

**Getting by: Perceived Facilitators and Barriers Encountered by Latinx-HIV
Serving Organizations in the US South**

by
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Dedication

This dissertation is dedicated to my family. They have been by my side from the first thought of returning to graduate school was present to the numerous thoughts of quitting and taking a long nap were stronger than the drive to finish this degree. To my lil' chickens; Tommy (I love you my buddy), we are so alike and for that I smile and frown every day, because I know how difficult and closed-off I can be, your "bad dad jokes", make me laugh on my darkest days, Anna (I love you my monkey-doodle), you have always been an independent individual from the time you were a toddler, I hope that you will always need me, Aaron (I love you mi gordo), my Ferdinand, my bull in a china shop, you have a big heart, never change. To my sisters, Rosa and Eva, you will always be my Nena and Isela. Now we can have as many sister lunches and dinners as we want and can afford. I love you.

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This degree is honoring my parents, Irene Chavez and Catarino Garcia, Mexican immigrants with no more than a junior high school education. They came to the US to give their daughters a better life, an opportunity at higher education, and everything they did not have as children, teenagers, and adults. This is for them, for their blood, sweat, tears and sacrifices that my sisters and I only saw as love.

“Mija, trabaja con tu cerebro para no tener que trabajar con tu espalda..” –

Catarino Garcia. Papi, I miss you every day.

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Abstract

Background: People living with HIV/AIDS (PLWHA) in the United States (US) South accounted for an estimated 45% of all PLWHA in the US. More than half of all new US HIV diagnoses were reported from the US South in 2018. Latinx individuals account for 18% of the population but are disproportionately affected by HIV, with 23% of Latinx individuals living with HIV/AIDS in the US (AIDS Vu, 2018; Centers for Disease Control and Prevention [CDC], 2018; US Census Bureau, 2019). HIV service organizations (HSO) are on the front lines of providing medical and social support services to communities impacted by HIV. Latinx-HIV serving organizations led by Latinx decision-makers are often smaller, grassroots organizations that provide a host of benefits that enhance the wellbeing of their communities. Latinx-HIV serving organizations rely on innovative facilitators and experience unique barriers in receiving funding (Rodriguez, 2008). More research is needed to address facilitators and barriers to funding for Latinx-serving HSOs. **Purpose:** This study utilized the Social-ecological Framework to explore the funding facilitators and barriers decision-makers face in Latinx-serving HSOs in the US South. Understanding these facilitators and barriers is crucial so that macro-level structural conditions can change to adequately support the work and address the unique needs of these organizations. Results will serve to make recommendations for organizations to continue their work with Latinx communities impacted by HIV. **Methods:** A narrative inquiry with a qualitative research design was used to analyze the data. Five participants were selected by criteria to complete a semi-structured interview and convey the story of the participants' perceived facilitators and barriers facing decision-makers in Latinx-HIV serving organizations in the US South.

The researcher used a thematic analysis to review and code the data. To ensure intercoder reliability, two different coders reviewed data and cross-referenced results. Each interview lasted between 60-75 minutes. Data were supplemented with field notes and personal reflection journal entries from the researcher. Interview results were categorized into broad themes and sub-themes. Results will be used to develop and implement action-oriented funding opportunities that continue to enhance and support capacity-building facilitators for organizations and, in turn, minimize barriers. **Results:** The data analysis revealed thematic codes; systemic facilitators and barriers, organizational facilitators and barriers, and cultural facilitators and barriers. Each broad thematic code had to emerge in at least three interviews, 60% of total interviews, to be considered a significant theme. A second review of the data from the interviews yielded at least one sub-theme under the broader theme. **Conclusion:** This research aimed to discover the facilitators and barriers that decision-makers encounter in seeking organizational funding in Latinx-HIV serving organizations. Additionally, decision-makers' need to continue serving Latinx communities in the US South to find perceived organizational strategies and capacity-building support related to funding access.

Keywords: grassroots, HIV, funding, facilitators, barriers, US South, Latinx

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Chapter I

Introduction

Background

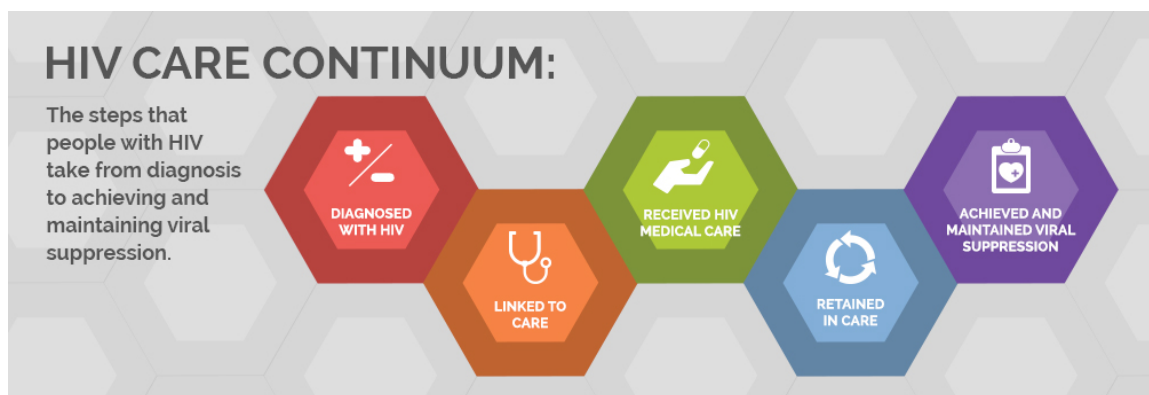
The Latino and Hispanic populations have grown significantly over the past few decades and comprise approximately 18.5% (estimated 60.6 million) of the US population (US Census Bureau, 2019). Additionally, 8.2% of individuals over five years of age reported Spanish as the primary language at home. An estimated 44% of those US self-identified Latino or Hispanic households reported speaking English “less than very well” (US Census Bureau, 2019). The growth of the Latino and Hispanic groups and the rising number of new HIV infections in the US South create a gap in services for this population. The unique language and cultural needs related to wellness and wellbeing in the Latinx community and HIV/AIDS intersection are significant for organizational leadership and overall wellness.

Approximately 1.2 million people are living with HIV/AIDS (PLWHA) in the US. Communities of color, such as Black and Latinx communities, are disproportionately impacted by HIV in the US South than Non-Hispanic Whites. Black and Latinx communities account for 69% of new HIV cases but only represent 31% of the US population in 2018 (CDC). The US South accounts for approximately 45% of all PLWHA diagnoses in the US and more than one half (51%) of all new HIV diagnoses in 2018. Latinx communities also face unique cultural barriers such as immigration status, stable income from jobs, standardize training, language barriers, understanding of US medical healthcare system, and access to medical and mental health resources that can

contribute to HIV status, access to prevention, and treatment, and continued care (Cristancho, et al., 2008; Ku & Matani, 2001; Palmer-Wackerly, et al., 2019).

Latinx-led and Latinx serving organizations also face unique barriers such as inequitable funding distribution to Latinx communities in most need. Decision-makers in smaller organizations typically manage funding with short-term funding from individual, community, or private donors and organizational fundraising such as unique events (Latino Community Fund Georgia, 2017). They often search for opportunities to sustain programs for individuals and communities, keep staff employed, and maintain operational costs. Disruptions and termination of these services create challenges and gaps for these Latinx individuals and groups and disrupt the HIV Care Continuum (see Figure 1).

The HIV Care Continuum is a patient-centered intervention in healthcare based on education and management to assist individuals living with cancer to reduce disparities, have better outcomes, and eliminate barriers to diagnosis, treatment, and engagement in medical care. It has been functional in HIV care to support PLWHA in navigating complicated healthcare-related systems to HIV/AIDS (Mizuno et al., 2018). Applying the HIV Care Continuum to the struggles and barriers faced by the Latinx community will guide the discovery of organizational leaders' perceptions of what is needed by Latinx PLWHA.

Figure 1*HIV Care Continuum*

Note. HIV Care Continuum, HIV.gov

The HIV care continuum represents the extent to which individuals living with HIV are diagnosed, engaged in care, and benefiting from antiretroviral therapy in terms of full viral suppression (undetectable lab values). The value of the continuum in managing the HIV epidemic is compelling: individuals engaged in care can manage HIV as a chronic condition and simultaneously reduce the risk of transmitting the virus to others. (HIV.gov, 2021)

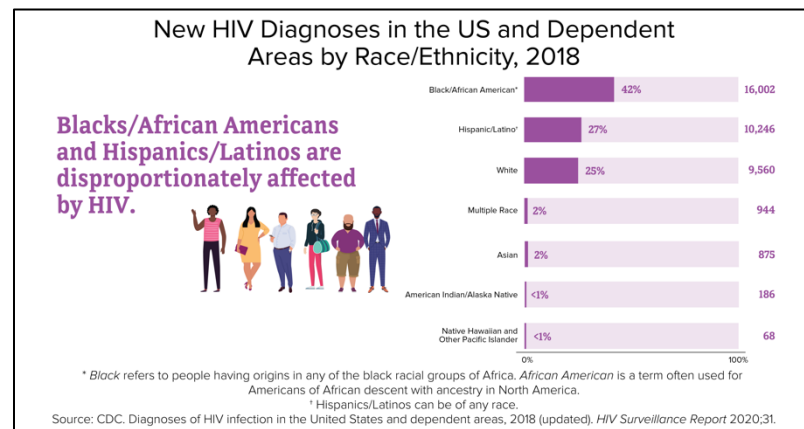
As the Latino and Hispanic populations continue to grow in the US, their identities also change from generation to generation. For this study, individuals or groups who identify as Afro-Latinx/e, Afro-Latino/a, Chicanx/e, Chicano/a, Hispanix/e, Hispano/a, Hispanic, Latinx/e, Latino/a, including any person of Indigenous, Mexican, Puerto Rican, Cuban, Latin Central or South American, Caribbean, or other Spanish culture, origin or descent, regardless of race or gender identity will be referred to in this study as Latinx. This study will focus on Latinx communities and warrants a clear definition of this group and how individuals in the community would like to be identified

and addressed in the intersectionality of HIV/AIDS and Latinx-HIV serving organizations.

Statement of the Problem

Since the first HIV cases reported in the New York City and Los Angeles areas in 1981, the HIV/AIDS epidemic has shifted from bicoastal urban regions to the 16 states and the District of Columbia that make up the US South (CDC, 2018). The US South now experiences a considerable burden of HIV and HIV-related deaths compared to any other area of the United States (Abara et al., 2013). Closing this gap is vital to the health of individuals in the area and the nation's long-term success in ending the HIV epidemic. Today, the US South accounts for approximately 51% of new HIV cases every year, yet only 38% of the US population resides in this region (CDC, 2018).

Additionally, the impact of HIV in the US South varies significantly by race, with higher infection rates among Latinx and African-American communities, which are already marginalized groups (Sutton & Parks, 2011). Despite stable numbers in HIV cases from 2014-2018 (see Figure 2), Latinx communities remain disproportionately affected, accounting for 27% of all estimated new incidences of HIV in the US (CDC, 2018). A significant factor driving the HIV epidemic in the US South includes barriers preventing people from accessing and receiving sufficient HIV and other health-related care and services (Pellowski et al., 2013).

Figure 2*Black and Latinx New HIV Diagnosis*

Note. New HIV Diagnoses in the US and Dependent Areas by Race/Ethnicity, 2018, CDC.gov

The Latinx community faces additional healthcare barriers and access to care, specifically lower health insurance rates and fewer healthcare resources in rural areas. Latinx individuals accounted for a 57% increase in uninsured individuals age 64 and under, with half of Americans with no insurance coverage living in the US South (Kaiser Family Foundation, 2020). This is exacerbated for the US South because while Medicaid is the primary medical coverage for HIV in the US, 16 states in the US South did not expand Medicaid coverage for their perspective states (CDC, 2018).

Funding gaps are the primary contributing predictor of the lack of HIV/AIDs prevention and treatment in the US South (Pellowski et al., 2013; Reif et al., 2017). HIV prevention and care are partially funded through federal funding sources, including the Substance Abuse and Mental Health Service Administration (SAMHSA), Housing Opportunities for Persons with AIDS (HOPWA), the Ryan White Care Act, and the Centers for Disease Control (CDC) completed of the total amount of federal funds distributed to each person living with HIV in the US South and found that the region

receives less funding per individual. Specifically, states in the US South receive \$13,313.80 in funding for each person living with HIV, compared to \$34,10.80 for other states. Federal funding per PLWH from HOPWA, SAMHSA, and Ryan White was comparable overall for the United States and the US South. However, there is a disparity in CDC funding of \$100 per individual; the US South receives \$494/PLWH vs. the US overall \$596/PLWH (Reif et al., 2017).

The US South received less funding from CDC categories such as community-based, surveillance, community building assistance, and community-based organization. Medicaid is another critical funder of HIV services and care but has expanded its status in 39 states, including the District of Columbia (Kaiser Family Foundation, 2020). Examining past data on Medicaid funding for HIV reveals that this program distributed 51% of social and medical services for PLWHA. More importantly, the US South has received less Medicaid funds than the national average. Of the 17 US South States, including the District of Columbia, only eight have expanded Medicaid as of July 2021, (see Table 1) even though 90% of individuals falling under the Medicaid coverage gap come from this region (Kaiser Family Foundation 2020; Reif et al., 2017).

Table 1*Medicaid Expansion in US South*

US Location	Status of Medicaid Expansion in US-South
Alabama	Not Adopted
Arkansas	Adopted
Delaware	Adopted
District of Columbia	Adopted
Florida	Not Adopted
Georgia	Not Adopted
Kentucky	Adopted
Louisiana	Adopted
Maryland	Adopted
Mississippi	Not Adopted
North Carolina	Not Adopted
Oklahoma	Adopted
South Carolina	Not Adopted
Tennessee	Not Adopted
Texas	Not Adopted
Virginia	Adopted
West Virginia	Adopted

Note. Status of Medicaid Expansion in US South, (Kaiser Family Foundation, July 1, 2021)

Throughout the past few decades, foundation funding in the US that was explicitly designed to benefit Latinx communities has remained relatively steady at an average of 1.3% (Shah, et al., 2011). Simultaneously, while funding has remained constant, the Latinx population has been increasing and is currently at over 18.5% of the US population (US Census Bureau, 2019). Funders included in the Foundation Center's yearly sample provide 0.9% of the total grants to the activities and organizations that could assist Latinx communities, compared to 1.2% in other states (Shah, et al., 2011). The funds do not target a specific racial or ethnic group, and instead, are used to benefit minority groups in general. It is evident that providing information, education, resources, providing appropriate care that is culturally based, and implementing community-based programs, foster the lives of Latinx individuals, including lesbian, gay, bi-sexual (LGB), transgender, gender non-conforming, and non-binary (TGNC), communities.

Support and culturally appropriate HIV prevention and care are integral factors for individual and community wellness and wellbeing. Yet, few resources exist which center on Latinx individuals and communities aimed at addressing their unique experiences. At the same time, it is evident that although most of the organizations are at the forefront in offering much-needed services and care to Latinx communities, decision-makers in these organizations lack the required resources to develop innovative programs due to funding gaps. Latinx-HIV service organizations often cannot keep up with the demand for assistance from the community compared to their capacity to operate due to funding limitations and restrictions.

Purpose of the Study

The purpose of the study was to apply the Social-ecological Framework to understand the perceptions of decision-makers at Latinx-HIV serving organizations in the US South in the context of barriers and facilitators to funding resources. Results were used to identify and develop capacity-building organizational strategies for Latinx-HIV service organizations and support those decision-makers. In turn, these decision-makers continue to support their Latinx communities. This study will clarify common perceptions community, grantmakers, funders, and researchers hold about small Latinx-HIV serving organizations (HSOs), Community-Based Organizations (CBOs), and grassroots organizations. Additionally, to put forth recommendations for funding access so organizations can continue their work with Latinx communities impacted by HIV.

Value of the Study

The study will present research findings that can be decision-makers of Latinx-HIV serving organizations and PLWHA communities. Upon completing this study, the researcher anticipates depicting usable data to present perceived facilitators and barriers experienced by decision-makers in Latinx-HIV serving organizations to funders, fellow educators, and researchers. In addition, the researcher plans to continue research from additional findings.

Research Questions

The following research questions were intended to increase knowledge of perceptions of decision-makers in Latinx HIV organizations.

Question 1: What are the perceived facilitators and barriers for decision-makers in Latinx-HIV serving organizations in terms of capacity to apply for funding in the US-South?

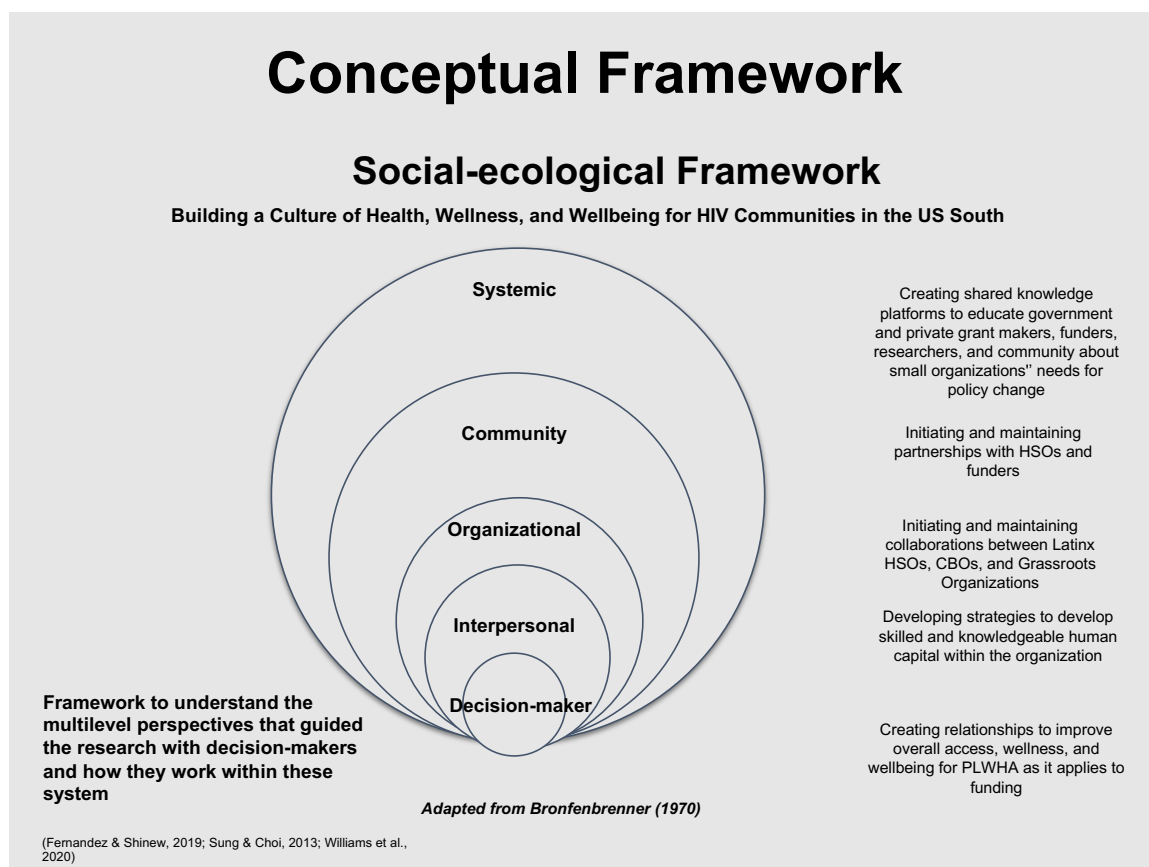
Question 2: What are the perceived organizational strategies and capacity-building support related to funding access that decision-makers need to continue to provide resources and services to Latinx People Living with HIV/AIDS (PLWHA) in the US-South?

The Context for the Study

The researcher will collect data using the social-ecological framework. The framework was used to assess reciprocal interaction between the systems in the framework from qualitative interviews with decision-makers in Latinx-HIV serving organizations regarding perceived facilitators and barriers related to funding. Data will be evaluated using a narrative inquiry by analyzing decision-makers' stories and experiences.

Conceptual Framework

To understand and contextualize the perceived facilitators and barriers that Latinx-HIV serving organizations encounter, this study will use the socio-ecological framework of human development by Urie Bronfenbrenner, adapted for later concepts of the theory, to focus on organizational and public policy (see Figure 3). Known as “ecological systems theory,” Bronfenbrenner’s original framework from 1979 situates a child’s growth in a series of expanding “environmental systems” of influence. These range from the child’s immediate family to the overarching cultural paradigm that they are raised in.

Figure 3*Organizational Social-ecological Framework*

Note. Adapted from Bronfenbrenner

This study is not centered on children or human development. The study will focus on Latinx-HIV serving organization decision-makers' perceived facilitators and barriers applicable to funding. Additionally, the study will use the social-ecological framework to assess the reciprocal interaction between the systems in the framework. This study emphasized that the relationship between the decision-maker and their socio-ecological influences define perceived facilitators and barriers and the relationships between the spheres of influence. Situating decision-makers of Latinx-serving HSO's within the socio-ecological framework of Latinx communities will reveal how relationships between these organizations and greater spheres of socio-ecological

influence their ability to serve their communities. The social-ecological framework was applied to understand the multilevel perspectives that guided the research with decision-makers and how they work within these systems. Furthermore, following this chain of analysis to the center of Bronfenbrenner's framework will show how these facilitators and barriers are translated into unique experiences decision-makers face.

Definitions

Defined are terms that were used in HIV/AIDS context and communities. Additionally, gender-neutral terms are defined for intent, clarity, and to include all genders and individuals that identify as gender non-specific (D5: Advancing diversity, equity, and inclusion in philanthropy, 2016; Gilead Sciences, Inc., 2019; Human Rights Campaign, 2011; Kabba, 2011; Lambada Legal, 2021).

- *Acquired Immunodeficiency Syndrome (AIDS)*-A disease of the immune system due to infection with HIV. HIV destroys the immune system's CD4 T lymphocytes (immune system's CD4 cells), vulnerable to life-threatening diseases and cancers. Acquired immunodeficiency syndrome (AIDS) is the most advanced stage of HIV infection. To be diagnosed with AIDS, a person with HIV must have an AIDS-defining condition or have a CD4 count of fewer than 200 cells/mm³ (regardless of whether the person has an AIDS-defining shape).
- *AIDS Service Organization (ASO)*-A non-governmental organization that provides services related to HIV/ the prevention and treatment of HIV/AIDS.
- *Antiretroviral Treatment (ARV)*-Regimen Simplification changes an HIV treatment regimen to make medication adherence easier. Simplifying an HIV regimen can include reducing the number of antiretroviral (ARV) drugs in the

regimen or changing to a combination ARV drug that provides a one-pill, once-daily complete regimen. Other changes can include switching to ARV drugs that cause fewer adverse effects or ARV drugs that can be taken without food.

Benefits of regimen simplification include long-term medication adherence, reduced risk of treatment failure, and improved quality of life.

- *Barriers*-For the purpose of this study, conditions that impede decision-makers' ability to access, navigate, write, submit, and manage a grant funding opportunity for their Latinx-HIV serving organization.
- *Capacity Building Assistance (CBA)*-Is a process for equipping the nation's HIV prevention workforce—including staff at state and local health departments, community-based organizations (CBOs), and healthcare organizations—through training, technical assistance, and other resources to reduce HIV infection and improve health outcomes for people with HIV in the United States. By building individual competencies and technical expertise, strengthening organizational capacities, and enabling supportive structural environments, the provision of CBA is critical to the foundation and performance of the HIV prevention workforce for Ending the HIV Epidemic.
- *Co-conspirator*-Someone who conspires with other people to do something
- *Commitment to Partnerships in Addressing HIV/AIDS in the Southern States (COMPASS) Initiative*-The Southern AIDS Coalition initially launched SPARK! (Southerners Promoting Awareness, Resources & Knowledge) in 2018 to fund community-led campaigns and education initiatives across the Deep South to address HIV-related stigma. In light of the impact of the COVID-19 pandemic,

we are currently accepting proposals to address both HIV-related stigmas, as well as isolation and loneliness.

- *Community-Based Organization (CBO)*-A public or private non-profit organization representing a community or a significant segment of a community and works to meet community needs; many community-based organizations provide prevention and treatment care to people living with HIV.
- *Culture*-The researcher defined culture for this study as essential attributes of Latinx communities in the US that decision-makers incorporate in resources and services for PLWHA in the US South. Additionally, culture is defined as attributes of Latinx communities in the US that decision-makers want to see from funders and funding opportunities for PLWHA in the US South. Some of these cultural attributes will be evident later in the research.
- *Diversity*-Encompasses a demographic mix and perspectives of a specific population of people, considering human differences. Diversity typically focuses on encompassing populations that have historically been marginalized in broader society.
- *Facilitators*-For the purpose of this study-conditions that enhance decision-makers ability to access, navigate, write, submit, and manage a grant funding opportunity for their Latinx-HIV serving organization
- *Gender-nonconforming (GN)*-People whose gender expression, the external communication of gender through behavior or appearance, differs from expectations associated with theirs at birth. Part of transgender, genderqueer, non-binary, indigenous, and gender non-conforming communities (TGNC).

- *Grassroots Organization*-Organizations use collective action at the local level to serve a neighborhood or geographic region to develop stronger relationships, common goals, and organizations to achieve those goals.
- *Health Disparities*-Are differences exist among specific population groups in the US applicable to overall health, wellness, wellbeing, and mental health potential that can be measured by differences in incidence, prevalence, mortality, and other health conditions.
- *Human Immunodeficiency Virus (HIV)*-The virus that causes AIDS is the most advanced stage of HIV infection. HIV is a retrovirus that occurs in two types: HIV-1 and HIV-2. Both types are transmitted through direct contact with HIV-infected body fluids, such as blood, semen, and vaginal fluids, or from a mother who has HIV to her child during pregnancy, labor, delivery, or breastfeeding (through breast milk).
- *HIV Continuum of Care*-The steps or stages of medical treatment for HIV. The continuum of care begins when someone receives an HIV diagnosis, and includes finding the proper health care, starting antiretroviral therapy (ART), adhering to treatment, and staying in care. The ultimate goal of the continuum of care is virologic suppression. The continuum of care can also refer to a model used by epidemiologists and other health care professionals to monitor HIV-related programs' success and identify and address gaps in HIV-related services. This model measures linkage to care, retention in care, and sustained viral suppression among people with HIV. Synonym(s): HIV Care Continuum, HIV Treatment Cascade.

- *HIV Service Organization (HSO)*-A non-governmental organization that provides HIV prevention and treatment of HIV/AIDS.
- *Inclusion*-Refers to the degree to which diverse individuals can use their voice, participate in the decision-making processes within a group, and the amount of power they have within that group. While a truly “inclusive” group is necessarily diverse, a “diverse” group may or may not be inclusive.
- *Latinx*-For the purpose of this study-individuals or groups who identify as Afro-Latinx/e, Afro-Latino/a, Chicanx/e, Chicano/a, Hispanix/e, Hispano/a, Hispanic, Latinx/e, Latino/a, including any person of Indigenous, Mexican, Puerto Rican, Cuban, Latin Central or South American, Caribbean, or other Spanish culture, origin or descent regardless of race or gender identity.
- *LGBTQ*-Acronym for lesbian, gay, bisexual, transgender, and questioning/queer.
- *People Living with HIV/AIDS (PLWHA)*-Infants, children, adolescents, and adults have HIV/AIDS.
White Care Act (RWCA)-August 18, 1990, Federal Legislation, named for a young boy who died of AIDS. Provides federal funds to cities and states for planning, implementing, and evaluating programs to prevent transmission of HIV and to improve the quality and availability of health care and social services for people affected by HIV/AIDS, now managed by the Health and Resources and Services Administration (HRSA).
- *Racial equity*-Is achieved when all people experience situational fairness – when race is not a determining factor in the allocation of societal assets and advantages, such that an individual’s race is not itself a liability or does not create unearned

privilege. Racial equity helps close gaps in the likelihood of success for different racial groups and improves overall community health.

- *Same-Gender Loving (Men / Women)*-A term preferred instead of men that have sex with men, women who have sex with women, lesbian, gay, or bisexual to express attraction to and love people of the same gender.
- *Transgender*- People whose gender identity, one's inner sense of being male or female, differs from their sex at birth. Part of transgender, genderqueer, non-binary, indigenous, and gender non-conforming communities (TGNC).
- *US South*-As defined by the United States Census Bureau, the Southern region of the United States that includes sixteen states plus D.C., Alabama, Arkansas, Delaware, the District of Columbia, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, and West Virginia.

Summary

Small Latinx-serving organizations face significant challenges in gaining access to HIV funds. Unfair allocations, as regions with higher HIV/AIDS cases, such as the US South, received the exact funding amounts as states with lower HIV/AIDS prevalence (Pellowski et al., 2013; Reif et al., 2017). This and additional barriers and facilitators are what current smaller organizations encounter and were further researched in this study. This study will review organizational leaders' perceptions of current barriers and facilitators experienced by Latinx-HIV serving organizations such as HSOs, CBOs, and small grassroots organizations in the US South. Even though these decision-makers operate in HIV prevention and treatment, they do not see a significant decline in new

HIV diagnoses for Latinx communities, as addressed in the literature review for this study.

Chapter II

Literature Review

This literature review provided a better understanding of Latinx communities, such as their cultural needs in the US South. It will also cover critical aspects of Latinx-HIV serving organizations that provide resources to communities living with HIV. The purpose of this literature review provided an understanding of prior work done in this field and offering for newly perceived information to be researched in this study.

HIV and Latinx Culture

Latinx Culture

Latinx culture encompasses in part religion, food, art, literature, music, fiestas, greetings, complete with a handshake, hug, and kisses on the cheek, as well as values rooted in family, friends, and storytelling traditions (Dolwick Grieb et al., 2016; Nuñez et al., 2016; Schmitz et al., 2019; Wang, L. 2017; Wilson, et al., 2013). The researcher defined culture for this study as essential attributes of Latinx communities in the US that decision-makers incorporate in resources and services for PLWHA in the US South. Additionally, culture was defined as attributes of Latinx communities in the US that decision-makers want to see from funders and funding opportunities for PLWHA in the US South. Some of these cultural attributes will be evident later in the research.

Self-Efficacy

“Self-efficacy reflects confidence in the ability to exert control over one's own motivation, behavior, and social environment” (Carey & Forsyth, 2009). Latinx culture can be seen as a barrier on its own. One specific belief that can be a barrier to prevention and care for Latinx individuals is the concept of *fatalismo* or fatalism, leaving a life event

up to God's or the universe's will. Meaning that the individual has no say so or control for a life event, an "*it is meant to be*" type of belief. Many Latinx individuals believe that "it is their fate to have HIV, thereby making HIV-prevention unnecessary (Wilson et al., 2013).

Stigma

One cultural belief in the Latinx community is *machismo*, the belief in a superior sense of masculine pride and traditional male gender roles such as being head of household and making all decisions for the home and family. *Marianismo* is the belief that Latina women do not have sexual desires or needs, do not need to express those desires and needs, and must be moral, wholesome, and pure, and expected to fulfill traditional female gender roles of family and home. These beliefs may lead to decreased prevention and treatment access for HIV.

Marianism may be related to the Latinx male population engaging in same-gender-loving men sexual contact that has faced significant prejudice and stigmatization from its Latinx community leading to high secrecy in their sexual encounters (Dolwick Grieb et al., 2016; Nuñez et al., 2016; Schmitz et al., 2019; Wang, L. 2017; Wilson, et al., 2013). Similarly, same-gender-loving Latinx men may have decreased access to HIV prevention tools such as Voluntary Counseling and Testing (VCT) due to fear of stigma, which creates access barriers preventing them from gaining knowledge and tools to prevent the spread of HIV. Therefore, there is a need to continue funding culturally appropriate programs to inform, educate, and promote the same-gender-loving men's safe sex practices in the Latinx community. Latinx individuals may also may be experiencing intersectional stigma, the intersection of multiple stigmatized identities, such as

identifying as Latinx, LGB, or TGNC community, and being PLWHA (Dolwick Grieb et al., 2016; Martinez, 2019; Schmitz et al., 2019; Wang, L. 2017).

Demographics and Socioeconomic Status

The Latinx community has been affected by various factors contributing to their high HIV/AIDS rates in the US South (Reif et al., 2017; CDC, 2017). There are significant HIV/AIDS disparities when you compare Latinx communities to White communities. Factors that impact these disparities are demographic, socioeconomic, and social-cultural factors.

HIV/AIDS has been a significant challenge for the Latinx community, which faces multiple barriers such as poverty and other social injustices related to accessing needed services. HIV/AIDS prevalence among the Latinx community was also higher in the US South (Galeucia & Hirsch, 2016; Godfrey et al., 2017). Statistical evidence from 2017 alone indicated that Latinx adults made up nearly 26% of America's new HIV/AIDS diagnoses, totaling 9,889 people (CDC, 2019). Most (86%) of the Latinx community's new HIV/AIDS infections were through sexual contact by same-gender-loving men, 4% via heterosexual activities, 4% via drug injections, and 3% for sexual contact of same-gender-loving men coupled with drug injection (CDC, 2019). HIV/AIDS prevalence among the Latinx community was high, especially for males engaged in same-gender-loving men sexual contact, who had higher prevalence factors (Galeucia & Hirsch, 2016; Painter et al., 2019). Among female Latinx community members, 88% of HIV/AIDS infections were through heterosexual contact, in contrast with males, and 12% were via drug injection (CDC, 2019). More research is needed to focus on essential HIV/AIDS prevalence rates towards eradicating the disease in the future.

Latinx individuals born in Puerto Rico and the US have higher rates of HIV/AIDS compared to individuals born outside of the US (CDC 2017; Gonzalez et al., 2008). Unemployment has also contributed to the high HIV/AIDS rates among the Latinx community. In October 2020, the employment rate for Latinx was 8.8% compared to 6.0% for Whites (US Bureau of Labor Statistics, 2020). An unstable job source has forced many Latinx community members to practice unsafe sexual encounters such as commercial sex work, which carries a higher incidence of HIV (Barnes, 2002; Gonzalez et al., 2008; Reif et al., 2017).

HIV, Latinx Communities, and the US South

The US South's unique structural issues contribute heavily to the spread of HIV/AIDS (Barnes, 2002; Gonzalez et al., 2008; Reif et al., 2017). The US South has several different regions. Each contains nuances in terms of their Latinx demographic and the politico-structural issues they face. Latinx communities in Florida, for example, are more likely to be of Cuban and Puerto Rican heritage, a situation further complicated by the acrimonious relationship between Cuba and the United States (Hoffman, 2004). In one Latinx demographic, Cuban-Americans, immigration to the United States increases their likelihood of contracting HIV. In a review of Cuba's HIV policy (Hoffman, 2004), the country has been highly successful in containing the spread of the disease through careful monitoring of blood transfusion products. However, in the United States, Cuban-American communities are subject to the same bias and general lack of support that pervades other Latinx populations. Furthermore, Hoffman notes that many emigrants' extreme difficulty traveling from Cuba to the US may expose them to the disease through unsanitary conditions.

This is a very distinct scenario from what might be experienced in Texas, where Latinx communities primarily comprise North, Central, and South American immigrants. Latinx communities here have proximity to a heavily trafficked border region shared with Mexico and neighboring Central and South American countries such as Guatemala, El Salvador, Honduras, Nicaragua, Costa Rica, Panama, and Belize, which are developing nations still struggling to contain their own HIV/AIDS epidemic (Barnes, 2002).

HIV and Government

In the United States, political power is divided and distributed equally among federal, state, and local governments. A local population amid an emergency can call on their local government for assistance. If necessary, calls for aid can readily travel up the political chain to federal agencies through well-developed lines of communication. The Ryan White Care Act (RWCA) is an example of this process in action. The AIDS epidemic initially impacted gay communities in metropolitan areas of Los Angeles and New York. However, these localities eventually spur action from their federal government (Barnes, 2002; Galeucia & Hirsch, 2016).

Exacerbating this issue is that government largely ignores many highly vulnerable communities along the border region. These include migrant workers, commercial sex workers, persons that traffic drugs, and persons that use drugs. Failure to work with, or even acknowledge, these communities has led to the spread of HIV/AIDS on both sides of the US-Mexico border. A unifying factor among these challenges is that healthcare providers are poorly prepared to help these communities due to funding, training, and the influx of clients and patients needing HIV resources. (Barnes, 2002; Galeucia & Hirsch, 2016).

Outside of Latinx communities, there are also prevalent socio-cultural beliefs regarding HIV/AIDS and the diseases associated with homosexuality built into the political structure of the US South. A brief review of the structural factors enabling the HIV epidemic in this area (Hiers, 2020) notes a spillover of the religious stigma surrounding homosexuality into local government policy regarding HIV/AIDS.

In some states, PLWHA suffers a curtailed set of fundamental rights. Furthermore, the religious zeal of their constituencies has caused many southern politicians to avoid acknowledgment of this health crisis entirely. Hiers describes a tragic interaction between these overtly religious politics and a widespread lack of services and infrastructure that buttress the US South HIV epidemic. Lack of access to quality health care, quality sex education, and public transit have contributed to the disease's continued spread (Galeucia & Hirsch, 2016; Ku & Matani, 2001; Kvasova & Buffington, 2020). This effect is significantly exacerbated in rural areas common throughout the south as such places are difficult to reach, both physically and culturally, by outside support.

HIV and Federal Funding

The National Institute of Allergy and Infectious Diseases (NIAID, 2018) realized the seriousness of HIV and HIV/AIDS among the Latinx community, especially in the US- South (CDC, 2019; Galeucia & Hirsch, 2016; Godfrey et al., 2017). The NIAID had dedicated significant resources, especially funding, to combating HIV/AIDS among the Latinx community. NIAID had undertaken the HIV/AIDS funding process through a collaborative approach of government, non-governmental organizations, and the private sector came as the federal government. Kaiser Family Foundation (2019) and the CDC

(2018) also partnered with other sectors to increase their efficiency and resource gathering towards combating HIV/AIDS in Latinx communities living in the US- South.

Funding from the federal US government had risen over the years to counter the challenges of population growth, new infection rates, and other issues (Henderson, 2010; Kaiser Family Foundation, 2019; CDC, 2018). Funding rose drastically in 2019; \$ 34.8 billion was allocated to fighting HIV/AIDS for private, public, and non-profit organizations. However, Congress has reduced its spending on HIV/AIDS research and prevention programs (Kaiser Family Foundation, 2019). Sixty-two percent of the FY 2019 HIV/AIDS budget was allocated for domestic use in its care and treatment, 9% for cash and housing assistance, 7% for HIV/AIDS research, and 3% for HIV/AIDS prevention. The majority of the Latinx community living with HIV/AIDS had the opportunity to compete for 2.6 million US dollars in 2019 for research, \$3.1 million for cash and housing assistance, and \$21.5 million in care and treatment (Aidala et al., 2016; Kaiser Family Foundation, 2019).

As such, the US South population of Latinx PLWHA communities has seen significant funding directed towards their local organizations helping to combat the problem (Reif et al., 2017; CDC, 2018). The CDC allocated specific funds for CBOs in the Latinx community areas of the US South; however, it showed a considerable funding gap, as not all of the CBOs in the region could apply for the funds, but only those located in urban areas of the US South (CDC, 2018). The approach significantly reduced the accessibility of HIV/AIDS resources to the Latinx community and contributed to the resurgence of new HIV diagnoses.

The majority of Latinx individuals lived outside the urban areas. For example, The Duke Global Institute showed that in Alabama, Mississippi, North Carolina, and South Carolina, Latinx communities and the general population living outside the urban areas. This meant that organizations in the outskirts had more clients than those in the metropolitan organizations. Therefore, The Duke Global Institute (2015) and the CDC (2018) showed considerable funding gaps as per the CDC budget allocations for the US South.

CDC has contributed nearly \$216 million in the last five years to a total of 90 CBOs combating HIV/AIDS. In addition, both the NAIDS and CDC have used collaborative measures to accumulate more resources for their HIV/AIDS funding programs, including those in the US South. CDC awards were nearly \$850,000 to the CBOs in the US South. Also, the CDC offers \$400,000 per year to qualifying individuals undertaking research or fighting HIV/AIDS in different approaches, and the exact applies to the US South.

HIV and Private Funding

Private funding opportunities directed towards the US South served the sizable Latinx community HIV/AIDS population. The organization revealed that the International Conference Centre Geneva (CICG) provided funds to CBOs in the US-South that focused on HIV/AIDS, especially among the Latinx community that has the highest HIV/AIDS existing cases. CICG provided nearly \$ 4,500 per CBOs that lived in Louisiana, South Carolina, Alabama, Florida, Georgia, Tennessee, Texas, Mississippi, and North Carolina. Additionally, Rural Health Information (2019) reported that Clinical Immunology Society (CIS) grants were another funding opportunity for the Latinx CBOs

in US South. CIS provided grants up to \$25,000 to CBOs in the US South, South Carolina, Alabama, Florida, North Carolina, Louisiana, Mississippi, Tennessee, Texas, and Georgia.

The CDC had requested Congress to change the fund allocation formula based on the needs-based approach. In the needs-based approach formula, funds will be allocated to the regions with the highest HIV/AIDS rates, such as the US South with a sizable Latinx community of PLWHA. The CDC showed that New York and California gained 36% of the total HIV/AIDS when it only had 19% of new HIV/AIDS cases while the US South combined received only 33% of the CDC funds while having a more significant 40% of new HIV/AIDS cases. Therefore, the CBOs in the US South faced significant barriers towards HIV/AIDS funding in this respect. They allocated inadequate funds to serve the high HIV/AIDS cases among the Latinx community (The Duke Global Institute, 2015; CDC 2018).

More recently, corporate funders such as pharmaceutical companies have increased efforts to make funding opportunities to organizations in the US South. ViiV Healthcare has been working with vulnerable communities in the US- South since 2010 with their *Positive Action Southern Initiative (PASI)* funding opportunity (ViiV Healthcare, 2018). These funding opportunities support HIV/AIDS community programs to be sustainable. Gilead Sciences, Inc., launched in 2017 a funding program known as *Commitment to Partnership in Addressing HIV/AIDS in Southern States (COMPASS) Initiative*. Four coordinating centers in the US South are supporting Gilead to lead these efforts, with Gilead committing to award \$100 million over ten years to support

organizations in the US South most impacted by HIV/AIDS, including Latinx communities Latinx-serving HSOs, CBOs, and grassroots organizations (Gilead, 2021).

Research Gap

The CDC, US Department of Housing and Urban Development, and other federal funding systems inefficiently allocate finances to CBOs. Regardless of having more HIV/AIDS prevalence among the Latinx community, the US South receives inadequate financial support. Nonetheless, the US federal government has identified these HIV/AIDS challenges among the Latinx communities living in the US South and has directed various resources to the region.

The literature review came up short with knowledge of how the private sector's HIV/AIDS funding for these HSOs affects their operations. The private sector was also identified to provide the funds. Little has been published in the private sector due to the lack of a framework to manage their funding and privacy issues. The review showed a lack of proper regulation for private financing for these CBOs, which meant that finding data about their funding operations and patterns was difficult. As such, the private sector must agree to avail their HIV/AIDS funding data for the CBOs to the public for more straightforward assessment, especially for the Latinx HSOs.

Funding for HIV prevention and treatment is key to reducing HIV prevalence among the Latinx communities, especially those in the US South. Funding allocations must be adequate to realize any impact on the communities with the most significant needs. Moreover, the process must be transparent and equitable to avoid bias and inefficiency in combating HIV among the Latinx community. The private sector should also establish a framework that would allow for effective management of the funding

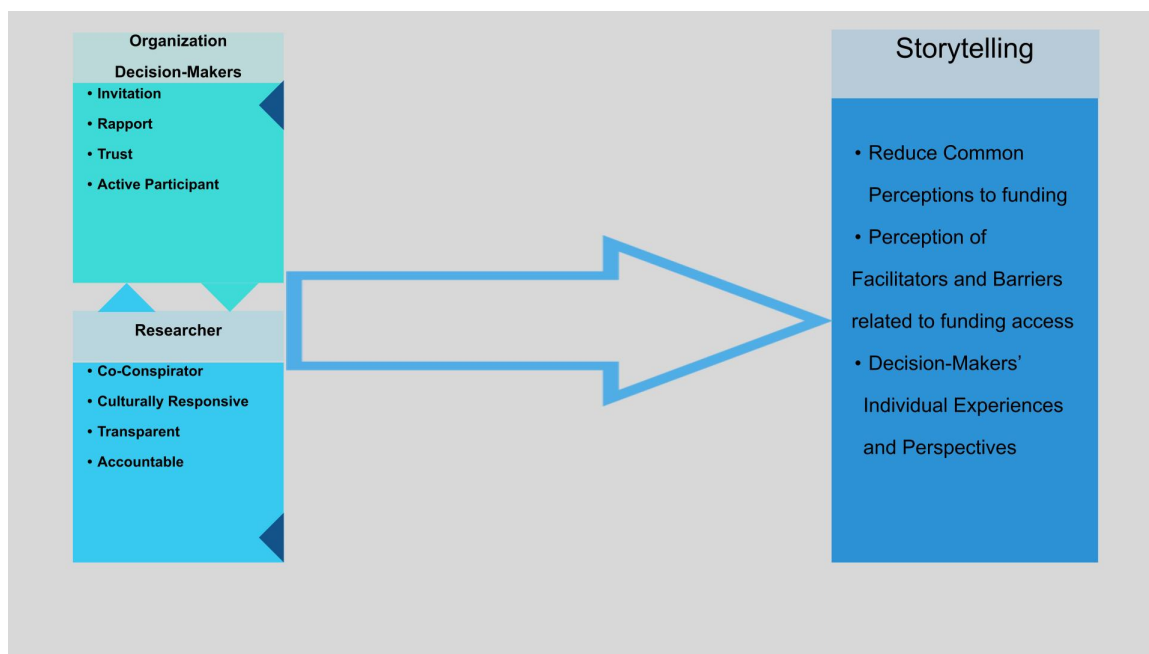
process. The CBOs help reduce the ambiguity of managing the entire Latinx community towards eradicating HIV/AIDS. They should be factored into the funding process in both federal, public, and private avenues.

Chapter III

Methods

Methodology

This study applied the narrative inquiry of storytelling by Connelly and Clandinin to analyze data. The narrative approach uses participant storytelling via interviews, conversations, field notes, journals, photos, etc., a research method for representing the study (Connelly & Clandinin, 1990; Moen, 2006). The study utilized a narrative inquiry with a qualitative research design to analyze the data and convey the story of the participants' perceived facilitators and barriers they faced as decision-makers in Latinx-HIV serving organizations in the US South (see Figure 4). The researcher adapted Connelly and Clandinin's narrative inquiry to highlight the decision-makers' rapport and trust as active participants in telling their story and the researcher's culturally responsive, open, and transparent engagement with the decision-makers. The researcher was knowledgeable with vulnerable communities that included these decision-makers. Additionally, the researcher considered participant hesitancy in allowing outsiders into decision-makers' space, mistrust of academia, and mistrust in the research process (Ellard-Gray et al., 2015).

Figure 4*Narrative Inquiry*

Note. Decision-maker and Researcher Narrative Inquiry Methodology adapted from Connely and Clandinin, (1990).

“Humans are storytelling organisms who, individually and collectively, lead storied lives. Thus, the study of narrative is the study of the ways humans experience the world” (Connely & Clandinin, 1990). PLWHA individuals, communities, and decision-makers have a narrative to share. The narrative is an individual or a group's story that may or not be similar to other individuals' or groups' histories. The storytellers recall a specific memory or event and the meaning of that story. The researcher will come into this virtual shared space and “ask questions that will help them [the participant] interpret and experience the world of the participant rather than try to explain or predict that world.” (Wang, C & Geal, 2015). The concept of a narrative framework does not analyze whether the story is accurate; it provides the space to give a personal narrative.

As a member of the Latinx community and an active participant in efforts to support Latinx-HIV serving communities, the primary researcher took significant efforts to suspend their personal experiences and opinions regarding the subject of these interviews. The practice of objectively investigating a phenomenon that the researcher is actively invested in is known as reflexive bracketing. It requires the researcher to identify thoughts and opinions that may emerge reflexively when considering the phenomenon and cloud future judgment (Gearing, 2004). Efforts to prevent the intrusion of the researcher's personal views included openly informing participants of the researcher's relationship with the subject matter before the interview. When interviews were scheduled, the researcher documented personal experience via journaling and reflexive bracketing before and after each interview to address and minimize possible bias and ethical considerations (Gearing, 2004). Additionally, the researcher debriefed with two members of the external dissertation committee regarding the process and personal experiences of the interviews.

Research Setting

The study took place at a state university in Southeast Texas. In-person meetings were not possible for interviews due to travel restrictions of COVID-19. Thus, interviews were completed via a virtual platform using Zoom version: 5.4.7 (59780.1220), a cloud-based video conference application.

Research Questions

The following research questions were intended to provide answers to the statement of the problem for this study. What are the perceived facilitators and barriers for decision-makers in Latinx-HIV serving organizations in terms of capacity to apply for

funding? What are the perceived organizational strategies and capacity-building support related to funding access that decision-makers need to continue to provide resources and services to Latinx (People Living with HIV/AIDS) PLWHA?

Research Design

The researcher implemented a qualitative research design to collect primary data with an IRB-approved semi-structured interview. Prompting questions for detailed qualitative measures and demographic data were obtained on participants (decision-makers) as supplemental documentation. The data was collected with decision-makers of small HSOs, CBOs, or grassroots HIV-serving organizations in the US South. The interviews were completed using a narrative storytelling theoretical framework to analyze broad and sub-themes. The discussion included culturally appropriate interview techniques with Spanish interpretation support for monolingual organization decision-makers.

Participant Criteria

Participants were identified based on their identification as Latinx per definition for this study. They must serve the role of a decision-maker, such as Chief Executive Officer, Executive Director, Program Director, Grant Writer, etc., in a Latinx HIV-serving organization. Additionally, participants' organizations must reside in one of the twelve states the researcher identified for this study (Alabama, Arkansas, Florida, Georgia, Kentucky, Louisiana, Mississippi, Oklahoma, North Carolina, South Carolina, Tennessee, or Texas). Participants were not duplicated in this study, each interview was different, and each decision-maker's experience with funding facilitators and barriers was unique. Additionally, their expertise with Latinx PLWHA communities was also

distinctive on how and why they work in HIV to their professional and personal connections with Latinx PLWHA communities. The researcher wanted to honor those experiences by analyzing the data using a narrative inquiry or analysis by incorporating the decision-makers' story, conversation, and prompting questions the researcher asked during the semi-structured interview. This narrative method of data analysis allows the researcher and participant to be equally involved in the conversation and discussion, allowing smoother interaction and experience (Connely & Clandinin, 1990).

Data Collection

The researcher completed targeted recruitment via email invitation to participants. A total of nine recruitment emails were sent to participants that fit the criteria for the study, with eight responses and five confirmed interviews. Participants were not asked to provide any personal identifying information. They were informed that digital recording and transcript of their interview would be stored in a password-protected account that only the researcher could access. The researcher explained the study and the *2021 Interview Questions for Community-Based Organizations* to participants before informed consent. Written consent for a virtual interview, permission to record, and license to use verbal statements from the participant as quotes for supplemental and supportive research data were obtained via Qualtrics, an online survey tool link. All five participants completed consent via the link as well as providing verbal consent before Zoom recording. Participant demographic data were also collected via a Qualtrics link.

Interviews were conducted in a semi-structured format, meaning, though a pre-set list of questions was referred to, the researcher could ask impromptu questions based on subject response. The researcher completed a total of five interviews, with the duration of

the interview designed for one hour to be respectful of participants' time. The researcher was open to continuing the discussion if the participant desired to continue past the one-hour allotted time. The recorded portion of the interview had an average length of 34-54 minutes. Average time spent with participants, including pre-recording, recorded time, and post-recorded time, had an average length of 75 minutes. Participants were compensated for their participation in this study and received a \$30 Amazon electronic gift card sent via email with a downloadable code.

Data Analysis

Preceding the data analysis process for this study, all video and audio versions of the recorded interviews were downloaded from the Zoom application and stored in a password secure file and laptop only accessible to the researcher. The researcher transcribed three audio files via Transcribe by Wreally online transcription software and reviewed by the researcher for accuracy. Two audio files were transcribed in Spanish via Transcribe by Wreally and then translated to English using DeepL online translation software and reviewed by the researcher for accuracy. The five completed files were then saved to a password-protected file and laptop. The researcher was responsible for downloading audio and video, transcribing and translating interviews via software, and securing storage. Dedoose, a web-based application, was utilized to analyze interview transcripts. To maintain consistency and validity, intercoder reliability was applied when identifying themes. Two coders managed data analyses in the Dedoose application and met four times, each meeting for one hour, via Zoom, for planning before data collection. Coders then met for one hour, twice a week, once interview data was ready to be analyzed. Although there were disagreements on identifying themes, sub-themes, and

codes, all coding decisions reached an agreement during weekly meeting time. The researcher served the role of primary coder and collaborated with a secondary coder. The second coder was a sociology graduate with master-level courses, with over ten years experience in research, five years' experience in the context of HIV, and three years' experience in data management and analysis. The second coder supported the researcher to closely examine data to identify broad themes and sub-themes in interviews. Additional discussions were prompted to interpret meaning, process areas of dispute and decipher the interpretation and application of data to reach a consensus.

Interview responses from each participant were reviewed for codification. This is a process in which interview transcripts are analyzed for recurring themes between participants. Once the themes were identified, answers relevant to the theme are extrapolated from the interview and organized accordingly (Olson et al., 2016). Interviews were thematically reviewed based on the perceived facilitators and barriers to funding by decision-makers of Latinx-HIV serving organizations.

Reflexivity Statement

For the past ten years, the researcher has worked to advance her career in higher education as a Latinx woman. She has faced obstacles that were related to gender, race, ethnicity, and immigration status. The researcher has worked with Latinx communities for 25 years and worked in HIV research with vulnerable black and brown communities for the past eight years. Equally so, she has made meaningful professional and personal relationships with individuals and the community where the research is being conducted.

As a former clinician and current HIV researcher, she had the privilege to serve professional roles in outreach, prevention, treatment, grant writing, and capacity building

with individuals, groups, and organizations in the US South. The researcher has also been part of organizations that seek grant funding to develop, implement, and sustain programs for Latinx communities in the context of HIV. Complete exclusion of bias is not possible in research, so it was important for the researcher to acknowledge concerns during the study. Recognizing that her professional and personal experiences and identity in the Latinx community could present bias and ethical considerations related to this research, a plan to address these concerns with her external dissertation committee was implemented. The researcher kept a journal during this study and would document before and after each interview would note any questions, concerns, and perceived successes and failures of the interview experiences. She would debrief with her external committee weekly regarding this process and as needed. The method of journaling and debriefing with the committee was deemed helpful for the researcher to reduce any harm to the participants.

Ethical Considerations

The researcher was familiar with participants and decision-makers and has collaborated with all five participants on various funding opportunities via the researcher's employer. Additionally, the researcher has a professional as well as a personal relationship with all five participants. The researcher was aware that decision-makers were considered part of vulnerable populations based on their answers to the demographic questions. To provide valid and reliable results in this research study, the researcher had to acknowledge possible ethical concerns, address them, and reduce potential bias (Sanjari et al., 2014). The researcher implemented a plan to limit ethical issues if presented by journaling and meeting with external committee members as needed. To reduce possible harmful effects on participants, they were informed as part of

their informed consent that their answers or their decision to withdraw from the research study at any time would not impact their relationship with the researcher or with the researcher's employer.

Summary

This chapter defined the research methodology for this study. The purpose of this research design was to collect narratives from decision-makers to interpret findings of perceived facilitators and barriers related to HIV funding and perceived organizational strategies and capacity-building support related to funding access. Data were collected by conducting semi-structured interviews, with a few prompting questions, via a recorded Zoom platform. The researcher practiced journaling, reflexive bracketing, and debriefing with the committee to minimize ethical issues and reduce participants' harm. Chapter four discusses how data was reviewed, interpreted, and coded to present analysis and findings.

Chapter IV

Results

Overview

“Living in the South is a challenge itself.” - Latinx Participant 03. HIV/AIDS disproportionately impacts Latinx communities in the US South (Sutton & Parks, 2011). Limited funding resources seem to be available to support Latinx-HIV serving organizations that provide resources to these communities impacted by HIV. The primary aim of this research was to answer two questions: the perceived facilitators and barriers for decision-makers in Latinx-HIV serving organizations in terms of capacity to apply for funding and the perceived organizational strategies and capacity-building support related to funding access that decision-makers need to continue to provide resources and services to Latinx PLWHA. A reminder from the literature review that facilitators are conditions that enhance decision-makers' ability to access, navigate, write, submit, and manage a grant funding opportunity for their Latinx-HIV serving organizations. At the same time, barriers are conditions that impede decision-makers' ability to access, navigate, write, submit, and manage a grant funding opportunity for their Latinx-HIV serving organization.

This chapter presents data collection results from participant interviews to assist the reader in understanding this study's outcomes. The research questions were answered through interviews with five decision-makers of Latinx-HIV serving organizations in the US South. Semi-structured interviews were constructed and analyzed using a narrative storytelling framework, creating a virtual space for decision-maker to share their personal and professional experiences. Subsequent analysis of these interviews involved

comparing interview responses for recurrent themes and subthemes and then coding interview responses accordingly. Synthesizing these responses based on these themes yielded a better understanding of facilitators and barriers these decision-makers face when seeking funding to meet the needs of Latinx communities impacted by HIV.

Participants

Five (n=5) Latinx self-identifying decision-makers of Latinx-HIV serving organizations in the US South participated in the study (see Table 2). Among the decision-makers, three identified as Chief Executive Officer (CEO), one identified as Program Director (PD), and one identified as Program Coordinator (PD) for their organization. The demographic makeup of these decision-makers was as follows: the mean age for participants was 39.6 (n=5), of the participants, two (n=2) identified as a heterosexual woman, one (n=1) identified as heterosexual transgender woman, one (n=1) identified as a queer, transgender woman, and one (n=1) identified as a gay man. There were three (n=3) participants that identified as White-Latinx, one (n=1) that identified as Latinx only, and one (n=1) participant that identified as Indigenous only. Additionally, the researcher inquired with decision-makers on the staff size of their organization, specifically salaried staff. Participants stated that they employed full and part-time staff, with the largest organization reporting having ten and the smallest organization having a team of one (including the decision-maker).

Table 2*Demographics*

Participant ID	Age	Geographic Location	Ethnicity Race	Gender	Sexual Orientation
Latinx Participant 01	43	Texas	Latinx	Transgender Woman	Queer
Latinx Participant 02	35	Texas	White-Latinx	Man	Gay
Latinx Participant 03	50	Alabama	White-Latinx	Woman	Heterosexual
Latinx Participant 04	35	North Carolina	Indigenous	Transgender Woman	Heterosexual
Latinx Participant 05	35	Texas	White-Latinx	Woman	Heterosexual

Note. Participant Socio-Demographics

These participants are not only identifying as decision-makers but as part of the community as well. All five participants identified as being part of vulnerable communities. Additionally, three of the participants identified as being LGB or TGNC as well. So, they are familiar with the additional barriers faced by identifying as part of these communities.

Research Questions

The following research questions were intended to provide answers to the statement of the problem for this study. What are the perceived facilitators and barriers for decision-makers in Latinx-HIV serving organizations in terms of capacity to apply for funding? For the purpose of this study, facilitators were defined by the researcher as conditions that enhance decision-makers ability to access, navigate, write, submit, and manage a grant funding opportunity for their Latinx-HIV serving organization. Barriers, for the

purpose of this study, as defined by the researcher as conditions that impede decision-makers' ability to access, navigate, write, submit, and manage a grant funding opportunity for their Latinx-HIV serving organization. The second research question was to clarify perceived organizational strategies and capacity-building support related to funding access that decision-makers need to continue to provide resources and services to Latinx (People Living with HIV/AIDS) PLWHA.

Broad Themes from Semi-Structured Interviews

The data analysis revealed thematic codes: systemic facilitators and barriers, organizational facilitators and barriers, and cultural facilitators and barriers. Each broad thematic code had to emerge in at least three interviews, 60% of total interviews, to be considered a significant theme (see Table 3). A second review of the data from the interviews yielded at least one sub-theme under the broader theme.

Table 3

Broad Thematic Codes

Broader Theme	Percentage of Interview Responses Discussing this Theme	Interview Participants that Discussed this Theme
Systemic Facilitators	80%	1, 2, 3, 4
Systemic Barriers	60%	2, 4, 5
Organizational Facilitators	100 %	All
Organizational Barriers	100%	All
Culture Facilitators	100%	All
Cultural Barriers	80%	1, 2, 3, 4

Note. Frequency of Broad Theme Codes in Interviews

Sub-Themes from Semi-Structured Interviews

A second analysis generated sub-themes within the broader themes from the first initial analysis. The sub-themes for systemic barriers were collaboration (n=3), communication (n=4), and funding limitations once money has been given to organizations (n=4) as sub-themes. Organizational barriers listed capacity (n=5) as the most mentioned systemic barrier by all five decision-makers. Culture barriers generated two sub-themes, cultural identity and cultural responsiveness (n=2) and language justice, having their voice heard (n=2). Even though there were only two monolingual, Spanish-speaking, decision-makers in this participant cohort, they mentioned that funding applications were not available in their native language and also stated that funding applications were structured to have complicated academic language that was hard to understand for those that did not have a college education.

The researcher found that the word facilitators had to be repeated and defined differently, with four out of five participants asking for clarification or “tell me more about facilitators” (Latinx Participant 04). Systemic facilitators generated two sub-themes with participants stating they felt supported by the funder when technical assistance that included feedback on applications and flexible deadlines (n=3) was part of their experience with the under. Also, participants mentioned that they would like more mentorship (n=3) from the funder, which included coaching, training, and capacity building for the decision-maker and their team. Organizational facilitators produced the following sub-theme, volunteers (n=4). The smaller organizations with a staff of <5 mentioned that they could not do the work in the community without the dedication and free labor hours that their volunteers offer to these Latinx-HIV serving organizations.

Table 4*Sub-Thematic Codes*

Broader Theme	Sub-themes	Percentage of Interview Responses Discussing this Sub-theme	Interview Participants that Discussed this Sub-theme
Systemic Facilitators	Funder Support	60%	2, 4, 5
Systemic Facilitators	Mentorship	60%	1, 2, 4
Systemic Barriers	Collaboration	60%	2, 4, 5
Systemic Barriers	Communication	80%	1, 3, 4, 5
Systemic Barriers	Funder Limitations	80%	1, 3, 4, 5
Organizational Facilitators	Self-Taught	40%	2, 5
Organizational Facilitators	Volunteers	80%	1, 2, 3, 4
Organizational Barriers	Capacity	100 %	All
Culture Facilitators	Serve Latinx Communities	100%	All
Cultural Barriers	Cultural Identity / Responsiveness	20%	2,3
Cultural Barriers	Language Justice	20%	1,4

Note. Frequency of Sub-Theme Codes in Interviews

Systemic Barriers*Communication*

Four of the five participants described communication as being a system barrier in funding access. The researcher defined communication for coding as the following; not being aware of funding opportunities and better contact with the funder, which included being informed of funding opportunities. The participants gave examples of the communication barrier as being excluded from phone calls, emails, and list-serves from funders announcing an upcoming funding opportunity for application. Participants shared

that not being invited and receiving information about funding opportunities via another route and encouraged to apply last-minute did not make them feel welcome, part of a network, and just viewed as an afterthought from the funder. Two participants mentioned feeling not being seen or heard in funding opportunity spaces.

Three participants mentioned that you need to have received a grant in the previous cycle to be invited to these grant funding opportunity spaces, listservs, or newsletters. Even if decision-makers or organizations were invited to apply, the criteria of being a prior grant recipient automatically canceled that opportunity. So, the only cycle these decision-makers are in is being left out due to not being in-network.

“Yes. So just looking at some of the application processes, accessing some of them, right? So, many times, you know, if you're not already within that network, those opportunities are not coming to knock on your door, right? So sometimes I'm like looking up grant opportunities through maybe a Google search or looking on a website. And um you know, the application is due in less than a month and and so preparing an application in less than a month. Is just it's not feasible for me, right?” – Latinx Participant 02

The money the county gave out. They gave it out to one entity, and they took a big portion of it, and that big entity...only invited certain agencies. When we got word of it, I was like, well then didn't send me no invitation to apply. Then I got in contact with other smaller agencies, and they are like, nope, I didn't hear about it either. So, at the end, it was only by invitation only. When these funds are supposed, be you know equal” – Latinx Participant 05

Collaboration

The researcher defined collaboration for coding as the following; funder support of smaller Latinx organizations and larger organizations supporting smaller organizations. Participants share that not having a partnership with the funder or with other organizations was a barrier. Organizations were often competing for the same funding opportunities, which made it awkward to reach out. Decision-makers did share that they started to reach out on their own. *We started doing more networking with organizations that were very similar to us but a lot farther in their process.* - Latinx Partner 2

Funding Limits

Participants shared that funder limitations impeded creativity and innovation in community-based program content. The researcher defined funding limits for coding as the following; funders spending approval on expenses aligned with funder outcomes. For example, decision-maker spending on food items was not approved on some federal grants as food was not seen as an expense needed to execute a project or program.

Let us be creative with our programs. You know, we were mentioned before like you know, sometimes you cannot do food, or you cannot do, you know other stuff, and you're like, oh my gosh, you know, so for us, food is very important, coffee is very important. I have my coffee maker for another grant, and I every time I see it, you know, it's a symbol of, of communities. But honestly is sometimes restricted, and I want to be able to create and have opportunity to have furniture, you know to have equipment to have, if we talking to, to mental health even provide a feast. For, for example, this is one of the things that they told me, you cannot do that in some other grants. – Latinx Participant 3

Systemic Facilitators

Funder Support

The researcher defined funder support for coding as the following; decision-makers' need for technical assistance and capacity building that included training, workshops, webinars, and funders' resources. *I need training to be able to know to work with a community or an individual to tell the story.* – Latinx Participant 03. Additionally, being invited to other networks and funding platforms kept them in the know with ample time to apply for funding. *To have the capacity for training...would provide to have a better reach and to have a better understanding of the work we are doing and also to be able to add leadership in Latinx communities.* - Latinx Participant 01

[This funder] has already done an excellent job of setting it up that way, you know, like setting up micro-grants, setting up coaching opportunities setting up, reaching out, right? Like, providing different options. You know, obviously not just for 501c3, but, you know, are providing the opportunity to do it through a fiscal sponsor, kind of like moving through some of those networks. - Latinx Participant 02

The last time was when [this funder] help[ed] us, that we pay for a training that our staff went to Washington and they came back, wow that it was amazing and it was important because it was from an organization that does mental health, that is [to] Latinos from Latinos. - Latinx Participant 03

Mentorship

Participants mentioned wanting additional support from funders. The researcher defined mentorship for coding as mentorship that included guidance, training, and coaching related to funding opportunities.

So, when we got our evaluation back, they said, you, know, we don't think you're ready for this opportunity, but we want you to start here, and we use that experience to build a more cohesive board to kind of kind of piece all our pieces together and learn. – Latinx Participant 02

Organizational Barriers

Capacity

Capacity was defined by the researcher for coding as the following; being a small organization, staffing less than 10 salaried staff, not having a designated grant writer, or not having a designated person that has the training and skillset to write grants for the organization. Organizational capacity was mentioned by all five decision-makers stating that their organization did not have a designated grant writer or a trained person in grant writing due to their staff size. Instead, this responsibility was shared throughout the organization, which means that securing funds always has to be balanced with other commitments, making it challenging to give each step the attention it requires.

Smaller organizations with a paid staff of <10 do not have the human capital to outreach to and serve the community, research fund opportunities, apply to grants, and receive training on managing the funding from grants. *I'm going to say it's just it's just me and George. It's a very, very small team.* – Latinx Participant 5. One participant filled the role of multiple staff at their organization as a team of one. This participant mentioned sacrificing time, energy, and limited resources not to ignore the

community's needs. If it meant mediocre grant writing or not applying, then that is what needed to happen.

Because we do not have the staff, so we don't have that capacity yet, that is why we are like organizing nothing else right, and later on, maybe, we dream about that, but, let's go, this, we are working. We are working; we are educating ourselves; I don't know much about this kind of work. - Latinx Participant 04

Because we don't have a grant writer there's been, and I'm not, I don't particularly have any experience in grant writing before becoming an executive director. So since then, I've written about, I don't know, 20 something, and I have been able to secure grants successfully, and I feel like I'm getting better at it. But up until now the majority of the grants that we've applied for have been kind of low barrier, not as cumbersome. - Latinx Participant 02

Organizational Facilitators

Volunteers

One decision-maker described hosting an annual pride event in their small community as a significant source of both funding and exposure for their organization (Latinx Participant 02, 2021). These events are possible due to the organization's volunteers. The researcher defined volunteers for coding as the following; as human capital that did not require payment, stipend, or salary for the work done at organizations. Many organizations during startup rely significantly on their volunteers to do the work later completed by salaried staff (Substance Abuse and Mental Health Services Administration [SAMHSA], 2005). Four out of five decision-makers mentioned that they could not do the organization's work and be out in the community if not for their

volunteers. *A lot of our staff are, umm, work on voluntary basis, so a lot of times we do not have the funding to compensate the time or training.* – Latinx Participant 01. One participant noted that two of their current part-time staff started at their organization as unpaid volunteers. Still, it has taken close to 4 years for the organization to have funds to provide a salary (Latinx 01, 2021).

I am always looking here and there for opportunities. I am thinking about the people that support us, our volunteers, and how I can support them to longer be volunteers and maybe get them training to be a case manager. I have to see where I am going to get money from, as I always said, prostitute myself, also with grants. – Latinx Participant 04

We have volunteers that are very passionate about doing this type of work in this community, people that really care about this community. Ummm, and that has really made a lot of this work possible because a lot of our work is done either through volunteer hours or by, you know, people that are willing to go the extra mile for very for very little, right? And so, uh, without that type of infrastructure, we wouldn't have been able to get these projects off the ground. – Latinx Participant 02

Self-Taught

Self-taught was defined by the researcher for coding as the following: decision-makers make it work, get it done, or get by; they figure things out on their own for their organization. They have written the grants and filled out applications independently and are learning because of this self-taught process. They can secure funds for their organization via either a small grant opportunity, community donor support, or

community fundraising. *I have been able to secure grants successfully, and I feel like I'm getting better at it.* – Latinx Participant 02

I do the majority of the writing, Jorge helps. I'm writing, and he's just reading, and I'm like, okay well, you know, he's like he's my edit, or but I'm the one actually do love doing the writing you know we talked about it the name or whatever we have a discussion, but it's just a very, very small team. – Latinx Participant 05

Latinx Culture

The researcher defined culture for this study as essential attributes of Latinx communities in the US that decision-makers incorporate in resources and services for PLWHA in the US South. Additionally, culture was defined as attributes of Latinx communities in the US that decision-makers want to see from funders and funding opportunities for PLWHA in the US South. Some of these cultural attributes will be evident later in the research.

Cultural Barrier

Cultural Identity and Cultural Responsiveness

Culture identity was defined by the researcher for coding as the sense of belonging with cultural responsiveness meaning how grantmakers and funders were responsive to community needs in the intersection of Latinx, sexual and gender identity, and PLWHA. *I think, honestly, I try to look for funding, you know, that encompasses a lot of things, but sometimes they are so narrow... And I have not seen too much funding for Latinx.* – Latinx Participant 03

Goodness of Fit

Participants mentioned funding opportunities not being the right fit for their organization as a barrier. This could be due to factors where the grant opportunity is too broad or too narrow. Additionally, some grant opportunities may leave out specific communities or group them with others and overlook meaningful inclusion of specific communities, including Latinx communities.

Mainly because those grant opportunities are ridden with barriers, there's so much that's built into being able to provide community-based services that it just didn't seem like a right fit for what we were doing at the time. – Latinx Participant

02

Language Justice

Language justice was another barrier that some participants mentioned. Even though only two participants said the language was a barrier, the researcher concluded that it was significant to note as they were monolingual Spanish speakers whose organizations primarily served Spanish-speaking communities. Translation or interpretation in funding opportunities was often overlooked or an afterthought mentioned by the participants. The researcher adapted the following definition for coding for language justice; individuals', groups', and communities' right to have their voices heard, including social justice forums (Scharrón-del Río & Aja, 2020).

People because they speak Castellano (Spanish) or they speak indigenous languages or because they are brown, no, they should not be excluded from the systems, we all need to deconstructed our internal systems so that we can build systems where we're all included and where everyone can receive the same opportunities regardless of skin color or language. – Latinx Participant 01

Participant 03

Cultural Facilitator

All decision-makers were interested in talking to the researcher about their organizations, programs, and the communities they served. They were proud of being bilingual and monolingual organizations that provided precise services to Latinx communities.

Despite the variation among organizations, all decision-makers primarily relied on community funding. This consisted of small, individual donations made by individuals or groups adjacent to the community being served. Most organizations supplemented their funding with online crowdfunding, selling of raffle tickets to events or gifts donated to the organization, cookouts where plates of food are sold in the community to supplement organizational funds (Latinx Participant 02; Latinx Participant 04, 2021).

Clarifying perceived organizational strategies and capacity-building support related to funding access that decision-makers face when providing services to Latinx PLWHA results were as follows. Decision-makers were able to continue to provide resources and services to Latinx communities due to the support of their volunteers. Four out of five participants mentioned that the work of their volunteers was valuable and allowed the organization to be able to continue daily operations. Additionally, two participants said that even though they were understaffed and small organizations, they could still apply for grants. They learned how to navigate systems they had access to and were improving in their skillset.

Summary

This chapter presented the qualitative data from semi-structured interviews with four Latinx and one Indigenous decision-maker representing three states across the US South. The research questions were to clarify the perceived facilitators and barriers faced by decision-makers in Latinx-HIV serving organizations in terms of capacity to apply for funding in the US South. Additionally, to illuminate perceived organizational strategies and capacity-building support related to funding access for decision-makers in HIV HSOs, CBOs, and grassroots organizations. Chapter five will serve to interpret the results and present and the study's limitations. Additionally, the chapter will outline implications for practice, education and training, future research, and policy and agency administration.

Chapter V

Discussion

Summary HIV/AIDS

HIV/AIDS is a significant epidemic in Latinx communities throughout the US South. As of 2018, Latinx individuals make up 24% of all new HIV cases in the United States (CDC, 2018). HIV-serving service organizations have emerged in recent years to assist Latinx communities impacted by HIV/AIDS and prevent further spread of the disease through outreach. Unfortunately, these organizations unanimously struggle with allocating adequate funding, especially in the US South (Reif, et al., 2017). This research aimed to dismiss any misinformation regarding the perceived facilitators and barriers related to funding opportunities available to Latinx HSOs and what significant barriers prevent them from sourcing additional funding. Additionally, the study aimed to understand decision-makers perceived organizational strategies and capacity-building support need to continue serving Latinx PLWHA.

Process of Interviews

The decision-makers of these Latinx-HIV serving organizations in the US South were asked about current funding strategies and facilitators and barriers they experienced in seeking funding. Their interview responses were synthesized using a narrative storytelling qualitative analysis by identifying consistent themes among their experiences. Six thematic codes were identified: systemic facilitators, systemic barriers, organizational facilitators, organizational barriers, culture facilitators, and cultural barriers. These broad themes in conjunction with a secondary analysis in which interview subjects were interpreted yielded additional sub-themes.

Primary and Secondary Coders

The researcher conducted the interviews, downloaded the video and audio, transcribed interviews, and translated the Spanish interviews with software support. Additionally, the researcher served as the primary coder and provided the definitions for facilitators and barriers for both coders. The researcher shared these definitions with the second coder but did not share the theoretical framework or the narrative inquiry methods to interpret data. Not sharing complete information with the second coder could have been the source of argument in analyzing data, developing themes, and creating codes.

When differences in opinion were presented, the researcher would take notes from meetings with the secondary coder. Both coders would discuss primarily, if themes should be coded as facilitators or barriers, or both. The researcher found it helpful to hear the second coder's perspective. During these meetings, the researcher and secondary coder would not make a final decision on codes but would agree to revisit the conversation at the next meeting before the final agreement on themes and codes were decided.

Summary of Results

Based on the findings in the results chapter, the following themes and sub-themes emerged from the data collection; as systemic facilitators, funder support and mentorship; as a systemic barrier, collaboration, communication, and funder limitations; as organizational facilitators, volunteers, and self-taught; as organizational barriers, capacity; as culture facilitators, serving Latinx communities and being part of the Latinx community; and as cultural barriers, cultural identity, language justice. The themes and subthemes provided new information and assisted in clarifying some of the common

misconceptions that the community, funders, and researchers had about the facilitators and barriers facing decision-makers in funding access. Previous research suggests that funding alone is a barrier. This study found that funding is a barrier; however, there are other multiple barriers and facilitators that were not discussed in previous research.

Most notably, funding, or money, was not mentioned as a primary barrier by the decision-makers. Four out of five participants discussed the importance of volunteers as facilitators, supporting Latinx-HIV serving organizations with their free labor.

Participants acknowledged that they could not do the work in the community if it were not for their volunteers. Participants also mentioned wanting a deeper connection with the funder, specifically seeking mentorship, coaching, and more than just a phone call once a month when reports are due. This information was essential data for the research to uncover. More qualitative interviews need to be completed as part of future research, as this study has only begun to present these perceived facilitators and barriers.

Meaning and Interpretation of Results

Small Latinx CBOs and grassroots organizations, including HSOs, are uniquely qualified to serve communities. Many of them are founded by and staff Latinx individuals who understand the complexity of Latinx communities, including how language, traditions, customs, values, and beliefs intersect in these communities' wellness and wellbeing of these communities (Latino Community Fund Georgia, 2017). They should be viewed as the experts in working with Latinx communities. We must not forget that “7% of philanthropic dollars go to organizations serving Black, Indigenous, Latinx, and POC [People of Color] communities, and 3% go toward serving disabled people,

according to this summary by Candid [Key Facts on U.S. Nonprofits and Foundation, 2020]. Trans communities, meanwhile, receive only .015%” (Le, 2021).

Community-based participatory research (CBPR) is a methodology that focuses on physical health, wellness, wellbeing, and disparities, in vulnerable communities (Suarez-Balcazar, 2020). CBPR is a good collaboration with communities, including decision-makers, where they can feel heard and have meaningful participation in the research process. CBPR fits nicely into the Social-ecological framework. It encompasses decision-makers' interaction with the community and other organizations doing similar work, as well as researchers, government, and private funders. This process would create meaningful working relationships with Latinx communities.

Government and private funders should recognize that Latinx-HSOs have needs beyond funding. With this knowledge, funders could provide other forms of capacity-building support for organizations. Grantmakers can learn from the research findings on how to strategize to apply inclusion and diversity in the grant application and funding opportunities as they develop. Strategizing could include staffing of Latinx PLWHA as part of a grant-making team.

Limitations of Study

It is important to acknowledge limitations in a research study due to the possible impact of the results (Price & Murnan, 2004). The researcher was aware that some limitations would impact the study. The researcher noted the following as limitations for this research.

Time

The timing of the interviews was one limitation that could reflect participant bias as the researcher's professional role is of grant developer and funder. Participants had applied to a funding opportunity led by researchers' employer during the implementation of interviews. While complete removal of bias may not be feasible, the researcher implemented a safeguard process to minimize bias in this research. The researcher minimized this by utilizing professional journaling and debriefing with external committee members to identify potential sources of bias.

Sample Pool

Even though qualitative research with a narrative inquiry approach calls for a smaller sample size (Crouch & McKenzie, 2006), the researcher anticipated a larger pool of participants. The sample pool for this study was small due to the unique characteristics of participants. Additionally, the additional criteria for participants, such as type of agency and geographical location, limited the size of the participant pool.

Language

"Spanglish," widespread use of the language utilized by Latinx individuals living in the US and code-switching during interviews which required additional interpretation, transcribing, and translation by the researcher (Otheguy & Stern, 2010), was a limitation. Code-switching is the practice of using one or more languages, dialects, or slang in the same sentence or conversation and going back and forth between the languages (Kvasova & Buffington, 2020). The use of both Spanglish and code-switching could add to this study's limitations as data is not reflected as accurate or a valid interpretation.

Labor Intensive and Added Time

More time would have been ideal to complete the study and dig deeper into facilitators and barriers. The researcher is a native speaker but still struggled to interpret Spanish academic language and current Spanish slang. Additionally, time to seek support for transcribing and interpretation and translating through professional services would have been beneficial to the researcher and study.

Participant Responder Bias

The researcher and precipitants had a prior relationship to the research study. The researcher was aware and concerned that participants would answer due to previous relationships and please the researcher. Additionally, as mentioned prior, participants had applied for a funding opportunity led by the researcher. The researcher reflected in journaling whether semi-structured interviews completed by a third party would have minimized this bias. Included in that reflection was also doubt that a third party would have obtained the researcher's data. It took four years for the researcher to foster relationships with these decision-makers.

Implications

Table 5

Findings, Recommendations, Implications

Findings Results	Recommendations What to do?	Implications Impact
Systemic Facilitators Funder Support Mentorship	Decision-makers voice needs; grantmakers and funders made accountable Shared learning platforms to understand the needs of unique communities	Education and Training Policy and Agency Administration
Systemic Barriers Collaboration Communication Funder Limitations	Decision-makers voice needs; grantmakers and funders made accountable Shared learning platforms to understand the needs of unique communities (applicable to funding limitations)	Practice Education and Training Policy and Agency Administration
Organizational Facilitator Volunteers Self-Taught	Decision-makers continue collaboration with volunteers Decision-makers voice needs; grantmakers and funders provide training, coaching, and mentoring	Practice Education and Training
Organizational Barriers Capacity	Decision-makers voice needs; grantmakers and funders provide training, coaching, and mentoring	Education and Training
Cultural Facilitators Being part of Latinx and Serving Latinx Communities	Shared learning platforms to understand the needs of unique communities	Education and Training Policy and Agency Administration
Cultural Barriers Cultural Identity / Responsiveness Language Justice	Shared learning platforms to understand the needs of unique communities	Education and Training Policy and Agency Administration

Note. Implications for Research Study

Future Research

This research could serve as a pilot for a more extensive study. Additionally, this study could serve as a foundation to replicate in other vulnerable communities facing funding barriers in the intersection of HIV. Black Americans are disproportionately impacted by HIV, comprising for 53% of new HIV diagnoses in the US South in 2017 (CDC). Research could expand to explore perceived facilitators and barriers in funding encountered by decision-makers in Black-HIV serving organizations in the US South.

Practice

An implication for practice would be to develop a culturally appropriate grant funding application, which is purposeful and not an afterthought. To consider, for example, immigration status, language justice, family and community connection, and education (see Table 5). Decision-maker access to websites, listservs, and invitations to notification of funding opportunities. Establishing and supporting collaborative communication with funders and decision-makers includes mentorship with coaching, training, and oral and printed resources beyond funding in decision-makers' preferred language.

Education and Training

Grantmakers and Funders

Black and minority-led organizations, and smaller local grass-roots organizations may not typically apply for grants. It is important to reach out to them so they are aware of available funding, and to provide support for applying, as a way of more equitably redistributing community resources and opportunities. (Curran, 2018)

How can grantmakers and funders include these smaller organizations and not feel like they are being left out? The researcher suggests targeted personal outreach by either doing focus groups or listing sessions with organizations that may have applied and not received funding or new organizations that have not applied for funding prior. Additionally, meeting with community members that use resources and services from small organizations that these members feel are providing adequate services to Latinx individuals, groups, and communities PLWHA.

The participants in this research study all mentioned capacity as a barrier, being a small organization with not enough staff to do the work in the community. Hiring staff posed a challenge due to funding needs to expand their team. Participants also mentioned that volunteers are what keeps their organization going and doing the work in the community. Funders could create specific opportunities that provide monetary resources to provide training and coaching to volunteers to become paid staff of the organizations they serve. Additionally, funders could offer decision-makers mentorship, coaching, and training around grants built into a funding opportunity. This opportunity could also build rapport and deepen relationships with the funder and the decision-maker mentioned previously in this study.

Research can assist in developing organizational strategies and capacity-building support for these decision-makers and others in their organizations. This could mean creating a shared knowledge platform with other funders and researchers to learn from each other. Additionally, to see what their grants development team looks like, who are the major players? Also, to learn what grant development strategies are being utilized or

considered to include diversity and inclusion? Are grants development teams including Latinx individuals? PLWHA Latinx individuals?

Are long grant applications that ask numerous and duplicate questions to be considered by the funder necessary? Are there other alternatives, especially for decision-makers that are not fluent in English? Maybe the question is not “how do we improve grant applications” but rather “are grant applications the best way for funders to determine who should be funded? Additionally, “maybe the question is not ‘how do we improve grant applications’ but rather ‘are grant applications the best way for funders to determine who should be funded?’” (Le, 2019). There are many ways to approach this, and grantmakers and funders need to listen more attentively to the needs of decision-makers and researchers working in this field.

Non-profit Leadership Programs

Partnerships should develop with non-profit programs and researchers. Non-profit leadership programs could create courses from the research in this study to establish specific grant writing and grant management curriculum. Additionally, the curriculum could be enriched by applying the social-ecological framework to highlight multilevel perspectives and how vulnerable communities, decision-makers, other non-profit organizations, and grantmakers and funders work within these levels.

Decision-Makers

Several factors can determine an organization’s success for organizational funding. Latinx-HSOs, CBOs, and grassroots serving organizations, as previously mentioned, do not have the human capital to do all the work that is needed in the community, including grant research, writing, implementation, and management. As

such, decision-makers should know they have a voice and hold grantmakers and funders accountable for zero funding opportunities to limited opportunities available for their unique community needs.

Policy and Agency Administration

Platforms need to be created and available for researchers and decision-makers to come together and voice concerns regarding limited government funding resources available to smaller vulnerable organizations that serve a particular community, specifically Latinx-HSOs in the US South (see Table 5). Community, decision-makers, and researchers need to be in development and decision-making spaces where outcomes about government funding for vulnerable communities are being decided. Researchers can learn from each other and the communities they work with to present research, community voice, and funding strategies learned to hold government funders accountable.

Conclusion

The aim of this research was to understand the facilitators and barriers that decision-makers encounter in seeking organizational funding in Latinx-HIV serving organizations. Additionally, to discover perceived organizational strategies and capacity-building support related to funding access needed by decision-makers to continue to serve Latinx communities in the US South. Based on the literature review and results of semi-structured interviews, the researcher came up with the following conclusions.

Interviews of the five decision-makers at Latinx HSOs revealed that all faced barriers in capacity. Not having paid staff to do the work needed in Latinx communities was a major gap. Due to a lack of salaried staff, organizations rely heavily on their

volunteers to continue to do work in the community. Participants also shared desiring a deeper relationship with their funder, providing training, mentorship, and knowledge sharing of funding opportunities. Additionally, the current disproportional distribution of HIV funding across the US and the US South continues to impact these organizations negatively.

Latinx communities have been one of the US's most prominent and fastest-growing groups for a few decades. As of 2018, over 18% of the U.S. population self-identified as Latinx, with projections estimated to reach 28% by 2060 (U.S. Census Bureau, 2018). As mentioned in the study's statement of the problem, disparities in funding are the number one causative predictor in prevention and treatment gaps for PLWHA in the US South (Pellowski et al., 2013; Reif et al., 2017). As funding gaps continue to exist for these communities, new rates of HIV will continue to rise for Latinx populations.

Although this study did not focus on existing funding sources that decision-makers can access, all five shared a unique story of how they 'get by' to maintain operations at their organizations. Additional conversations are needed with other decision-makers at Latinx-HIV serving organizations in the US South to further this research and these communities' narrative.

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Appendix A

IRB Approval of Submission



DIVISION OF RESEARCH
Institutional Review Boards

APPROVAL OF SUBMISSION (page 1 of 3)

June 17, 2021

Samira Ali
sbali@uh.edu

Dear Samira Ali:

On June 17, 2021, the IRB reviewed the following submission:

Type of Review:	Initial Study
Title of Study:	Understanding community and community-based organizations' perspectives on HIV prevention/treatment, mental health, and harm reduction in the Southern US
Investigator:	Samira Ali
IRB ID:	STUDY00002900
Funding/ Proposed Funding:	Name: UH-Indirect Cost Funds; Name: Gilead Sciences, Inc, Grant Office ID: 000181282
Award ID:	000181282;
Award Title:	
IND, IDE, or HDE:	None



APPROVAL OF SUBMISSION (page 2 of 3)

Documents Reviewed:	<ul style="list-style-type: none"> • 03.29.21.Clarifications , Category: Stipulation/deferral clarifications; • CBO Interview Protocol, Category: Study tools (ex: surveys, interview/focus group questions, data collection forms, etc.); • Consent 3, Category: Consent Form; • Maria Wilson CITI, Category: Other; • Social Media Post 2, Category: Recruitment Materials; • Protocol, Category: IRB Protocol; • Recruitment Email 2, Category: Recruitment Materials; • Consent script 2, Category: Consent Form; • Marcus CITI, Category: Other; • Interview Protocol for Community Member, Category: Study tools (ex: surveys, interview/focus
	<ul style="list-style-type: none"> group questions, data collection forms, etc.); • Survey, Category: Study tools (ex: surveys, interview/focus group questions, data collection forms, etc.); • Katie M CITI, Category: Other; • June 3 - Clarifications, Category: Stipulation/deferral clarifications; • Megan Stanton CITI, Category: Other;
Review Category:	Exempt
Committee Name:	Not Applicable
IRB Coordinator:	Alicia Vargas

The IRB approved the study on June 17, 2021; recruitment and procedures detailed within the approved protocol may now be initiated.

As this study was approved under an exempt or expedited process, recently revised regulatory requirements do not require the submission of annual continuing review documentation. However, it is critical that the following submissions are made to the IRB to ensure continued compliance:



APPROVAL OF SUBMISSION (page 3 of 3)

- Modifications to the protocol prior to initiating any changes (for example, the addition of study personnel, updated recruitment materials, change in study design, requests for additional subjects)
- Reportable New Information/Unanticipated Problems Involving Risks to Subjects or Others
- Study Closure

Unless a waiver has been granted by the IRB, use the stamped consent form approved by the IRB to document consent. The approved version may be downloaded from the documents tab.

In conducting this study, you are required to follow the requirements listed in the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library within the IRB system.

Sincerely,

Research Integrity and Oversight (RIO) Office
The University of Houston, Division of Research

713 743 9204
cphs@central.uh.edu
<http://www.uh.edu/research/compliance/irb-cphs/>

Appendix B

Human Participant Consent

Title of research study:

Understanding community and community-based organizations' perspectives on HIV prevention/treatment, mental health, and harm reduction in the Southern US

Investigator: Samira Ali, PhD, MSW

Key Information:

The following focused information is being presented to assist you in understanding the key elements of this study, as well as the basic reasons why you may or may not wish to consider taking part. This section is only a summary; more detailed information, including how to contact the research team for additional information or questions, follows within the remainder of this document under the "Detailed Information" heading.

What should I know about a research study?

- Someone will explain this research study to you.
- Taking part in the research is voluntary; whether or not you take part is up to you.
- You can choose not to take part.
- You can agree to take part and later change your mind.
- Your decision will not be held against you.
- You can ask all the questions you want before you decide and can ask questions at any time during the study.

We invite you to take part in a research study about your perceptions, experiences, resources, and needs surrounding mental health, wellness, telehealth, and substance use/harm reduction services throughout the US South. This research is being funded by Gilead Sciences.

In general, your participation in the research involves a one-time one-hour virtual interview.

The primary risk to you in taking part is discomfort in responding to the interview questions since some questions ask about your perceptions and experiences surrounding mental health, wellness, telehealth, and substance use/harm reduction services. There is no personal benefit to you; however, the possible benefit to society may be improved services in these areas. You will receive compensation for participation.

Detailed Information:

The following is more detailed information about this study, in addition to the information listed above.

Why is this research being done?

HIV service organizations play an integral role in serving communities disproportionately impacted by HIV in the US South. However, there are gaps in knowledge about community and community-based organizations' perceptions, resources, and needs. By conducting qualitative interviews, we will be able to assess individuals and HIV service organizations, which will be used to later inform a tailored set of trauma-informed care, mental health, harm reduction, and wellness capacity-building opportunities and resources (i.e., training, grants, interventions).

How long will the research last?

We expect that you will be in this research study for one hour.

How many people will be studied?

We expect to enroll about 100 people in this research study.

What happens if I say yes, I want to be in this research?

If you agree to take part in this study, you will be asked to participate in a single one-hour virtual interview with the Research Team via UH-licensed Zoom, which enables either phone or virtual interview. The interview will be scheduled at your convenience. We will ask questions about your perceptions, experiences, resources, and needs surrounding mental health, wellness, telehealth, and substance use/harm reduction services throughout the US- South. Some questions may cause discomfort. You will be able to stop the interview at any time or skip questions you do not wish to answer. The interview will be audio-recorded with your consent. Your participation is completely voluntary.

- I agree to be audio recorded during the research study.
 - I agree that the audio recording can be used in publication/presentations.
 - I do not agree that the audio recording can be used in publication/presentations.
- I do not agree to be audio recorded during the research study.

Participation in this study is completely voluntary. You may still participate if you do not agree to be audio recorded.

What happens if I do not want to be in this research?

You can choose not to take part in the research, and it will not be held against you. Choosing not to take part will involve no penalty or loss of benefit to which you are otherwise entitled.

What happens if I say yes, but I change my mind later?

You can leave the research at any time, and it will not be held against you. If you stop being in the study, already collected data will be removed from the study record.

Is there any way being in this study could be bad for me?

There are no foreseeable risks related to the procedures conducted as part of this study. If you choose to take part and undergo a negative event you feel is related to the study, please inform your study team.

Will I get anything for being in this study?

You will receive compensation for your participation in this study. You will receive a \$30 Amazon gift card.

Will being in this study help me in any way?

We cannot promise any benefits to you or others from your taking part in this research. However, a possible benefit is that society may be improved services in the areas of mental health, wellness, telehealth, and substance use/harm reduction services throughout the US South.

What happens to the information collected for the research?

Your taking part in this project is confidential, and the information you provide will not be linked to your identity.

We may publish the results of this research. However, unless otherwise detailed in this document, we will keep your name and other identifying information confidential.

Who can I talk to?

If you have questions, concerns, or complaints, or think the research has hurt you, you should talk to the research team at sbali3@central.uh.edu or (713) 743-0321.

This research has been reviewed and approved by the University of Houston Institutional Review Board (IRB). You may also talk to them at (713) 743-9204 or cphs@central.uh.edu if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research subject.
- You want to get information or provide input about this research.

**Consent was provided via a Qualtrics link. An electronic signature was obtained via the same Qualtrics link.*

Appendix C

Qualitative Interviews: Socio-demographic Questions

1. In what year were you born?

- ☐ Write In: _____ *
- ☐ Prefer not to answer

2. Which of the following best describes your ethnicity?

- ☐ Hispanic/Latinx, or of Spanish Origin
- ☐ Non-Hispanic/Latinx, or of Spanish Origin
- ☐ Insert _____
- ☐ Don't know
- ☐ Prefer not to answer

3. What is your race?

- ☐ Write In: _____ *
- ☐ Prefer not to answer

4. Which describes your current gender identity?

- ☐ Genderqueer
- ☐ Non-binary
- ☐ Man
- ☐ Woman
- ☐ Transgender man
- ☐ Transgender woman
- ☐ Not listed above (please specify): _____ *
- ☐ Prefer not to answer

5. Do you consider yourself to be one or more of the following? (check all that apply)

- ☐ Bisexual
- ☐ Gay
- ☐ Lesbian
- ☐ Queer
- ☐ Questioning
- ☐ Straight/Heterosexual
- ☐ Not listed above (please specify): _____ *
- ☐ Prefer not to answer

6. Do you work at an HIV service organization?

7. If Yes, what is your role?

**Consent was provided via a Qualtrics link. An electronic signature was obtained via the same Qualtrics link.*

Appendix D

Interview Questions for Community-Based Organizations

1. What are the facilitators to providing services of HIV treatment and prevention of your organization?
2. What are the barriers to providing services for HIV treatment and prevention for your community-based organization?
3. What type of services/training do you need more capacity for? As related to:
 - a. Mental health/trauma-informed care
 - b. Wellness
 - c. Substance use
4. Does your organization use telehealth?
 - a. Would your organization be interested?
5. What are the aspects of grants that make you want to apply?
 - a. What are the barriers to grant writing for your organization?
6. What kind of support would you need to help measure program outcomes?

Prompting questions related to funding for questions 2 and 5, 5a

1. If you had unlimited funding at your organization in regards to services/resources for Latinx communities how would that funding be used?
2. What are barriers that you and your organizations encounter in regards to funding opportunities (grants) available to Latinx-led and Latinx-serving organizations?
3. What are some facilitators that would reduce some of the barriers for you and your organization mentioned in the previous question?