piece of information. They were labeled as "PA\_01," for example, interpreted as "Central PA, US\_Participant 1." Transcripts were uploaded into MAXQDA, as mentioned in Chapter 1, and analyzed using the Framework Analysis method. Now, even though there was close reading of the data throughout this entire analysis process, the individual who analyzed the data in Dakar was the same individual who analyzed the data in Central PA: Laura Guay. The concern here is that although extracting information through this qualitative analysis allows a close review of data, it may result in projecting information, given that it will be viewed and assimilated through the reviewer's own biases. This has been recognized in the methods, and it was guarded against through the reviewer, Laura Guay, leaving three weeks between the analysis of the Dakar and Central PA data. Moreover, the codes within MAXQDA that were assigned to the data collected in Dakar were not present in the MAXQDA sidebar when analyzing the new data from Central PA, as a new project file was created. Still, one person was extracting the themes out of both sets

of data which could make them more similar than they might actually be. This is because the individual reviewing this is more likely to perceive and extract similar themes both because of their position, but also because they are sensitized to the originally identified themes and might be more vigilant to extract similar themes from other datasets. Although there were noted measures to guard against this, it was not a perfect process, and that is a noted weakness.

In order to better understand provider beliefs about loneliness and overall mental health of PLWH in Central PA, it was necessary to speak with providers, case managers, and social workers who work with PLWH. The organizations that were represented in the interviews included health professionals at REACCH Clinic, Penn State Hershey Medical Center, and Alder Health as well as case managers and mental health therapists at AIDS Resource and Crossroads.

## Results

**Table 5: Interviewee Characteristics Central Pennsylvania, United States**

Characteristics		Central PA, United States		
		Mean/Percent (%)	SD	Range
Age		37.17	7.08	24-46
Gender	Male	17%	-	-
	Female	75%	-	-
	Non-binary	8%	-	-
Race	White	92%	-	-
	Asian	8%	-	-
Ethnicity	Hispanic/Latino	17%	-	-
	Non-Hispanic/Latino	83%	-	-
Subregion	Harrisburg	50%	-	-
	State College	17%	-	-
	Williamsport	33%	-	-
Education	Bachelor's	42%	-	-
	Master's	33%	-	-
	Doctorate	25%	-	-
Employment	Physician (specializing in HIV)	17%	-	-
	Nurse (specializing in HIV)	33%	-	-

Table outlining demographics of all participants, since all 12 interviewees provided responses for all items above

Participants included providers ranging from 24 to 46 years old with an average of about 37 years old. Nine participants (75%) were female, two participants (17%) were male, and one participant (8%) was non-binary. Moreover, 11 people (92%) were white, two people (17%) were of Hispanic/Latinx origin, and one person (8%) was Asian. Most people had either a Bachelor's degree (42%) or a Master's degree (33%), with three people (25%) having a Doctorate degree. Participants had been working in the field of HIV for about 9.25 years, on average, and their positions included either physicians, nurses, mental health therapists, case managers, or social workers. All interviewees stated they had either current or previous experience working with PLWH with either the identity of LGBTQ or PWID and were asked to tailor answers to these categories throughout the interview. For the purposes of these interviews, participants were not asked to talk about the cases of all three intersecting identities (PLWH, LGBTQ, and PWID). Geographical sub-regions in which the participants worked included Harrisburg, State College, and Williamsport.

#### **Four Themes: Internal Processing, Trauma, Healthcare System, Relationships**

Four major themes were identified from this data. From these four major themes, stratified based on whether reflecting about PLWH at large versus PLWH with either the intersecting identity of LGBTQ or PWID, a total of 10 subthemes were identified. These subthemes ultimately all answered the research questions as seen in the data presented in Table 4. Identified subthemes addressing Research Questions 1-3 allow for a comparison of social environments between Dakar and Central PA to occur. Identified subthemes addressing Research



Question 4 allow the new Research Question that was developed after Study 1 in Dakar to be addressed:

**Table 6: Identified Themes Central Pennsylvania, United States**

Theme	Sub-theme and Corresponding Research Question
Internal Processing	<ul style="list-style-type: none"> <li>• Denial – RQ1</li> <li>• Self-stigma – RQ2</li> <li>• Self-acceptance – RQ4</li> </ul>
Trauma	<ul style="list-style-type: none"> <li>• PTSD – RQ1</li> <li>• Trauma-informed care – RQ3</li> </ul>
Healthcare System	<ul style="list-style-type: none"> <li>• System limitations – RQ2</li> <li>• Education – RQ2</li> <li>• Healthcare team – RQ3</li> </ul>
Relationships	<ul style="list-style-type: none"> <li>• Relationship with addiction (IV) – RQ4</li> <li>• Shared identity communities – RQ4</li> </ul>

Representation of themes and sub-themes identified through framework analysis of interview transcripts from Central PA

### Internal Processing

The way providers perceived that their clients were individually impacted by HIV status was a common occurrence throughout interviews. One participant stated these processes:

*“There's the denial and then there's the fear that people are going to find out, but then there's the I need to maybe be on the billboard, the face of HIV” (PA\_02).* As other participant data was reviewed, three subthemes emerged: denial, shame, and acceptance; therefore, they are the three resulting identified sub-themes.

### Denial

Participants often spoke to how, particularly at the beginning of the diagnosis, but sometimes years later, too, they believe their clients are in shock and do not want to be seen as someone living with HIV. They believed that many PLWH never thought this was going to

happen to them. When it does, they try to ignore it, often affecting their feelings of loneliness, mental health, and subsequent care related to their HIV:

*“I have a patient...in the hospital, and I know he doesn’t take his ART, will adamantly say he still calls for his refills, his drug levels are still negative, came in with an infection which might have been a component of his CD4 count being low. And is still not recognizing, ignoring the fact that the illness is real. Part of his hospitalization is actually related to that.” (PA\_01)*

*“Some people...don't take [their] meds, [don't come to their] appointment...just like put [their] head in the sand. If I don't talk about it or don't think about it, it's not going to happen. I don't necessarily deserve to be healthy. Certainly, has a huge impact because I think loneliness can, if not addressed immediately, easily morph into severe depression...then it's harder to reach people too and have them be engaged in their care.” (PA\_11)*

Denial was also closely linked to negative overall effects on well-being, and this idea that providers perceived their clients to feel undeserving of good health. Not only would this affect other mental health-related concerns, but many participants also explained how the isolation or separation from treatment can lead to their clients dropping out of care and loss to follow-up. However, this experience and these feelings were also influenced by fears around sexual and romantic relationships:

*“I feel like [my patients who struggle with their new diagnosis] haven’t gotten over their diagnosis, and usually will struggle with new partners, with what to say and how to identify themselves or when to mention or disclose that they’re living with HIV.” (PA\_01)*

*“I think it's particularly part of the conversation early in the diagnosis. So, I think that many people...express feeling shocked: ‘How did I get this?’ But then think: ‘I can never have an intimate relationship with someone else again’ ...so that can be very isolating. There are some who step away from relationships because they don't want to have that conversation.” (PA\_05)*

This close connection between feelings of denial, which providers believe are particularly common at the beginning of diagnosis, and general disbelief of having contracted the virus being motivated by struggles to maintain relationships provides an appropriate transition into the next identified subtheme: self-stigma.

### *Self-stigma*

Self-stigma was also commonly reported in interviews. Many participants noted the self-stigma PLWH feel, given the stigma surrounding lifestyle choices and the diagnosis itself. Providers perceived this to isolate and exclude their clients and not allow PLWH to truly be themselves. This takes a toll on their mental health:

*“We’ve had patients who have said, ‘I knew this was a risk. I never thought this would happen to me. I thought that I was going to be smarter and make smarter decisions. I wasn't gonna be ‘one of those people.’” (PA\_11)*

*“Whether it's sexual activity, whether it's drug use, so many folks come in and beat themselves up and say, ‘I wish I didn't do that. I wish I wouldn't continue to do this,’ as a reflection of them being upset with themselves and taking on stigmatizing language or attitudes towards their own behavior or identity. It's not unusual to see particularly early in their HIV diagnosis.” (PA\_05)*

Again, in alignment with denial being perceived by providers to occur soon after the diagnosis, this shame and self-stigmatizing behavior was also noted by providers as occurring around initial diagnosis. Other participants described how this then opens the door for a conversation regarding the need to change this self-stigmatizing mindset. It is a feeling of not being worthy or deserving and that PLWH did this to themselves that is trying to be broken. Once again, providers perceived these feelings to translate into relationships. This time, it was noticeably in the romantic partner category – with slight mention of family, friends, and faith communities – impacting self-worth:

*“[Clients will say] I’m managing this, [family members] don’t need to know or maybe there is some internalized stigma involved there and they might feel ashamed to let them know.” PA\_08*

*“A lot of my clients feel that they’re dirty, they’re not lovable, nobody wants them. They can’t reveal their diagnosis for fear of jeopardizing relationships. They are you detached from personal relationships. Maybe they want to have strong relationships with family members and peers, and now that they have this new diagnosis, this new burden, they are unable to continue those relationships and feel some despair from that.” (PA\_03)*

Some interviewees mentioned how they believed that advancements within the field of HIV have helped reduce some of this shame, internalized stigma, and lack of self-worth. Again, this was particularly in the realm of romantic relationships:

*“Over the years, the medication has gotten so much better, and a lot of [PLWH] will almost be undetectable. So, they don’t necessarily have to disclose to every partner that they have HIV. I think that has helped significantly just so that they don’t necessarily have that stigma attached to them or disclose that to everyone.” (PA\_04)*

*“I think even folks that have been diagnosed for 20 years, I've had people just in the past year in tears, ecstatic that they really don't have to have that anxiety every time they have sex with their longtime partner, as they have greater confidence knowing that when they're on the treatment and undetectable the risk of transmission is zero. That has certainly improved sexual relations which ties into support in relationships and loneliness.” (PA\_05)*

However, despite more confidence in sexual encounters and building relationships that provide support, the fact that HIV is not your typical chronic illness is perceived by providers to weigh heavily on PLWH. In addition to PLWH oftentimes living with other chronic illnesses (diabetes was commonly mentioned), providers believed that HIV is a chronic illness for which individuals are treated much differently than others living with another type of chronic illness. This was reported to oftentimes affect personal relationships and inner self-worth:

*“One of the best examples I heard from a client is they've been positive for a while and their friend was diagnosed with cancer. And the client said to me, ‘I feel badly for my friend, and I want to be there to help. At the same time, I'm living with [HIV] that affects my health and people don't want to be there to help me because they say I brought it on myself.’” (PA\_07)*

*“[When interacting with people they don't know yet, PLWH are] kind of feeling it out because they have this feeling of this is something to be ashamed about. It's because of this perception that HIV is a disease of behavior...so I think that impression really, really impacts people.” (PA\_08)*

So, despite the aforementioned medical advancements helping in one regard, the shame around the illness remains. Participants noted that awareness and public perception might be a contributor to this, specifically in the context of a rural setting where there are fewer PLWH:

*“Stigma is huge. I think our patients really have so much shame when it comes to HIV. Because it really is not accepted any more than it was before, but people just don't really talk about it. It's not in the news anymore. People don't even really know it's a problem anymore.” (PA\_12)*

*“I do think that the experience of those living in rural areas can be generally a bit different in terms of their safety and acceptance...that really changes who they interact with and talk to and how that status is shared and how the community understands and respects people living with HIV. So, you have to be very thoughtful and careful about sharing status with others and how that factors into their relationships and getting supportive people.” (PA\_05)*

### *Self-Acceptance*

Again, as participants explained above, although the perception is that this illness is chronic but livable, HIV is not your typical chronic illness. When addressing acceptance, providers expressed the belief that people come to terms with their status in different ways:

*“I think acceptance is one thing because if it's that fear like someone's going to find out that I have HIV, working on that, and what does acceptance look like because it's different for everybody.” (PA\_02)*

Participants commonly noted that the difference in acceptance is really impacted by the age of their clients, with older clients transitioning away from some support, and instead, openly sharing their experience with others:

*“Our older population, most of them have had [HIV] for a long time, so their needs may be a little bit different than our younger population...There are some middle to older adults who are outspoken about their diagnosis and well known in the HIV community. So, they may have come to terms a little bit more with their diagnosis than some of our younger populations.” (PA\_03)*

*“There are some [clients] that will tell a stranger, ‘Hey I have HIV, this is what you need to do to protect yourself’ and like in your face. Old timers are more likely to share because they want to give that ‘here’s what I’ve had go on in my life, if I can tell you this, to help you.’” (PA\_07)*

So, the diagnosis becomes part of the identity of some, particularly for older people, *“as their purpose in life is for education awareness and stigma reduction” (PA\_11)*. The actual physical evidence of becoming undetectable was another perceived key feature by providers in the acceptance process for PLWH. This was thought to especially occur when PLWH see their labs improve. Additionally, there was a bit of an emphasis on LGBTQ patients here, particularly their role in advocacy, and how coming out impacts their journey with acceptance in a unique manner:

*“For the LGBTQ community, in particular, for some of our patients, they bring awareness to that lifestyle and acceptance. I think there’s a couple that I can think of, they do drag shows, benefits, fundraisers things like that, to get support from the community and awareness.” (PA\_11)*

Focusing on self-actualization, self-acceptance, and self-worth was a commonly discussed strategy by providers when describing this nature of care and particularly corresponding with LGBTQ and PWID identities:

*“We’re always working to find that self-actualization point. We do a lot of what’s called radical acceptance work. It’s finding that internal validation and most of the people I work with, it’s a self-esteem issue. So, we work to increase self-esteem, improve who you’re willing to spend time with, eliminating toxic people from their lives.” (PA\_04)*

*“Also, that emotional part of trying to get rid of stigma and help the people who don’t feel like they’re worth anything because of what they’ve done in the past, whether it’s IV drug use, MSM, heterosexual contact, anything, getting their self-worth elevated to help with treatment.” (PA\_10)*

### Trauma

Although internal processing certainly speaks to the perceived provider perception of experiences of PLWH, another battle providers suspect PLWH face is trauma. Providers explained that this was sometimes related to the way PLWH had contracted HIV, their experience in society while living with HIV, and always about the care that these medical providers, case managers, and social workers provided.

### PTSD

To continue noting the age phenomenon that was presented above, but also how the phenomenon of this experience is perceived by providers to affect the overall treatment plan of PLWH, one participant explained:

*“Some of my patients who are young who are diagnosed who really struggled with ART adherence...there is a component of them feeling depressed from their diagnosis...I think there’s a lot of, I don’t know if it’s truly defined PTSD, but I think it does bring up some kind of PTSD like symptoms of the time they were diagnosed, when they were diagnosed, how they were told they were diagnosed.” (PA\_01)*



The theme of the diagnosis being a constant reminder does not always adhere to age, though. Providers noted that a more common experience of general exhaustion is felt by PLWH possessing this identity due to the responsibilities that go along with it:

*“I have individuals that don't want to go to providers...it's just a constant reminder of their status. Even if they've been undetectable and have managed their HIV for years, they still have to go to this physician all the time, and some people just get sick of it and fatigued and that goes along with taking medications as well. Every day they take that pill; it's a constant reminder...I had to go with an individual to the provider, because they just don't like going to the physician. They don't want to have to tell their story, and I did most of the talking for that client because they just didn't want to.” (PA\_09)*

Participants expressed some hope in the injectable medications coming out, since clients only need to go every so often and will not be reminded of their diagnosis daily. For now, though, a pill is still the most common medication. In addition to the medications being a constant reminder, providers explained that sometimes the way people contracted the virus, or the way stigma is directed towards their clients, connects with this sub-theme:

*“A lot of times, how they became infected: was it an assault? It could be any type of assault: sex work, injecting drugs.” (PA\_02)*

*“The vast majority of our patients have severe traumatic histories...I think in a way that kind of kills some of your passion, sometimes for different things, your purpose. I mean we have a very high percentage of patients who are taking their meds on a daily basis. They're healthy as far as our standards go...I would say that the medication has given them a new lease on life because you can live a full life. It's everything else that can affect them.” (PA\_12)*

Other participants explained that their clients, mostly those who were older, saw many friends die from AIDS, since they lived through the beginning of the virus. So, providers believed that their diagnosis brings up old memories and traumatic experiences. At the same time, though, since these clients lived through the beginning of the virus, they witnessed the response by the medical community, which also brings up conflicted feelings about current events:

*“In older gay men, so many friends died, and actually I think with COVID that brought a lot up. And on the flip side of that, it brought up, why did they work so fast to try to get a vaccine for COVID, and why didn't they do it for HIV when the science is there? Once again, we're put on the back burner. I think there's going to be a whole new mental health wave with that” (PA\_07)*

Although HIV treatments have come a long way, the fact that the disease still is not given as much attention as other infectious disease pandemics creates deep frustration that clients are forced to process. It also points to the importance of trauma-informed care that must occur at all care and treatment sites.

### *Trauma-informed Care*

As a result of respecting the traumatic situations providers thought PLWH experience, it is important to recognize that providers also perceived PLWH to be exhausted. Moreover, they considered their clients to be in a state of fear and constant worry about how people in their lives will react if they discover this about them:

*“They're scared they will be looked at differently. They're worried how the person is going to react. They're worried about giving it to somebody else. They don't know how to go about informing loved ones or friends about their new diagnosis... We have a team of*

*case managers who can provide emotional support and scripting with how to [disclose status].” (PA\_10)*

Therefore, those on the care team, given the minimal outside support (participants indicated either one family member or maybe a partner), need to be aware of this and work to build trust and a collaborative environment where PLWH feel safe and that their basic needs are being met. If not, participants explained that it is easy for their clients to internalize everything. As a result, empathy and compassion and anti-stigma talk is needed from the care team:

*“Compassion and empathy need to really go a long way, because you don't know the baggage that they're walking in with, whether it be from that week or from years past. So, a sense of understanding of where they're at develops a really good sense of trust and rapport, to the point where they are really listening to you, and they want to engage with you and then with information that you give them, then they want to engage with themselves.” (PA\_08)*

*“We talk about this isn't you, this is just something that happened. We don't want to classify it as a chronic illness, but we often tell people that are newly diagnosed this is just something that can be managed. We don't focus on that negative aspect of stigma.” (PA\_09)*

This support and relationship building, as well as adjustment by those on the care team to meet the needs of the client, are the major components of trauma-informed care.

### Healthcare System

Another recurrent theme arising from the interviews was how providers perceived PLWH to experience the US healthcare system, the care team to be engaged in supporting PLWH, and the role of HIV education in supporting PLWH.

### *System Limitations*

Many participants indicated how they believed the presence of certain barriers, including rural barriers and not having access to certain basic necessities, make accessing needed care or staying in care difficult for their clients:

*“People might be lacking transportation; they might not have food...There's lack of affordable housing. A lot of our patients have criminal backgrounds, a lot of our patients have poor credit, or both of those things. So, trying to find a decent apartment with those things from a decent landlord is really, really hard. And so, we end up working with a lot of slumlords for lack of a better word and apartments that are less than ideal and maybe puts people back into neighborhoods that really are not the healthiest for them.” (PA\_12)*

In addition to the difficulties with housing (which were amplified due to COVID-19) and transportation, providers believed that PLWH are often faced with the burden of ensuring that they have a certain job and follow a certain lifestyle if they want to be engaged in care:

*“One specific example I can think of, [the client was] worried about getting another job...they were worried about getting health insurance because of their diagnosis, because it costs so much to treat HIV. They felt like they didn't have a purpose anymore because they were stuck doing something they didn't want to do, but they were tied to it because of their health needs.” (PA\_03)*

In addition to how providers perceived HIV status to impact general lifestyle choices, sense of purpose, and employment, participants explained that lack of psychiatric resources in rural areas also presents challenges to clients:

*“Even in patients who've had this for years and years, and we actually have on site psychiatry as well now, getting into mental healthcare is really challenging. There's a*

*shortage of that in our area to begin with, especially that takes Medicaid insurance. And then, on top of it, a lot of those patients struggle to remain engaged in care and stay on their medicines. So, they burn bridges with their providers, they have to find a new place to receive care.” (PA\_03)*

*“The other thing is [getting into psychiatry] timely, because when [clients are] asking for help or crying for help, that might be the moment to have an intake when the intake could be scheduled in a month or a month and a half...Even though we work with psychiatry, it’s very hard to get some of our patients connected to psychologists or therapists or even mental health.” (PA\_01)*

The lack of quality psychiatric care was a particularly noted difficulty throughout COVID-19, adding to the already strained system:

*“With the pandemic, loneliness that I am seeing has significantly spiked. I think we were taking 18 to 20 referrals a day some days for new clients. And so, I think that has really impacted people feeling isolated and lonely and drug use has significantly increased, alcohol usage significantly increased. We are in desperate need in Centre County of additional providers. Every psychologist, every psychiatrist, every counselor is full.” (PA\_04)*

In addition to psychiatric services, the way that the US healthcare system operates was a perceived noted barrier in providing quality care. Still, with the way that different community organizations operate, and particularly Ryan White funded programs (named after the US teenager who died as a result of contracting HIV/AIDS from a blood transfusion), providers believed that there are ways to work around this to ensure comprehensive and quality, well-rounded, care:

*“So, as a Ryan White program, one of the things is that we have team members who are in good communication with their patients. So, we have case management, we have pharmacists, we have nursing, we have [physicians], and I think what’s nice about that mix is that some patients will identify better with someone on that treatment team, and I usually find that that’s the person where if something’s not going right, that’s who they’re going to reach out to.” (PA\_01)*

*“In our program, we have two therapists. We also have, within the last six months, a psychiatrist who works remotely. We’ve had the counseling for a long time now, but now we’re able to get some of our patients who we identify as having that loneliness, that anxiety, depression, PTSD, we’re able to get them linked to our psychiatrists and our therapist and started on medication and monitor them regularly in hopes to get their emotional state a little better.” (PA\_10)*

Therefore, although there are system limitations, providers reported that the healthcare team works to find solutions and models to provide the best comprehensive care, treating the physical illness, but also looking at the holistic picture.

### *Education*

In addition to barriers to care, providers noted that education impacted the care system. Although more specifically targeting the general community, providers believed that it ultimately benefits PLWH, given that participants spoke passionately about how education is low in the region:

*“Stigma is an issue everywhere with people living with HIV, but especially in Central PA, in rural communities, when the education level around HIV is low and there’s a lot of stereotypes and misconceptions about HIV.” (PA\_08)*

*“And unfortunately, I think a lot of the general public, because they don't deal with HIV, they don't know a lot about it. They feel that stigma is still there, like if I kiss this person, I'm going to get HIV, if I share their spoon, I'm going to get HIV, but you can't pass it that way. So, a lot of what we do is education, try to outreach to the public...we set up a table, have free HIV testing, and we educate and that's important for what we do.”*

*(PA\_10)*

Given that this contamination fear continues to exist today, it is no surprise that participants frequently noted that the beliefs that existed at the beginning of the crisis (e.g., HIV being spread through saliva and only being present in gay men) continues today in some forms:

*“I mean the client stories that we hear from 20 years ago of like they had their own plates, their own towel, their own silverware, just talk about loneliness, like, you don't hear that as much, but we still hear stories, which is insane. It's the lack of education or wanting the education. That information is out there, it is such a simple search.”* (PA\_07)

All of this points to the necessity of keeping clients in care and offering them the services that are available through the specific health center or organization. Participants explained that these efforts continue in some capacity, despite less of an investment in education:

*“Our funding has been cut for a lot of the educational programs...it's actually nonexistent. Most of our prevention funds are put into making sure our clients are engaged in care for their adherence to medications and giving necessary referrals.”*

*(PA\_09)*

### *Healthcare team*

One of the noted areas of support for PLWH, as expressed by interviewees, was through their healthcare team. This included both psychological and medical support in centers, case management, and community agencies:

*“The agency in general is...they're like the most caring people. They do anything for the people that they serve...they're very knowledgeable and keep up on things.” (PA\_02)*

*“Our physicians and providers and even our nursing team, we're constantly viewing webinars and reading articles and we're up to date on the best way to care for men who have sex with other men, with IV drug users. There's no stigma...we provide really, really good care.” (PA\_11)*

The noted ability of the healthcare team to adapt to situations, such as violence directed towards organizations, also shows how they support clients and gives a more comprehensive picture of their role:

*“Before I started, rocks had been thrown through our windows. So, it made it hard for clients to feel safe to come in. Our office doesn't have any sort of signage saying that this is a resource so that we can be as discreet as possible. As far as clients, I know there's a few that refuse to come into the office. They don't want any association with it. I've met clients at Burger King to go over paperwork and such so they don't have to face that and possibly come under scrutiny.” (PA\_06)*

The healthcare team was also described in interviewees as playing a major role in helping PLWH better experience relationships in their lives:

*“We do a healthy relationships intervention. It's an evidence-based intervention where people talk about disclosure and situations. It's supposed to get people to share their*



*positive experiences so that individuals who haven't shared yet, they can share that experience and see that it doesn't have to be this negative situation.” (PA\_09)*

### Relationships

In addition to the above-listed relationships that are formed with health professionals when connecting to care, there is support outside of this structure; however, providers believed this very much depends upon whether the PLWH identifies as LGBTQ versus a PWID.

### *Relationship with Addiction*

Many interviewees specifically pointed to IV drug use and how they perceived the relationship PLWH have with their substance often impacts their personal relationships, as well as their lived experiences and sense of purpose, and intersects with their HIV status. Providers believed that asking for help is a significant difficulty. Moreover, IV drug use was also described as resulting in things like increased rates of loss to follow up and unstable housing, given that people are dealing with an addiction in addition to their HIV status:

*“And then for injection drug use and just substance use in general, there’s a lot of stigma I see actually asking for help...connecting with mental health services.” (PA\_01)*

*“The people who use injection drugs, they tend to fall back on other things rather than their responsibilities. I have clients who struggled to get to their physician's appointments because they don't have that support. They have us, but sometimes they don't feel like they can fall back on us. They would rather deal with things on their own, which can be isolating.” (PA\_06)*

Some participants explained that they believed part of this to be attributed to the self-stigma, and asking for help largely depends on where their clients are in their recovery, or whether they are in a healthier place with their addiction:

*“One of my newer patients didn't want to disclose to me that he uses methamphetamines, but he disclosed to the provider when she saw him. So, there is a sense of loneliness, and until a patient can become comfortable with us, might not want to disclose [IV drug use].” (PA\_10)*

Moreover, providers believed that there is a community that is created amongst PWID living with HIV, which can have a negative impact on their recovery, sense of purpose and worth, and battle with loneliness:

*“Methamphetamine use is very prevalent among MSM who are HIV positive. We have several patients who are in a group together. They have sexual relations, they inject methamphetamines. There's a sense of loneliness and that they only can feel supported while they're doing those types of things. They definitely have that feeling of unworthiness and loneliness but they're with another person. They just continue to be in this terrible cycle.” (PA\_10)*

*“There has been a history of some clients using support group to find other people who use drugs. I think that's it's interesting because maybe there's the component of addiction...and then, on top of that, for some clients who are using, they try to find community among other users to sort of address that loneliness.” (PA\_08)*

In addition to how this shared community of PWID living with HIV can positively and negatively affect loneliness, self-worth, and well-being, providers believed that it is often difficult for people who are actively in addiction and trying to get sober to find community. This is because a lot of their friends are actively still using drugs, and PWID may not want to associate with that anymore. The way that society views addiction is another challenge providers perceived PWID living with HIV to face:

*“I think just the physical and mental health of addiction is so complex. And I do think they're judged harsher, and it would lead to more loneliness. Because more people think addiction is a choice, and you use because you want to and why don't you just stop.”*

*(PA\_07)*

As with many of the other identified subthemes, everything concerning this relationship with addiction came back to the overarching idea of self-care. However, this then translates to how this difficulty of PLWH properly caring for themselves impacts social and emotional relationships:

*“These patients struggle to maintain a home...take care of themselves...A lot of them have some socio-economic issues, too. So, then that puts a burden on them to take care of basic needs. They're struggling to put food on the table, so maybe they're not able to afford prescriptions or things. So, my IV drug abusers probably have their closest relationship with a spouse or parent, although it's not always a good relationship...They're dependent on them for housing, food. They tend to rock the boat a little bit, and they have slip-ups and violate trust.”* (PA\_03)

### *Shared Identity Groups*

As alluded to above, many participants indicated the importance of social and emotional support found within those who share identities. Providers believed that support in such spaces is often paramount for PLWH, even when compared to familial support or support within other categories of people:

*“They may talk to their family, but when [my patients are] describing their social support system, it's usually friends or other persons who are very similar to themselves.”*

*(PA\_01)*

*“There are a lot of benefits to a group setting. They can have peer support, they can see that they're not alone in the community, other people are walking in their shoes.”*

*(PA\_03)*

The importance of this supportive space being other PLWH (in that broad category of everyone possessing this identity) was one of the noted support systems by providers:

*“Pre-COVID, we would have client events that [PLWH] would show up to, like support group. We would have potluck dinners and people would gather and be able to share their experiences with each other and just kind of have that social interaction.” (PA\_06)*

*“There's individual counseling and support in case management, but there are also group online activities, virtual activities, in person activities to work at empowerment in a comfortable setting, a safe setting where those affected by HIV, with HIV, at risk for HIV, come together.” (PA\_05)*

*“We have a social hour with our clients that we do every Thursday. We get about three to four clients. It is virtual so we're able to connect people from State College to [Williamsport], and they get to talk, and they play games.” (PA\_09)*

That being said, providers thought that it was important to recognize other intersecting identities that impact the lived experiences of different PLWH as well as the roles of sub-regions throughout Central PA and how that intersects with support groups:

*“We've tried to do support groups. We had a women's support group for a very long time. We tried to start a general support group for [PLWH]. It definitely seems like support group should be focused in on one specific [group]. Maybe women or maybe gay men or IV drug users...Just to throw everyone into one large group has not worked very well.” (PA\_12)*

*“There is a stark difference in State College. They get a lot of individuals participating. But in Williamsport, we may only get two or three individuals...it’s such a small town, people know [their] business. State College has more acceptance or perceived acceptance.” (PA\_09)*

Taking into account the difficulties with support groups across those with intersecting identities and different subregions, providers noted specific support within shared identity communities of LGBTQ:

*“There are resources out there and we have a group called GLO that is specifically for people of color, gay or transgender, not necessarily with HIV, but they have a safe space where they can feel welcome. They can be themselves. They can feel safe.” (PA\_03)*

*“For [LGBTQ living with HIV] support it’s usually amongst themselves...not so much family...I see mostly older gentlemen or young Black or young Hispanic men. And I think with my Black and Hispanic men, it’s even more isolation. There’s just fewer resources.” (PA\_01)*

*“We have a number of clients who are LGBTQ identifying [and living with HIV] who are estranged from their parents or their children...But just the general social aspect, being able to have LGBTQ spaces is nice in terms of just going to a gay bar, having a drag show, things like that because obviously they don't have to disclose their status, but they're still among [LGBTQ-identifying] people” (PA\_08)*

This same idea of receiving support through shared identity groups (outside of HIV status) is also believed to be present within PWID, according to providers:

*“Alcoholics Anonymous, Narcotics Anonymous, if they get connected to the ones that they are comfortable with, that has been helpful. There’s a lot of newer resources, just*

*because of that's where the funding has been because of the whole crisis with the IV drug using.” (PA\_12)*

*“A lot of the people that I see get support from local support meetings so 12 step recovery groups, any other community recovery groups, things like that...In the drug world, there’s a large percentage of people that have HEP-C that we work with, and so I think that helps normalize HIV as well...everybody kind of has something that they can relate to in that way. So, I think that's beneficial to HIV-positive clients, particularly those who inject drugs” (PA\_04)*

Similar to the provider-noted difference between attendees at HIV-related support groups depending on the sub-region of Central PA, there was also a provider-noted difference between what that outside support looks like for LGBTQ and PWID living with HIV between Williamsport, State College, and Harrisburg. Interviewees explained that they perceive LGBTQ living with HIV to receive more support in Harrisburg/State College; however, in Williamsport, providers perceived less support, and AA and NA were more commonly referenced:

*“Unless you're a huge advocate who fights for the rights of the [LGBTQ] community in Williamsport, there's not really that support. There's still a stigma with being LGBTQ.” (PA\_06)*

*“Currently we have more options [in Harrisburg] for those who are sexual and gender minorities [living with HIV] than we do for those that are actively engaging in drug use.” (PA\_05)*

*“I think there's more resources for IDU [living with HIV in Williamsport], just because of NA/AA and the giant support network that it is...NA/AA have been established for so long and the people in the programs truly believe in them, and they want other people to*

*experience them. I think there's plenty of pockets that are trying to do LGBTQ [living with HIV support]. It just takes time and acceptance.” (PA\_07)*

Providers believed that this support from within community, particularly racial/ethnic groups, LGBTQ, and PWID, is vital. As discussed above, providers perceived family relations to often be strained for PWID living with HIV; however, at the same time, participants believed that it is not usually the entire family who knows LGBTQ and HIV status. Maybe it is just one person, and they are rarely the primary method of support.

## **Discussion**

The themes identified through these interviews make it clear that providers believe that it is both the internalized stigma that PLWH, themselves, have about the disease, in addition to the societal stigma, impacting feelings of loneliness as well as available support. The perceived isolation that providers reported PLWH experience because of these main factors affects their care, which ultimately impacts loss to follow-up and patients falling out of care, a commonly noted concern by interviewees. When dividing PLWH based on intersecting identities of LGBTQ or PWID to look at intersectional differences, the lack of similar communities in certain sub-regions of Central PA was reported to play a role in impacting feelings of loneliness for both groups of PLWH with these intersecting identities.

Although not prominent enough in responses to be identified as its own separate theme, providers perceived COVID-19 to have played a role in affecting feelings of loneliness in their clients, particularly in terms of how PLWH feel they are perceived by society. Even though agencies and clinics, the main aspects of intervention noted throughout these interviews for

PLWH (of all identities), were reported to have tried to transition to a virtual environment to support their clients, providers perceived their clients to feel increased loneliness due to feelings of being even further at the margins of society: *“It brought up why did they work so fast to try to get a vaccine for COVID, and why didn't they do it for HIV when the science is there” (PA\_07)*. This is an interesting point that again feeds into this recurrent provider perception of self-worth that was present across themes; unfortunately, only one interviewee brought it up. Even so, it provides insight into how health professionals are in touch with the history of HIV, how it has affected their clients over time, and how it may make their clients feel excluded and rejected by society.

In addition to this lack of self-worth impacting the mental health of PLWH, tying in strongly with all the subthemes identified under “Internal Processing,” many providers believed that PLWH face trauma that impacts their feelings of loneliness. Trauma was believed to be closely related to directly personal experiences of PLWH, such as contracting the disease, being reminded of the diagnosis every day when taking ART, or seeing friends die from AIDS. Fortunately, the support their clients do have, although minimal at times, was perceived to be through people at health clinics and community organizations who are well-versed in responding to these sensitive situations and life occurrences and regularly attend trainings. This is important, particularly in this time and context, as there is already this presence of denial, shame, self-stigma and belief that PLWH are not deserving of good care. This existential loneliness was described by health professionals to have negatively impacted their clients’ ability to share status with others, form connections, and sense of belonging to a group outside of their shared identity.

Providers believe that connecting with others is particularly hard when many community centers and non-profits experience education cuts that require them to focus more on prevention



and treatment, rather than fighting stigma. This is particularly relevant to Central PA, a rural area with low prevalence of HIV, as previous research has found that stigma and discrimination in these areas is due to less understanding and more fear about HIV, as there is less education about HIV (Hubach et al., 2015). This can lead to PLWH feeling more shame and socially isolating themselves (Zukoski & Thorburn, 2009). In addition to general community recognition and acceptance to reduce feelings of social loneliness, on an emotional level, there was clear mention by providers that an altered connection with a romantic partner is a main stressor PLWH experience. This particularly occurred at the beginning of diagnosis, similar to the aforementioned feelings of lack of self-worth.

However, due to the societal stigma and the fact that this is considered a disease of behavior, providers explained that many PLWH may receive minimal support – perhaps even less support than those with other chronic illnesses receive. For example, it has been reported that when PLWH are compared to cancer patients, besides coping through acceptance and faith, PLWH cope with loneliness differently than cancer patients (Rokach, 2000). This is attributed to less available support for PLWH, as compared to cancer patients (Rokach, 2000). In addition to comparing PLWH to those with other chronic illnesses, interviewees pointed out that many PLWH have other comorbid chronic illnesses. Another study that examined physical, mental, social, and environmental factors around loneliness found that PLWH who had other illnesses experienced loneliness at greater levels, heightened by the increasing levels of internalized stigma and their small support network (Harris et al., 2020). Moreover, providers from both urban and rural areas have reported that HIV is more stigmatized than other illnesses (both physical and mental illnesses), and this is highest in rural areas (Brems et al., 2010).

To address the support network that is present, however, particularly when looking at LGBTQ-identifying individuals living with HIV, providers believed that those who access community resources are more likely to feel connected to the LGBTQ community. This is supported by research performed in other rural communities in the US that found this connection to shared identity communities for the LGBTQ community helped to fight loneliness that they otherwise might experience in these areas (Li et al., 2015). Still, providers believed that fear of disclosure is very common in this population, as they are more likely to be depressed, report less social support, have lower rates of self-esteem, and be less likely to have a romantic partner (Dowshen et al., 2009). Stigma concerns around disclosure are a top priority, particularly among young MSM living with HIV, as it affects health outcomes and mental and social well-being (Dowshen et al., 2009). However, one interesting finding from these interviews is that providers perceived LGBTQ-identifying individuals living with HIV to be more involved in acceptance work. Interviewees in all three sub-regions studied explained that they believed older LGBTQ living with HIV were more likely to want to take on the identity of being the spokesperson of HIV. They perceived these individuals to want to share their knowledge and experience with others, as compared to PLWH without this intersecting identity.

To further address the research question focused on studying provider perception of intersecting identities in PLWH, in terms of PWID living with HIV, providers believed that asking for help to get support was one of the most noted difficulties for this group. Although there may be support in addiction communities, providers believed it is hard for their clients trying to distance themselves from that space to find support. Providers thought that internalized stigma around asking for help was impacted by the societal stigma of people thinking that addiction is a choice. The literature has shown that, for PWID living with HIV, social and

emotional loneliness is elevated, particularly at the level of romantic partners and family members (Hosseini et al., 2014). Other research has found that there has been a significant increase in the number of PWID living with HIV living in rural areas (previously more concentrated in urban areas), but there is a lack of research in specific services and support for such individuals in these areas (Paquette & Pollini, 2018). Where these services and support networks do exist, though, they are not expansive in their coverage (Paquette & Pollini, 2018).

In addition to the intersecting identities of LGBTQ and PWID with HIV status that were specifically examined in this study, providers also discussed age and race/ethnicity; however, it was not extensive. Prior research by Mazonson et al. (2021) has shown that PLWH who experienced more loneliness were younger and single and lacked closeness to friends. The older group felt more connected to friends and was less likely to be depressed (Mazonson et al., 2021). Given the number of older PLWH, and the experiences of ageism, racism, and homophobia they may experience in response to HIV, it has been found that the stigma and social and mental support they receive may be factors contributing to loneliness (Quinn et al., 2020). These intersections in stigma affect support and mental well-being, particularly among rural older PLWH (Quinn et al., 2020). When thinking about racial/ethnic support, providers only discussed this in reference to PLWH utilizing LGBTQ spaces and explaining that trans people of color living with HIV really have the hardest time in this region. Moreover, race was only discussed by providers in Harrisburg, which was a sample of entirely medical providers. The fact that this was so rarely mentioned could be because interviewees were specifically asked to focus on distinctions between LGBTQ and PWID living with HIV or because Central PA is predominantly white.

In terms of interventions, the literature supports the participants' perception that transportation, food, housing, and the US insurance system serve as structural barriers that make it hard for PLWH to access support (Gant et al., 2012; Zeglin & Stein, 2015). Sometimes, clients are forced into a particular job to access health insurance and are then unable to access psychiatric services because the psychiatrist is overbooked or only takes certain types of Medicaid plans (Bishop et al., 2014). Although these are structural challenges to face, given the involvement of long-term survivors in community advocacy work, community organizations, local/state/national governments, and civil society should enhance their partnerships with these individuals to continue to stress that HIV is still an issue that needs to be addressed (Harris et al., 2020). However, the aforementioned structural issues impact physical ability as well as economic factors to access interventions that promote support, belongingness, and community (Harris et al., 2020).

Interventions related to phone calls, although not shown to be effective with the general population, have been more successful with LGBTQ living with HIV, as reflected in a study performed by Perone et al. (2019). When paired with a phone buddy, it was found that those of different ages, and to a lesser extent race, reduced feelings of loneliness and strengthened feelings around a sense of community (Perone et al., 2019). These types of interventions are particularly useful in rural areas, as they provide PLWH with access to people outside of their small communities and combat transportation barriers that exist when trying to access in-person services (Perone et al., 2019). The fact that case managers in the interviews already explained this is something in which they regularly engage is significant, especially because benefits have been shown in previous research with LGBTQ, whether or not the person on the phone was also LGBTQ (Perone et al., 2019; Ransom et al., 2008).

To battle the loneliness more generally, and related to psychiatric care specifically, therapy delivered interpersonally over the phone has been shown to help PLWH in rural areas (Ransom et al., 2008). In these interviews, although all regions had some sort of in-service psychiatric care (either through an agency or because they worked in a clinic that receives psychiatric funding) there was still a need for psychiatrists. According to Heckman et al. (1998), rural PLWH often experience loneliness differently from urban PLWH, reporting less satisfaction with life, lower levels of support from people close to them (e.g., family, friends), less access to healthcare (particularly mental health-related care), higher stigma, greater fear of disclosure, and worse coping strategies. Programs that have been helpful in supporting PLWH in such areas have been those that help increase access to care, social support, and belongingness and that fight poor coping mechanisms (Heckman et al., 1998).

### *Limitations*

Although this study has formed many connections to previous research and generated some new findings, there are several weaknesses to note. First, since these findings are from a qualitative research design, they lack generalizability. The entire population of this study was recruited through AIDS Resource contacts and Penn State Hershey contacts. Therefore, the provider perception of the client experience might have been different from those attending other clinics that were not in some way connected through this network or networks in other rural areas of the country. This does not allow results to be generalized to the entire population of providers working with PLWH in rural America. Moreover, PLWH, themselves, were not interviewed to understand their true lived experiences. Speaking to the direct population would present more findings and new knowledge, as several participants during these interviews mentioned that they could not speak directly to everything their clients were feeling. Moreover,

even though interviewees were people who specifically specialized in working with either PLWH who are also LGBTQ or PWID living with HIV, all respondents worked with both. This shows the lack of HIV-centric care in the region, as other places in the country have specific support based on different key populations.

### *Future Directions*

Despite these limitations, the findings presented several avenues for future research on this subject. One avenue is through studying MSM who inject drugs. Moreover, including quantitative data collection or using a mixed methods approach would be helpful in future research on this topic. Although the qualitative approach provided depth, it did not provide breadth, and it is important to get this breadth to fully understand the extent to which PLWH in the US experience loneliness, stigma, and intervention. Additionally, several people, overwhelmingly representing State College and Williamsport agencies rather than health clinics (and reported by case managers and mental health therapists), mentioned how spiritual leaders and those in the faith community support PLWH. Future researchers could examine the opinions of those who engage with PLWH outside of the healthcare setting, such as religious leaders.

Moreover, there was not as much attention to trans individuals when discussing feelings of loneliness in LGBTQ living with HIV, as compared to gay men, which arose most prominently. Even though, in this study, the group was categorized as the entire LGBTQ community living with HIV, future research should divide this even further. This is because only one participant (a physician in Harrisburg) discussed trans PLWH (besides when people mentioned the organization, GLO, in Harrisburg, which supports gay and trans individuals of color):

*“Transgender support groups have been super valuable. I think that's been a big need and then there have been added groups sort of young trans individuals, older trans individuals. That has been really a key way for people who are exploring their gender identity...talk to others and hear their experience and hear about connections, resources around the area.” (PA\_05)*

There were also some interesting data elements that unfortunately could not be analyzed or linked to a theme because it was only noted by one person; however, they point to future ways to pursue this research and make it very clear that we are not at a full understanding of this intersection just yet. This is mainly because of the lack of consistency of ideas, which leads to a lack of clarity in evidence. For example, one participant described the disconnect they perceived to be present between state government and the reality of the situation PLWH live. This particular experience is relevant to this research, as it points to how the influence of people at the policy level possess views that do not relate with what practitioners are seeing in the field. This could then impact care and treatment of mental health issues in PLWH. The disconnect between policymakers and implementors shows just how distanced those who make decisions and create policy that affect lives of PLWH are from reality: *“We had a person who just [said] that there's no more HIV discrimination...this year, and it was a Department of Health employee that said this so then you're dealing with the loneliness of like, what...so that one's really crushing.”* (PA\_07). Unfortunately, this was only shared by one participant, but future research around this disconnect and insensitivity would be important to study how knowledge around HIV in the medical community, particularly those in positions related to policy, impacts the mental health of PLWH.

*Conclusion*

Several layers were explored in this Chapter, particularly based on how providers perceived internal processing, trauma, the healthcare system, and relationships to impact the experiences of loneliness in PLWH in Central PA. Providers believed that the presence of existential loneliness at the beginning of care could result in a loss to follow up with clients as is the case in Senegal; however, the trauma in which providers believed their clients lived their HIV-positive status (unlike any other chronic illness due to how it is transmitted and being considered a disease of behavior) was a repeated way they perceived their clients to experience stigma and loneliness. Moreover, providers expressed much concern over a lack of emotional connection their clients had with existing or future romantic partners. Still, individuals in this group usually had at least one person outside of their HIV-related care network to disclose status. When the intersecting identities of LGBTQ or PWID were explored in combination with HIV status, providers perceived interventions to be dependent on such intersecting identities, but also on the geographic sub-region in which PLWH living with intersecting identities were based. Given the 12-person sample size, and due to convenience sampling, which resulted in over-representation of some health professionals, it was difficult to peel back all such layers to form different distinctions. Still, there is sign of development and growth with these interviews, given the fact that the interview questions here were much more open to hearing the thoughts of many individuals and not so structured/numerous (i.e., yes/no questions and then just a suggestion to respond if they wish), as was done in Dakar. Future avenues of research were identified, both looking at potential different intersecting identities to explore as well as different research methods.



## **Chapter 4**

### **Country Comparison**

#### **Summary of Previous Chapters**

The provider's perspectives from Dakar, Senegal, and Central PA, US presented both similar and different challenges regarding the lived experiences of PLWH in their respective regions. Although there were not any repeated themes or subthemes across the two countries, there was similar content supporting the themes and subthemes identified. This is particularly the case when examining providers' perspectives on acceptance/part of identity and the role of the healthcare team/cascade of care in attending to the needs of PLWH that were perceived to result in being rejected, withdrawn, or feeling isolated from society, themselves, and existentially. With that said, there were also differences, based on social, cultural, and political contexts in which the population is situated across the two different countries.

Moreover, the data in Central PA was collected during COVID-19, a pandemic that brought greater recognition to the topic of loneliness, whereas the data in Dakar was collected two years prior. This data on provider perception of loneliness in PLWH in Dakar was collected in an area (Senegal) where mental and social health issues, including loneliness, are not as frequently discussed as the physical aspects of HIV (Soltani et al., 2004). This chapter will offer a country comparison, identify opportunities for future research, and reasons why future research is needed in this realm. Overall, the main takeaway message is that policies, in conjunction with the specific country's context, may serve to increase the extent to which HIV status occupies the

lives of PLWH, increasing feelings of loneliness. The social environment, however, independently affects experiences of loneliness of PLWH because of the taboo nature of the disease and how it is contracted.

The major findings in Dakar, Senegal all relate back to providers' beliefs that the concerns around sharing status, the culture of gossip, the role of religion in relation to perceptions about intersecting identities with HIV status (namely MSM), and the lack of emotional support (particularly from the level of family) impacted ability to disclose status and increased feelings of loneliness. There was minimal support outside of community organizations. The feelings of worthlessness and meaninglessness were noted barriers to individuals connecting with these important resources that become their main tools to tackle emotional loneliness. The major findings in Central PA, US point to providers' beliefs of the importance of examining PLWH as a function of different intersecting identities (i.e., key populations) to better understand feelings of loneliness. In this sample, there was similar emphasis by providers on their clients' feelings of existential loneliness at the beginning of care that could result in loss to follow up. However, the trauma in which providers believed PLWH lived their HIV-positive status (unlike any other chronic illness) was more overtly named. This does not suggest that it is more traumatic to experiencing living with HIV in Central PA. Rather, providers in Central PA simply use this language as part of their care model, given the training they must go through related to trauma-informed care in the US. Providers reported that PLWH were most supported by people of their same intersecting identity (not HIV status alone), and there was much concern over a lack of emotional connection with existing or future romantic partners.

An important basic demographic difference occurred between the two regions. In Dakar, the majority of providers interviewed were men, whereas in the US, the majority of providers

interviewed were women. Moreover, in the US, there were many more medical practitioners (nurses and physicians) participating in interviews than in Dakar, where mostly community health workers were interviewed. This is important to note, as it gives a medical rather than psychosocial perspective. These medical providers also reported rather infrequent contact with PLWH, compared to the community health workers in Senegal, who reported daily or at least weekly contact with most clients. Again, due to the convenience sampling and limited sample size, it is hard to perfectly compare the responses of those in a clinical setting versus a community organization setting. Moreover, because one set of data was collected in 2019, and the other was collected in 2021 during the COVID-19 pandemic, all Dakar interviews were in person, whereas all Central PA interviews were conducted via Zoom. It is noted that the 2021 data was collected during a time when the entire world was experiencing a pandemic of loneliness, with a heavier burden on PLWH (Jones et al., 2021; Marziali et al., 2020).

To begin with the structural side of things (showing the role of policy in feelings of loneliness), seeking insurance was a US issue that was not an issue in Senegal. In the US, obtaining insurance and meeting basic healthcare needs is a very complicated process. Until recently, people could be discriminated against for living with a pre-existing condition like HIV and not obtain access to insurance (Graydon, 2000). Moreover, although PA expanded Medicaid in 2015, psychiatric services, important for tackling feelings of loneliness in PLWH, can still be difficult to access (Kaiser Family Foundation, 2015). In Dakar, although participants explained that medication is covered and insurance is not an issue, the actual services, such as appointments to follow-up on treatment and viral loads, are not. These structural level burdens that place a price on healthcare needs, or lack of equitable access to such needs, impacts the ability of PLWH to access services in both contexts.

Different policies exist in these two countries, but in both contexts, there were additional social-related barriers to connecting with healthcare resources that are the ultimate connection point to community resources. Religion was a social factor impacting access to resources largely refined to interviews in Senegal, while addiction was a social factor impacting access to resources refined to the US sample, given that provider perception of PWID living with HIV was studied. Poverty, societal stigma, and sexual orientation, however, were social factors emphasized in both areas that impacted one's ability to access community resources. Community resources, in both areas, were perceived by providers to be the spaces that help fight feelings of loneliness through the creation of meaningful connections with others. As a result, the fact that social environments interact in this way to impact access to resources is of great concern.

### **General Experiences with Interviewees Takeaways**

Before transitioning to how social environments create different lived experiences of loneliness for PLWH in these two different regions, it is first important to note some trends of interviewee responses. First, provider participants in Central PA more openly talked about loneliness than provider participants in Dakar; participants in Dakar tended to mostly talk about psychological distress at large. Although part of this could reflect more clearly developed skills and ideas about the topic after two additional years of experience with and research about loneliness, it is also consistent with previous research showing that Senegal has seen a more recent rise in the burden of noncommunicable disease, compared to the West, where that has been more consistently the case (Reubi et al., 2016; Wainberg et al., 2017). This shows how even the general expertise and training background of HIV professionals in different contexts, as well

as how stigma around mental health might be perceived in different social environments, impacts the ability to even provide care around loneliness. Moreover, although participants in both regions talked about the advances in fighting HIV, providers in Central PA specifically pointed out obstacles to this battle, including how HIV is an atypical chronic illness. Again, given the contextual situation that the US is a country whose healthcare providers have much experience in addressing chronic illness, given the countrywide prevalence, this likely informs their positioning to make such a statement.

It is also interesting that Senegalese participants more frequently cited UNAIDS goals, whereas the US participants strove to get individuals to be undetectable. This may reflect how the trends of a more collectivist culture (Senegal) compared to an individualistic culture (the US) interact to impact the mission and goals in Senegal. This collectivist versus individualistic contextual piece was also exhibited when thinking about general advice or steps in the care process, as specifically described by people working as community health workers in Dakar and as nurses and case managers in the US. In Senegal, there was not really a proposed solution for how to deal with existential loneliness other than to use the organizations for support to break that self-stigmatizing mindset. Then, the suggestion was to use the support from this community (who becomes their family) to combat emotional loneliness. In the US, however, there was very specific advice around work on self-actualization and how to process internal thoughts that ultimately affect relationships outside of community organizations, including family members or romantic partners. Therefore, although community organizations had certain goals around the approach to treating HIV in both contexts, the idea in Senegal was to support clients in their feelings of belonging to groups, while in the US, it was all about capacity building around individual-focused processes (i.e., self-actualization).

Finally, it was much easier to find interviewees who had some time to talk in Central PA; this might reflect how HIV-related care in Dakar is less abundant and that many people are serving multiple roles on the care team. However, this is not necessarily the case. Other reasons could have been because of the urban setting of Dakar versus the rural setting of Central PA, with more PLWH seeking services in Dakar than in Central PA. It could also be reflective of the *laissez faire* attitude in Senegal where time is a construct and does not really matter, a commonly observed occurrence by Laura Guay with other meetings and events that occurred at AIDES Senegal. In this context, meetings are more commonly forgotten or asked to be rescheduled. Another reason could have been because of the positionality of the researcher, Laura Guay, and the fact that she did not live in the Senegalese culture, but rather, had spent virtually her entire life in the Central PA region. The key takeaway, no matter what the reason here, is that although HIV exists in these two different areas and physically affects the body in the same way, the social environmental factors that impact the different care PLWH experience also impact the ability to conduct qualitative interviews.

### **General Experiences with Coding Takeaways**

As was observed in Chapter 2, there were not any themes identified from this data that did not relate to at least one of the research questions in some way. Part of this is certainly because the research questions are broad and the interview script is strongly correlated with the research questions; however, there was also a bias due to the fact that the person who created the research questions was also the person coding the data. In future studies of this nature, it is recommended that there are multiple coders and reviewers of the data. Additionally, it is

preferable that cross checking of the data is performed by an individual who did not create the research questions. Finally, these interviews involved the healthcare community and not PLWH directly. Therefore, their own biases, particularly in terms of where support comes from, could have impacted the data. Future research should engage directly with PLWH. That being said, this population is one of the most protected groups in human subject research; however, overcoming this challenge is vital to compare whether the perceptions and informed opinions of health professionals is on par with the actual lived experiences of PLWH.

### **General Experiences with Loneliness Takeaways**

There were many similarities in the way that PLWH between the two countries experienced loneliness. First, providers reporting the experience of trauma in their clients was one of the main connections in Central PA that resulted in feelings of loneliness. This was an integral part to everything in Central PA, but nonexistent to responses from participants in Dakar. Part of the reasoning behind this is certainly the difference in use of language around “trauma” in the two different contexts and the prevalence of trauma-informed care as a specific route of health services in the US. However, one aspect of trauma was present in both datasets: the provider perception that taking medication every day is an exhausting task that weighs on PLWH, as it constantly reminds them that they live with a chronic stigmatized illness. The feelings of loneliness and helplessness at the beginning of diagnosis were similar, too, which makes sense given that the internal process of receiving a diagnosis is a universal human phenomenon: you now have something that you did not used to have. In other words, although the specific terminology of trauma was not used in Dakar, the experiences of PLWH described

represented forms of trauma labeled as such by participants in the US. Again, given the training related to trauma-informed care in the US and that all respondents who used that terminology were medical providers, the clear contextual position created this difference. Still, the description of the trauma in both social environments emphasizes the common human experience of shock when diagnosed with an illness that is highly stigmatized in society.

Moreover, in the US, providers reported a lot of concern around spreading HIV to other people. This was linked to emotional loneliness, in terms of PLWH not wanting a romantic partner. In Dakar, again, providers reported that the isolation at the level of the family was always the emphasis, but it tied back to familial rejection or the inability to have a family due to the HIV diagnosis. One reason might be because of cultural traditions and expectations of getting married at a certain age, and the fact that this belief is not so widely held in the US. Laryea & Gien (1993) support this, as they found that HIV diagnosis impacts interactions that individuals have with others, with most reporting loneliness and trying to figure out how to manage family and friend relationships that were altered post-diagnosis. However, people that PLWH would usually talk to about their fears could not provide them with the emotional support PLWH needed, as these were the exact people to whom PLWH were fearful of disclosing status (Laryea & Gien, 1993). Therefore, although this broader theme of social connections is clearly integral in both contexts, providers perceive that multigenerational familial and collective support impacts this experience for PLWH in Dakar, while finding a specific person with whom to independently share life impacts this experience for PLWH in Central PA.

Although providers reported that PLWH in both countries oftentimes lived their HIV-positive status alone and had a lack of self-worth and inner loneliness because of it, the stronger emphasis in Dakar by all participants was on the interest in keeping status confidential. In the



US, participants more often shared stories of positive ways that people shared their status with family or their partner and how they were accepted, but these situations were not reported in Senegal. This may indicate that although societal stigma is a commonly shared experience in both environments, in Central PA, there is more acceptance, just by the nature of there being stories of acceptance to share. However, it is also possible that this is due to the different indirect provider reports collected across the two samples. There were different types of providers in the two countries based on country-specific relevance of who makes up the HIV care team (different provider professions), so the difference could be due to this instead. To further emphasize this idea of providers perceiving that their clients keep their status to themselves, in both regions, the importance of the cascade of care and healthcare team to intervene was paramount. This included advocacy work, awareness raising, and education. Although this again places the community organizations at the center of the puzzle for PLWH experiencing loneliness in both contexts, it is important to note that there might be some bias here, given that all interviewees were part of this continuum of care in some form.

### **Experience with Stigma Takeaways**

One of the most mentioned aspects related to stigma by provider interviewees in the US addressed how things have changed over time in regard to stigma, such as refusing to share plates or silverware. This was oftentimes followed by an explanation that in some cases, those same things exist today. In Dakar, the fear related to not wanting to touch a PLWH was perceived to be more closely related to not wanting to touch an MSM. One potential explanation for this is the presence of religion, particularly Islam, in this social environment where 95% of

Senegalese practice Islam (Ansari & Gaestel, 2010). Refusing to touch MSM was explained by providers to be a commonly held Islamic religious belief. However, through this explicit example being shared, the association with HIV being a gay disease persists in Senegal today. In Central PA, though, when key populations were mentioned in interviews, a third of participants specifically then made note of the need to have less of an association between all PLWH being a part of a key populations. This is particularly interesting, given that the incidence rate of HIV is much higher in key populations (such as gay men and PWID) in the US, as compared to Senegal (Mukandavire et al., 2018; USAID, 2019). Still, it also emphasizes a fight against stigma that has occurred in Central PA that has not occurred in Dakar: showing any sexually active individual is at risk for HIV (U.S. Department of Health and Human Services, 2021). Even though societal stigma influences both social environments, the degree and level to which it interacts with other factors in Dakar (predominantly religion) results in more societal barriers that must be broken in order to even decrease to the level of stigma seen in Central PA.

HIV stigma can result in avoidance and rejection from others, abusive behavior directed toward PLWH, and shame (Swendeman et al., 2006.) In Dakar, providers believed that people often left the country if they were rejected because of societal stigma, whereas in the US, providers reported that people preferred to leave and go to an urban area. In other words, in both social environments, societal acceptance was perceived by providers to be desired by PLWH. This pushed PLWH to flee to areas where they perceived there would be more acceptance or hide their diagnosis and avoid stigma in an area where they could have a clean slate. Even if the new location to which they relocated was not any more accepting, it was perceived as an opportunity to regain the meaning and support in their lives through being around people who were unaware of their status.

It is important to consider that the clientele was different in Dakar than in Central PA, based on both different key populations existing in the two contexts as well as the fact that there was specific probing around two specific key populations in Central PA. However, in Dakar, other intersecting identities, namely MSM, was perceived by providers to lead to MSM living in fear about potential employment and housing situations if their sexual orientation was discovered. Therefore, status was kept to themselves, given that providers explained there is often an automatic assumption that a man is an MSM if he tests positive for HIV. In Central PA, the housing and job loss was prominent in responses addressing PWID living with HIV. Moreover, research conducted by Biancarelli et al. (2019) shows that PLWH who possess the stigmatizing identity of IV drug use prefer receiving support from community-based organizations over healthcare settings, in efforts to receive non-stigmatized care. The low stigma in those settings not only decreased depression and loneliness but was also associated with increases in their CD4 count (Biancarelli et al., 2019; Rendina et al., 2019).

This desire for non-stigmatized care was a common theme repeated throughout the interviews in Central PA and Dakar, too. This shows that providers working with different populations of people living with HIV in two different social environments perceived the acceptance of stigmatized identities by HIV care providers to be paramount in treatment environments for PLWH. This shows two groups in two different parts of the world, with two different healthcare systems and established policies, sharing one identity of an HIV-positive status experiencing societal stigma that impacts their loneliness. Despite these differences, the method to cope with their loneliness, although ultimately confronted in different ways, involved the same types of organizations.

## Support and Intervention Takeaways

To speak more to techniques to battle loneliness, overall, shared identity spaces in both environments were commonly noted by providers as important, perhaps even essential; however, this was not always the community of just other PLWH. In Central PA, interviewees explicitly mentioned the need to go beyond that single shared identity of living with HIV and focus on other intersecting identities of LGBTQ or PWID with HIV status. Part of this could have been that interviewees in this location were specifically asked about certain intersecting identities. However, within these explanations, providers pointed out that those specific spaces (LGBTQ or PWID), not HIV-specific spaces, provided more support. In Dakar, interviewees mentioned the importance of hosting women's groups and LGBTQ support groups to build emotional connections, too. Moreover, in both cases, it was mentioned that it did not always necessarily involve sharing HIV-positive status with people in this shared identity group. This aligns with research on self-disclosure that shows how it occurs over time and includes both people disclosing personal information (e.g., emotions), responding, and supporting each other (Falk & Wagner, 1985; Laurenceau et al., 1998). These factors are what makes it more likely for a relationship to be built and increase levels of trust and emotional support and connection (Falk & Wagner, 1985; Laurenceau et al., 1998). Overall, the idea that shared identity groups go beyond identifying as living with HIV was a commonly shared factor contributing to relationship building in both social environments.

Provider interviewees in Dakar, whether they worked at AIDES Senegal, another organization, or a health clinic, each talked about the support that AIDES Senegal specifically provided to patients. They described the process of walking PLWH through feelings of

existential loneliness to connecting them with groups of people with whom genuine connections could be formed. In Central PA, however, each provider participant, whether it was a medical provider, case manager, or social worker, mentioned their respective clinic or organization in addition to other resources in the area. It is likely because providers working in clinics interviewed in Central PA had comprehensive care models or community organizations directly partnered with them, but it also shows the increased availability of care in the region. It is another example of increased attention to mental healthcare, given a longer history of chronic illness in the US. Health centers in Dakar were reported to not take this sort of comprehensive approach or provide psychiatrists, which was reported in Central PA. Therefore, even though there is mention of a lack of HIV-centric care and psychiatric-related care in Central PA, it is relative. After all, organizations in Central PA (which are largely involved in promoting overall well-being, including psychosocial well-being) do not fear being shut down, as was the case with AIDES Senegal. This occurs in Senegal due to it being a social environment with more intense homophobia that is deeply connected to their religious beliefs and morals (M'Baye, 2013).

Although making homosexuality illegal in Senegal is a policy, as shown in the work of M'Baye (2013), suddenly removing the prison sentence and fine would likely not eliminate the rejection PLWH would experience. It certainly adds an extra burden and is involved in exacerbating feelings of loneliness, working in combination with the social environment, but social environments can impact such feelings of loneliness independently of policy, as reflected throughout this chapter. Similarly, in the US, the insurance and lack of affordable housing in the US creates challenges to get in and access that comprehensive care (Mongelli et al., 2020; Patel & Saxena, 2019). However, just enacting universal healthcare and increasing government social support in the US would not eliminate the rejection PLWH experience. These policies exacerbate

feelings of loneliness, but these findings from these providers show they work in combination with social and cultural factors that are already engrained in society. Overall, the attitudes and beliefs in both countries are surprisingly similar despite important historical, cultural, political, and social distinctions. Regardless of differences in the way concepts were represented and their level of impact on PLWH, social interaction, emotional support, societal stigma, and acceptance were commonly identified perceived factors by providers that impacted the lived experiences of their clients living with HIV.

### **Limitations**

Although gathering qualitative data allowed a comprehensive analysis, there are some limitations. For one, there was a relatively small sample size (a total of 23 interviews) which is insufficient to make proper recommendations for interventions. This paper is more focused on pointing to a problem and highlighting the differences between two different countries. Further research is needed for interventions to be tailored on a specific cultural basis, as this was just focused on two geographic areas. Still, the key takeaway message is that providers perceive that social environment, not just policies, affect loneliness experienced by PLWH. Both studies give this reflection, even though they are from very different social environments.

### **Future Directions for Loneliness in PLWH**

This research, although preliminary in nature, emphasizes the key point of how people living with similar identities experience the human condition of loneliness (existentially,

socially, and emotionally), but also how the extent to which they experience loneliness is based on the individual context of their respective country. This analysis provides examples of how providers in these contexts attribute feelings of loneliness to social environments, and intervention at the individual/programmatic level is what really matters in fighting loneliness in this group, compared to policy. This study provides two in-depth qualitative analyses that reflect these points; however, there is another relevant example that every reader can personally relate to: the COVID-19 pandemic. Although tragic in myriad ways, the COVID-19 pandemic brought recognition to the importance of work around both loneliness and infectious disease on a global scale, due to the necessary physical distancing measures that made human contact more difficult (Killgore et al., 2020; Luchetti et al., 2020). Take this as a call to action: there is a need to also understand loneliness within the most marginalized. As shown by this research, these individuals are at particular risk for loneliness, especially at the level of self-worth and lacking meaningful human connections. If we want to end this global epidemic of HIV by 2030, it is vital that the UN and global health actors work with governments to not only eradicate laws that criminalize behavior and marginalize certain communities, but also invest in tailoring loneliness interventions to different social environments.

## Appendix A

### Interview Scripts

#### Interview Script Dakar, Senegal

##### Introduction

I'm going to record the interview, but it's only for me, no one will hear it but me, and it's to make sure I don't miss anything during the interview. Does that work?

I'll start recording. Today is [date] at [time] and we are about to begin interview No. \_\_\_\_ for participant No. \_\_\_\_\_.

Hi! Welcome to the interview. I'm Laura. Thank you for coming and participating.

I want to know more about your thoughts and opinions on your professional experience with HIV to help me identify the factors that increase the risk of loneliness in the lives of PLWHIV in Senegal and the DRC, the two countries where I will be researching this topic.

Specifically, I will ask you questions about how you have noticed people in treatment since their diagnosis, your general opinion of mental health experiences related to HIV status, and whether you notice that clients are having difficulty or are struggling to adhere to the treatment plan outlined by their doctor. Some of the questions might seem very similar, but we need to understand that this is for emphasis on certain topics to ensure that people answer the questions the way we want. Also, I want to add something so that you understand that even though these questions are very general about PHAs (you must understand that I am making a comparison between two countries so the questions must be general), I understand the context of Senegal, so you are completely free to speak specifically to key populations in your answers.

Please be aware that you must not disclose any identifiable information or client names during the interview.

The data from these interviews will be used in Laura Guay's dissertation that she is doing to graduate from college. However, everything you share here today is confidential. No part of this interview including names or other identifying information will be used in any reports or articles resulting from this research. I have obtained approval from the University of Minnesota and WARC (my university in Senegal), to conduct this research.

The interview will last between twenty and thirty minutes. Before we begin, I want to ask you if you have any questions about the interview.

##### **Section 1. The Context**

1.) I'd like to start by asking some general questions before I talk about your experiences working with people living with HIV (PLWH).

- a. How old are you?
- b. What is your gender?
- c. Where do you live? Is it an urban or rural area?
- d. What is the name of the area you live in?
- e. What is the highest level of education you have completed?
- f. What organization do you work for?



- g. And what is your role in this organization?
- h. When did you start working in this professional position?

**Section 2. identifying stigma, isolation, loneliness, etc.**

2.) I'd like to talk a bit about your experiences with people living with HIV and whether the onset of the disease has caused people to see your clients differently or your clients to see people or other situations differently.

- a.) Have you noticed that your clients feel isolated from the people in their lives that they were close to before their HIV diagnosis? (Ask to expand if they do not)
- b.) Have you noticed that your clients feel they have not found a partner or friend with whom they can talk about their HIV? (Ask to expand if they do not)
- c.) Have you noticed that your clients feel like strangers and are excluded in social situations? (Ask to expand if they do not)
- d.) Have you noticed that your clients feel that there is no one who shares their interests and ideas? (Ask to expand if they do not)
- e.) Have you noticed that your clients feel rejected by society? (Ask to expand if they do not)
- f.) Have you noticed that your clients feel like there are no people in their lives who know them well? (Ask to expand if they do not)
- g.) Have you noticed that your clients feel that they have no meaning in their lives now that they are living with HIV? (Ask to expand if they do not)
- h.) Have you noticed that your clients feel that no one shares their spiritual beliefs? (Ask to expand if they do not)
- i.) Have you noticed that your clients feel a sense of detachment and lack of comfort in their spirituality? (Ask to expand if they do not)
- j.) Have you noticed that your clients feel connected to their culture and cultural traditions? (Ask to expand if they do not)
- k.) Have you noticed that your clients feel connected to their neighbors and other members in their communities? (Ask to expand if they do not)

3.) Studies show that some people have difficulty doing exactly what their healthcare team asks all the time.

- a.) What makes it difficult for your clients to take care of themselves?
  - b.) What makes it easier for your clients to take care of themselves?
- 4.) In general, with whom do your clients share their HIV status?  
(probing: Did they tell you how they felt after sharing their status with these people?)
- 5.) When your clients experience stigma, what kind of stigma is it? For example, is it gossip, verbal and/or physical abuse, or something else?  
(probing: Do they share their feelings with you when it happens? Do they express how they would prefer to be treated by people who know their HIV status with you? What type of stigma is most disliked among your clients? Difference based on gender/age?)
- 6.) Do you see self-stigma in your clients/your clients internalizing the societal stigma and attitudes? (Ask to expand if they do not)
- 7.) What does access to mental healthcare services look like for your clients?
- 8.) Do you know of an organization or group where your clients can seek help for HIV-related issues?

(probing: If yes, what is the name of this organization(s)? How do people know that this organization(s) exists? Do you know of any clients who have supported other PLWH?)

### **Section 3: Stress, Access to Care, Resources, etc.**

I now have some questions about specific events that your clients may have experienced because of their HIV status.

11.) In the past 12 months, have your clients been forced to change their place of residence or been unable to rent housing partially or completely because of their HIV status? Because of their sexuality?

12.) In the past 12 months, have your clients lost their jobs or source of income because of their HIV status? Because of their sexuality?

13.) In the past 12 months, have your clients generally had meaningful discussions with healthcare professionals about HIV care options?

14.) Do your clients perceive their HIV status as a factor that limits their access to health services?

15.) Do you think there is enough awareness that your clients know they can have children, if they want children, now that they are living with HIV?

16. Did your clients ever have any problems receiving ARVs?

### **Section 4: Conclusion**

So, to summarize, today we talked about your experience working with PHAs, and the barriers and experiences in general of PHAs. Do you have any other thoughts that I should add?

Thank you for participating in this interview. I also wanted to reaffirm that everything you have shared here today is confidential. No part of this interview that includes names or other identifying information will be used in any reports or articles from this research.

Finally, I want to give you the opportunity to ask questions or share other ideas about this research. Do you have any questions for me or additional ideas about this research?

### **Interview Script Central Pennsylvania, United States**

Welcome, thank you so much for being here today. As a review of what was in the consent form, I'll be asking you questions about your general thoughts about mental health experiences related to HIV status in order to help identify factors that put individuals living with HIV in our region who also identify as either LGBTQ+ or a person who injects drugs to also look at this from a key population perspective and dissect that at least a little bit, at an increased risk for loneliness, broadly speaking. Please be aware that you are not to disclose any identifiable information or names of any clients during the interview. The data from these interviews will be used for the sole purpose of my senior thesis and everything you will share here today is confidential. I have obtained ethical approval to conduct the interviews. I will be recording the interview to create transcripts and aid with analysis of the qualitative data. Does this all sound ok to you and do I have your consent to proceed?

Ok, great, so as I said, interview should last close to 30 minutes, depending on how in-depth your answers are, and I want to start off with some basic demographic and background info about you.

### **Demographics/Background**

- 1.) What is your age?
- 2.) With which gender do you identify?
- 3.) What is your race?
- 4.) Could you please describe your role in your current position and how long you have been working there and any previous experience working in the field of HIV?
  - a. And do you happen to specialize with working with members of the LGBTQ community living with HIV or people who inject drugs living with HIV?
    - i. Ok, that's fine, since I said part of it is to look at intersecting identities through the realm of key populations I might ask you at times since you deal more generally to distinguish if these other identities might have an impact, but no worries that you don't specialize.

### **Main Section of Interview (Loneliness Assessment)**

**Ok, great, thanks, so now I want to dive into the main section of the interview asking about your expert opinion on what you see in your clients living with HIV**

- 5.) Tell me how you would define loneliness. Great, thanks, I like to see kind of how people think about it before probing more. the experience of conflict between what is desired in a social relationship and what is present, particularly emphasizing one's perception of isolation
- 6.) So, first, to preface this next question,
  - a. we're thinking about feeling loneliness in a very general sense, we'll get more specific later about different categories and groups of people, but can you describe whether your clients living with HIV feel isolated or withdrawn from people and/or from experiences in their lives?
  - b. Can you describe any impact or differentiate between the experiences of people living with HIV who identify as LGBTQ versus being a person who injects drugs might have on this?
  - c. Would you have anything to say about internalized stigma/ (so self-stigma)? - people internalize societal stigma and attitudes
  - d. Can you describe any impact that this experience has on general care related to their HIV or other lifestyle behaviors? thinking about things like alcohol and tobacco use, also experiences of depression and anxiety, sleep quality, just examples, so feel free to expand?
- 7.) Now I'm looking to hear about the people your clients living with HIV feel close to.
  - a. Can you describe the relationships that they have with people in their lives, and who these people and groups specifically are where they feel support, love, connection?
  - b. And now looking at groups where you didn't talk about, and going back to societal stigma, talked about it at large, but when specifically dividing it down into community, family, faith-based stigma could you talk about it more within

different categories? And could be their community, with the context of being in Central PA, family, friends, romantic partner, spirituality, a more existential approach?

- c. Can you describe any impact or differentiate between the experiences of people living with HIV who identifying as LGBTQ versus being a person who injects drugs might have on this?
- 8.) Can you describe whether
- a. your clients living with HIV feel connected to a sense of purpose, completeness, and wholeness in life?
  - b. Can you describe any impact or differentiate between the experiences of people living with HIV who identifying as LGBTQ versus being a person who injects drugs might have on this?

Probe: Good availability of mental health services?

Ok, great, thanks, this was all really great. Now I want to shift slightly and talk more about different interventions you might have practiced or seen yourself or maybe what has been expressed by your clients around loneliness.

### **Loneliness Interventions**

- 9.) What do you think is needed to make it easier for your clients to get what they want in their day-to-day life, specifically related to fighting loneliness and increasing connection to others, themselves, a higher being, sense of purpose?
  - a. Anything that you think needs to be added to what currently exist/what's lacking (e.g., proper training for professionals, lack of mental health services/support)?
  - b. Distinction between support available for LGBTQ vs. people who inject drugs here
- 10.) From what does exist, maybe what you do or what other providers or community partners do, what do you think has contributed the most to your client's adjustment to living with HIV?
  - a. Do you think identifying as LGBTQ or being a person who injects drugs had any impact on this?
- 11.) Ok, so that brings us to the end. Do you have any other ideas that you want to share?

### **Section 3. Summarize the Discussion**

#### **Debriefing**

Thank you for participating in this interview. I wanted to restate that everything you have shared here today is confidential, and I also want to give you a chance to ask any questions you might have about this research, if you might have any, feel free to ask now. [Answer any questions].

Thank you so much for your time, you really did have some great insight and shared some ideas that will be incorporated into my paper so thank you.

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## ACADEMIC VITA

### Laura M. Guay

#### EDUCATION

**The Pennsylvania State University (PSU), Schreyer Honors College** *December 2021*  
 B.S. in Biobehavioral Health | B.S. in French and Francophone Studies | Minor in Global Health  
**Study Abroad:** Dakar, Senegal | The West African Research Center *Spring 2019*  
**Honors:** Phi Beta Kappa | Peace Corps Prep Certification | Dean's List

#### RESEARCH EXPERIENCE

**Emory University Global Health Case Competition Participant, PSU Hershey, University Park, PA** *March 2021*

- Surveyed ~50 Philadelphians (phone call interviews) about food insecurity experienced during COVID-19
- Selected to represent PSU (one of 6 PSU students and only undergrad) at international university case competition
- Collaborated with a diverse team to find solutions to global health challenges that require a multidisciplinary approach
- Placed 4th out of 52 teams (first time in PSU history to place) fighting COVID-19 vaccination hesitancy

**Team Collaborator, PSU Food Decisions Research Lab, University Park, PA** *May 2020-Present*

- Surveyed ~50 Philadelphians (phone call interviews) about food insecurity experienced during COVID-19
- Conducted literature reviews, collected data through survey, and analyzed survey data regarding why restaurants are acting in socially responsible manners during the COVID-19 pandemic

**Research Assistant, PSU Stress Health and Daily Experiences Lab, University Park, PA** *January 2018-Present*

- Researched effects of stress (weight stigma, fear of cancer recurrence, loneliness) on overall well-being
- Conducted literature searches and reviews, designed questionnaires, performed participant screenings and visits, and applied for ethical approval to examine how person-level and contextual factors influence within-person experiences
- Created a 250-card game as a loneliness intervention and a 30-item scale to assess multi-dimensionality of loneliness
- Prepared 11 site evaluations (and one comprehensive) regarding impact of the Creativity Circle program
- Awarded Health and Human Development \$3000 Summer 2019 Research Grant for loneliness research abroad
- Selected as a featured undergraduate speaker for President Barron's report on "The Transformative Impact of Research" for the September 2021 Board of Trustees meeting

**Research Assistant, PSU Health and Human Development Design for Impact Lab, University Park, PA** *August 2017-Present*

- Initiated the redesign of the Women's Leadership Initiative to add experiential learning opportunities to the program as well as re-entry programming for PSU Education Abroad
- Orchestrated and guided the 10 student Youth as Researchers High School program through the recruitment phase, the research phase, and presentation phase of their research project

#### WORK EXPERIENCE

**Individual Specialist, UNESCO Youth Programme, UNESCO Headquarters, Paris, France (Remote)** *January 2021-Present*

- Coordinated the "Youth as Researchers on COVID-19 (YAR)" initiative communications team, raising awareness of the initiative and developing and translating communications products for participants and the broader global audience
- Advised research teams in consolidating, managing, and analyzing data to compile information sheets and documents
- Elaborated policy-oriented knowledge products of the YAR initiative by identifying and consolidating and organizing appropriate and relevant data and information collected by research teams in a detail-oriented manner
- Mobilized overall coordination and information-sharing with YAR by recruiting participations, supporting the organizations of events (Meet & Greets, Global Launch events, informal events among teams)

**Fellow, UNESCO Youth Programme, UNESCO Headquarters, Paris, France (Remote)** *June 2020-December 2020*

- Evaluated 6000 applications, prepared training materials for 300 participants, and directed a communications team of ~10 people for the Youth as Researchers initiative, a response to COVID-19
- Elaborated policy-oriented knowledge products of the YAR initiative by identifying, consolidating, and organizing appropriate and relevant data and information collected by research teams in a detail-oriented manner
- Gathered capacity building tools and recruited 120 pilot phase participants for UNESCO's Global Youth Community
- Facilitated weekly meetings of and drafted letters/concept notes/talking points on the Global Youth Community
- Authored four articles on UNESCO's global website regarding youth peacebuilding projects during COVID-19
- Described UNESCO's structure and activity to introductory PSU global health governance class (guest speaker)

**State Department Intern, Kinshasa, Democratic Republic of the Congo** *May 2019-August 2019*

- Executed French-language interviews with 10 medical professionals to feed President's Emergency Plan for AIDS Relief annual funding justification
- Designed gender and sexual diversity panel for 100 U.S. government interagency employees with USAID colleagues
- Evaluated partner performance, prepared quarterly performance review in advance of high-level U.S. government visit

- Engineered and directed ongoing “Conversations with America” event at three American Corners, recruiting U.S. Ambassador and Embassy officials to present talks to build mutual understanding between Americans and Congolese  
*Intern, AIDES Senegal, Dakar, Senegal* *March 2019-May 2019*
- Consolidated 20-page report into short summary to brief US Embassy in Dakar on two workshops that taught about human rights for LGBTQI+ (24 people in attendance) and the current state of HIV (30 people in attendance) in Senegal
- Navigated the grant writing process to apply for 45,000 euros to invest in a project in Dakar, Thies, and Mbour to create equitable access to STI/HIV care for the LGBTQI+ community  
*Peer Educator, AIDS Resource, State College, PA* *August 2018-May 2021*
- Implemented Condom Bingo events in the residence halls for special living option opportunities where I presented to 50 students about safer sex and free testing of STIs and HIV by organization
- Promoted AR through tabling at LGBTQI+ events and de-stigmatization of HIV/sex work events  
*Tennis Instructor/Customer Service Representative, PSU Tennis Center, University Park, PA* *August 2017-May 2021*
- Coached tennis to children aged 5 to 15 for 3 hours per week and created drills specific to age groups
- Resolved customer disputes and advocated for colleagues on campus recreation advisory boards  
*Camp Counselor, Inglese For You, Florence, Italy* *June 2018-July 2018*
- Executed behavioral management, decision making, and conflict resolution skills through organizing and leading activities for 30 children at an English-speaking camp

### COLLEGIATE LEADERSHIP EXPERIENCE

- Selected to be 1 of 4 Penn State students involved in the listening process to select the next president of the university  
*Next Gen Penn State Advisory Group Student Representative, PSU, University Park, PA* *April 2021-Present*
- Co-founded Social Movement Student Group to organize students around social justice issues on campus  
*Team Collaborator, PSU Center Philadelphia, University Park, PA* *July 2020-Present*
- Facilitated discussion at anti-Black police brutality 250+ person symposium
- Guided workshops for first-year students to develop a social change project on a social justice issue of their choice  
*Team Leader, PSU Schreyer Honors College Career Services, University Park, PA* *June 2020-Present*
- Recorded career services introductory/informational video for Schreyer New Student Orientation event
- Conducted focus groups to gauge interest and receive student input regarding social impact-related opportunities
- Student guest speaker for Schreyer Honors College philanthropy event hosted by Schreyer Career Services employee
- Provided student voice to “Civic Engagement and Leadership among Schreyer Scholars” task force  
*Member, Health and Human Development's Women's Leadership Initiative, University Park, PA* *August 2019-May 2020*
- Showcased and further developed leadership skills in a yearlong Friday afternoon program that taught foundational leadership values and knowledge through panelist events, network events, and service events to 35 women  
*Program Participant, PNC Leadership Development Center, University Park, PA* *February 2018*
- Identified leadership skills through participation in real-world simulations with top leadership researchers and professionals to receive individualized, detailed feedback to create a comprehensive leadership development plan  
*Representative, PSU Student Health Advisory Board, University Park, PA* *September 2019-May 2020*
- *Representative, PSU Campus Recreation Advisory Council, University Park, PA* *September 2019-May 2020*

### VOLUNTEER EXPERIENCE

- Tracked close contacts of COVID-19 cases 5-10 hours per week to inform of quarantine procedure, enroll contacts in a monitoring system, and respond to needs and concerns  
*Contact Tracer, Pennsylvania Department of Health, University Park, PA* *July 2020-September 2020*
- Guided sessions of 15-20 youth aged 8-16 in mental health camps 2 hours per day, 3 days per week  
*Volunteer, Jana Marie Foundation, State College, PA* *June 2020-July 2020*
- Corresponded with local organizations to mobilize a floor of 80 residents to engage in community service  
*Community Service Chair, PSU Globe Special Living Option, University Park, PA* *August 2018-December 2018*
- Monitored tennis matches and effectively communicated tennis techniques to Olympians  
*Special Olympics Volunteer, Special Olympics Pennsylvania Summer Games, University Park, PA* *June 2013-June 2017*

### AWARDS/SKILLS

- PSU 2021 Homecoming Student Court Member (1 of 10) representing the student body and its ideals (2021); Edith Pitt Chase Exceptional Student Leader/Outstanding Scholar Award (2020); Carey Lynne DeMoss Memorial Award for Building a Global Perspective in Schreyer Honors College (2020); Helen Skade Hintz Biobehavioral Health Scholarship for Academic Excellence and Leadership (2020); Frances DiGesio Women's Leadership Award (2020);
- Data analysis capabilities in SPSS and SAS software