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Providers' Socioecological Perspectives on the Supports for and Challenges to Engagement in Care for Latino Youth Living with HIV: A Qualitative Study

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PROVIDERS' SOCIOECOLOGICAL PERSPECTIVES ON THE SUPPORTS
FOR AND CHALLENGES TO ENGAGEMENT IN CARE FOR LATINO
YOUTH LIVING WITH HIV:
A QUALITATIVE STUDY

A Dissertation

Presented in Partial Fulfillment of the Requirements for the Degree of Doctor of
Philosophy to

BY

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June, 2015

Department of Psychology

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VITA

The author was born in Chicago, Illinois on June 9, 1981. She graduated from Wells Community Academy High School, received her Bachelor of Arts Degree in Psychology from the University of Illinois at Chicago in 2003, and a Master of Public Health degree in Health Education and Health Promotion from the University of Texas Health Science Center at Houston School of Public Health in 2005.

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OVERVIEW

Much of the research on engagement in care for youth living with HIV (YLWH) has examined the behavioral and structural barriers that impact adherence to medication. With clinical and medical advances achieved in the HIV field, HIV has evolved into a chronic and manageable disease, when proper medical treatment with antiretroviral therapy is available (Uphold & Mkanta, 2005). With the introduction of the National HIV/AIDS Strategy, attention is now shifting toward improving engagement across the continuum of care.

The continuum of care for people living with HIV (PLWH), operationalized by the Health Resources and Services Administration (2006), includes engagement across the cascade of services including being aware of one's status by being fully engaged in HIV care. Embedded in this continuum of care are the processes of engagement, which include testing, linkage, retention, and reengagement for those who do not follow up (Cheever, 2007). It is important to explore engagement across the continuum of care, because engagement in care is a strong predictor for improved overall health for PLWH (Giordano et al., 2007; Heckman, Catz, Heckman, Miller, Kalichman, 2004; Mugavero et al., 2007, 2009).

Unique challenges affect engagement in care for youth, which may differ from the challenges facing children and adults living with HIV may face (Hosek et al., 2008; Kazak, Segal-Andrews, & Johnson, 1995). Among youth, marginalized groups, such as Latino YLWH (LYLWH), may face multiple social stigmas, including such concerns as limited English-language proficiency, sexual-

minority status, and immigration status (van Servellen, Chang, & Lombardi, 2002). One necessary step toward increasing understanding of the facilitators and barriers to this group's engagement in HIV care is to examine engagement in care through a socioecological framework to better understand each of the multiple factors impacting Latino youth's engagement in HIV care (Bronfenbrenner, 1986; Mugavero, Norton & Saag, 2011).

Hosek and colleagues' (2008) socioecological model for newly HIV-positive diagnosed youth's psychosocial adjustment asserts they face unique challenges across multiple socioecological levels, including the individual, interpersonal, clinical, and sociocultural levels. These levels of influence can also impact YLWH's degree of engagement in care. In addition, by extending the Hosek et al. (2008) socioecological model to include macrolevel factors from the Mugavero et al. (2011) socioecological framework for engagement in care, one can better understand critical factors influencing YLWH across the continuum of care. Thus, a hybrid model for LYLWH may emerge that examines those factors unique to adolescents living with HIV, along with the factors unique to engagement in care for PLWH to more descriptively understand their experiences.

Accessing some marginalized groups of YLWH, such as Latino youth, for testing, linkage, retention, and reengagement in HIV care has been particularly challenging. Such access difficulties have also translated into the research arena; therefore, researchers have performed scant research with this population. To conduct research with this understudied population, healthcare providers' experiences and perceptions of barriers and facilitators to the various components

of the cascade of care for Latino youth can yield important and insightful information on how to better address the needs of these youth. Healthcare service providers can make an important contribution to understanding factors impacting LYLWH's engagement in care because of their knowledge of, experience with, and ability to connect members of this community with health services. In addition, they often have gained trust from the community through their community-based partnerships.

I conducted qualitative interviews with 26 providers who provide services to LYLWH. Using a qualitative–phenomenological approach, I examined data to conceptualize these barriers to and facilitators of engagement across the continuum of care for these youth. Obtaining a more nuanced understanding of the influence of various factors on engagement in care for these youth can serve to inform individual-, group-, and structural-level interventions seeking to promote engagement in care.

CHAPTER I

INTRODUCTION

HIV in the United States is a serious concern. Despite intensive efforts to curtail the epidemic, an estimated 50,000 new HIV diagnoses emerge in the U.S. annually. Young people living with HIV (YLWH; see Appendix A for a glossary of acronyms) increasingly risk acquiring HIV due to a complex set of socioecological factors including those at the individual, interpersonal, community, structural, and cultural levels, that influence the acquisition of HIV (Lightfoot, 2012). For example, HIV has disproportionately impacted marginalized communities including communities of color and sexual-minority youth. One such community that has been impacted by the HIV/AIDS epidemic is the Latino community. In particular, cases of HIV are increasing among Latino young men who have sex with men (MSM) and are occurring at an earlier age. Additionally, foreign-born Latinos are more likely to enter care at later stages of the disease than their U.S.-born counterparts.

With the availability of effective treatment for HIV/AIDS, the focus for HIV has shifted toward understanding how to engage PLWH across the continuum of HIV care (Cheever, 2007). Despite efforts to engage PLWH in care, researchers only demonstrated that health disparities continue to increase. For example, Gardner, McLees, Steiner, del Rio, and Berman (2011) conducted a review to explore the challenges related to HIV care and determined that incomplete engagement in HIV care is common in the United States and that incompletely engaged individuals account for the largest proportion of HIV-

infected individuals with detectable viremia. Factoring in all socioecological barriers impacting the continuum of care suggests that only about 56% of those eligible for antiretroviral therapy (ART) will receive needed care. This lack of care suggests that disparities already exist in who is fully engaged in medical care. Overall, few studies have focused on barriers and facilitators for full and continuous engagement in care. Of those, the majority have been clinic-based programs that have demonstrated some success in improving linkage and retention to care. However, interventions for Latino YLWH (LYLWH) are lacking. These findings indicate that new strategies may be needed to sustain longer term engagement and researchers need to conduct additional research on mechanisms by which supportive systems help LYLWH who are further marginalized to maintain engagement across the continuum of HIV medical care.

Overview of the HIV Epidemic in the United States

Current trends in HIV demonstrate that youth continue to risk acquiring HIV infection. There are 1.1 million PLWH in the United States (Centers for Disease Control and Prevention [CDC], 2012); of these 6% are YLWH between the ages of 13 and 26 years of age. In the United States an estimated 50,000 people acquire HIV annually, and almost 26% of new cases, approximately 12,000 in 2010, occurred among adolescents and young adults between the ages of 13 and 26 years (CDC, 2012). Among YLWH, an alarming 60% of youth are not aware of their diagnosis (CDC, 2012). This lack of awareness presents a public health challenge in curtailing the epidemic in the United States.

The HIV epidemic has disproportionately impacted marginalized communities in the United States, primarily ethnic/racial minorities and sexual minorities. Minority youth, in particular, disproportionately risk acquiring HIV (CDC, 2008). African American and Latino youth account for a disproportionate proportion of YLWH (CDC, 2012). HIV infection rates are seven times higher among African Americans and three times higher among Latinos when compared with Whites (Prejean et al., 2011). Although no significant increase in HIV incidence emerged from 2006 to 2009, an overall significant increase in HIV incidence among youth 13–29 years of age did arise. However, in that age group, the only group experiencing increases in new infections was MSM (Prejean et al., 2011). The dramatic increase among African American young MSM drove this increase in incidence. However, Latino and African American MSM continue to be disproportionately impacted at a younger age than White MSM (Prejean et al., 2011; see Figure 1). It is important to note that these findings are based on estimates from 16 states and 2 jurisdictions from which data were consistently collected and excludes areas such as Washington DC and California which also have large proportions of Latino population. Thus, these estimates could underrepresent the overall prevalence by approximately 3% due to this limitation.

On a larger scale, the HIV epidemic impacts the Latino population second most of ethnic or racial groups, as African Americans continue to bear the burden of the HIV epidemic. In 2009, Latinos accounted for 20% (9,400) of new HIV infections and represented approximately 16% of the total U.S. population (CDC, 2011). Currently, Latino youth (13–24 years of age) account for 17% of the youth

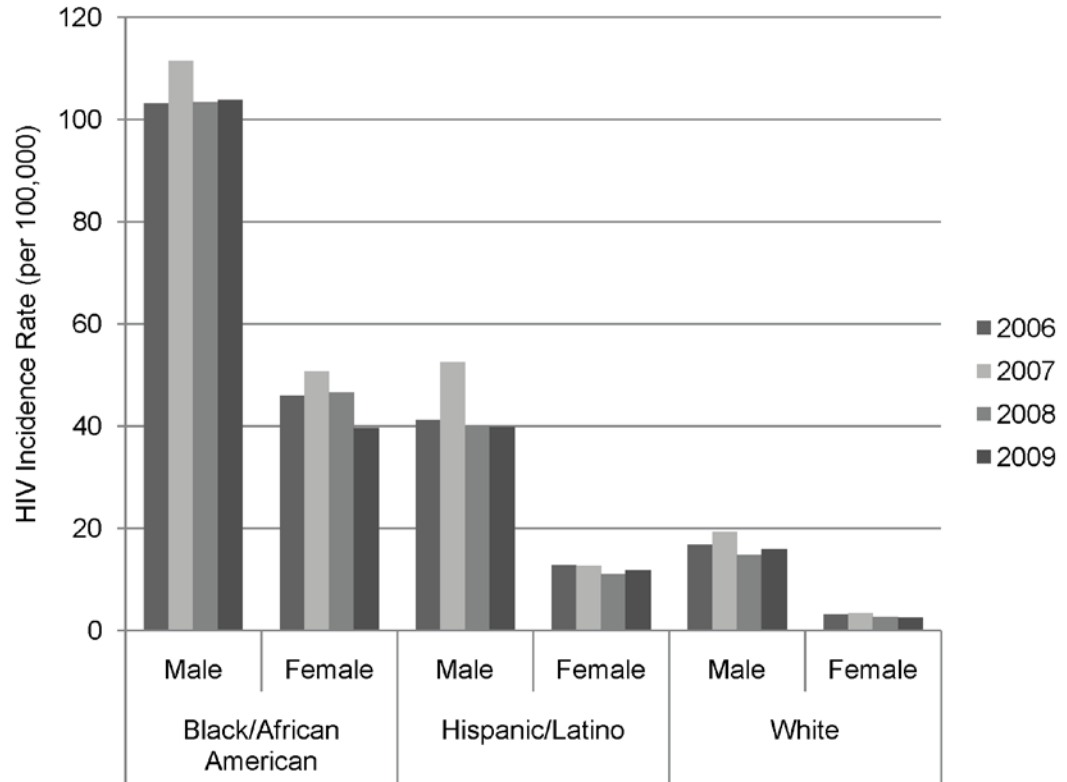


Figure 1. Rate (per 100,000) of new HIV infections by gender and race/ethnicity – United States, 2006–2009.

population, yet they disproportionately represent 19.6% of YLWH (CDC, 2012). Furthermore, Latino youth account for 19% of AIDS diagnoses among youth aged 13–19 and 21% of AIDS diagnoses among youth aged 20–24 (CDC, 2012). Overall, HIV was the sixth leading cause of death for both Latino men and Latina women, ages 25–44, in 2007 (CDC, 2008). In 2009, Latino men accounted for 79% (7,400) of new infections among all Latinos. The rate of new infections among Latino men was two and a half times as high as that of White men: 39.9/100,000 versus 15.9/100,000 (CDC, 2009). Among Latinos, the greatest increase in AIDS case rates are among foreign-born Latinos, mostly among those of Mexican descent (Kaiser Family Foundation, 2004). These data demonstrate the urgent need for prevention and treatment efforts focusing on Latino populations (CDC, 2012).

With the increasing growth of Latinos in several U.S. states and metropolitan areas such as Arizona, Texas, and Los Angeles, efforts to curb the HIV epidemic among Latinos are warranted. The National HIV/AIDS Strategy (NHAS), implemented by the Obama Administration, outlined a coordinated approach to curb the HIV epidemic by addressing barriers across the continuum of HIV care. This approach may help reduce the disproportionate HIV rates impacting communities of color and sexual minorities. The Strategy specifically outlined efforts to curb the epidemic among gay, bisexual men, transgender individuals, African Americans, and among the Latino community.

The incidence of HIV/AIDS among Latinos, particularly among Latino youth, is a growing concern because it is disproportionate relative to the

proportion of the Latino population in the United States. In addition, prevalence trends are not decreasing among Latinos; among some subsets or groups, prevalence is actually increasing. These trends point to the need to explore Latinos' barriers to and perceptions of engaging in HIV care and to account for the diversity of experiences in the Latino population (van Servellen et al., 2002).

Overview of the Latino Population

Latinos, composed of a variety of nationalities and countries of origin, are the fastest growing population in the United States. Currently, the Latino population of the United States is the nation's largest minority ethnic or racial group, estimated at 50.7 million (U.S. Census, 2010). According to the U.S. Census, this represents a 43% increase in the Latino population from April 1, 2000 to April 1, 2010. A variety of demographic factors, including high levels of immigration and a combination of high fertility coupled with low mortality partly explain the alarming growth (Population Council Bulletin, 2010). Another major underlying factor is the young age structure of the Latino population, compared with the rapidly aging population structure of the White population. For example, in 2009 the median age of Latinos was 27, compared with 41 among Whites.

Of all U.S. immigrants, nearly half come from Latin America. The terms *Hispanic* and *Latino*, used interchangeably, refer to persons of Latino origin.¹ It is estimated that 47% of U.S. Latinos are first-generation immigrants (U.S. Census,

¹ While the term Hispanic is used interchangeably with Latino, the term Latino is the preferred term when referring to people of Latin American descent. Therefore, I will use the term Latino throughout this review.

2010). Of the 50.7 million Latinos in the United States, nearly two thirds (65%) self-identify as being of Mexican origin (U.S. Census, 2010). Puerto Ricans, the nation's second largest Latino group, make up just 9% of the total Latino population in the 50 states and the District of Columbia. Overall, the 10 largest Latin American origin groups—Mexicans, Puerto Ricans, Cubans, Salvadorans, Dominicans, Guatemalans, Colombians, Hondurans, Ecuadorians, and Peruvians—make up 92% of the U.S. Latino population. Among Latinos of geographic and cultural diversity from 20 countries in Latin America are significant differences in language, socioeconomic status, customs, and values. The reasons for migrating to the United States also vary widely among Latinos. For example, although the majority of Latinos may leave their country of origin for economic opportunity, others may be escaping political, violent, or social turmoil in their home countries. These differences impact the various socioeconomic and health indicators once they reside in the United States.

Although a complex set of causes contributes to the HIV/AIDS epidemic in the U.S. Latino community, the HIV epidemic is among those health indicators that appear to vary between foreign-born and U.S.-born Latino populations. Immigrants in particular are a “vulnerable population” because, as a group, they risk poor physical, psychological, and social health outcomes as well as inadequate healthcare (Derose, Escarce, & Lurie, 2007). Immigrant youth, in particular, face a high risk for acquiring HIV, given their social vulnerabilities. For example, about 58% of foreign-born Latino youth were unauthorized immigrants in March 2008 (Pew Hispanic Center, 2009). In addition, an estimated

13% of Latino immigrant youth reported living with nonparents or nonrelatives, increasing their vulnerability (Pew Hispanic Center, 2009). Using a socioecological framework can provide insight into the complex factors fueling the HIV epidemic among U.S. Latino youth. In particular, this framework can be used to examine the facilitators of and barriers to engagement in care faced by LYLWH. By focusing on LYLWH, one can explore the diverse experiences among LYLWH who may hold other socially marginalized statuses including foreign-born undocumented status.

Socioecological Factors Impacting HIV Risk and Resilience

Using a socioecological framework to understand the HIV/AIDS epidemic among LYLWH facilitated an exploration of how the HIV epidemic is “embodied” among persons through the numerous biologic and social factors that influence engagement across the continuum of care (Mugavero et al., 2011; Poundstone, Strathdee, & Celentano, 2004). From this perspective, one can explore the barriers and facilitators influencing engagement on the individual, interpersonal, clinical, societal, structural, and cultural levels (Hosek et al., 2008; Mugavero et al., 2011). Greater attention is warranted to further explore how the conditions in which individuals are born, live, and develop influence health outcomes (Adimora & Schoenbach, 2002; Lightfoot, 2012). Given the paucity of research focusing on engagement of care across the continuum of care for Latino youth, in this literature review the focus will be on the socioecological factors influencing the HIV epidemic among Latino youth. Data on these racial/ethnic disparities in HIV outcomes among Latinos have important implications for engagement in care in

this population. For example, once Latino youth are infected with HIV they must worry about secondary HIV infection or coinfection with another sexually transmitted infection. Thus, the following sections will explore how each of these levels and protective and risk-related influences contribute to the HIV/AIDS epidemic among LYLWH.

Individual-Level Factors Influencing the HIV Epidemic

Individual-level factors are the biological and personal-history factors that influence HIV acquisition and disease progression, including age, education, income, substance use, HIV knowledge, perceptions of risk, and use of healthcare services (Mugavero et al., 2011; Poundstone et al., 2004). Behavioral factors that affect the HIV epidemic among Latino youth include earlier onset of sexual debut, increased rates of unprotected sexual intercourse, multiple sexual partners, and injection-drug use (CDC, 2011). In a recent analysis of trends in HIV-related risk behaviors among U.S. high school students from 1991 to 2011, Latino youth demonstrated a stable and higher number of self-reported HIV-related risks over time compared to White and African American youth who demonstrated a decrease over time in multiple-risk behaviors (CDC, 2011). The lack of any significant decrease since 1991 in the percentage of Latino students who have had sexual intercourse, four or more sex partners, and current sexual activity is concerning. In addition, only African American and Latino youth experienced an increase in self-reported injection-drug use over time. Recently, data from the Youth Risk Behavioral Surveillance System reported that Latino youth are more likely to report sexual debut before age 13 (7% versus 3.9% for White youth) and

to have multiple sex partners (14.8% versus 13.1% for their White peers; CDC, 2011).

In a national study by the Pew Hispanic Center (2009) among a randomly selected, nationally representative sample of 2,012 Latinos aged 16 and older, Latino youth were more likely to become teenage parents before the age of 19 than youth of other ethnic and racial groups, suggesting high rates of unprotected sexual contact. In addition to the behavioral sexual risks, 15% of Latino high school students reported never receiving HIV/AIDS information while in school; a significantly higher proportion than found in their African American and White peers (CDC, 2011). Lack of information about HIV/AIDS transmission may increase the risk factors for acquiring HIV because youth will not have the knowledge or skills to engage in protective sexual behaviors. Furthermore, Latino youth are more likely to drop out of high school compared to any other groups, further limiting their access to HIV/AIDS education at a critical time during their adolescent development (Pew Hispanic Center, 2010). The lack of knowledge about HIV/AIDS transmission, coupled with early sexual debut, multiple sex partners, and high rates of unprotected sexual intercourse, presents opportunities for increased transmission of HIV infection among Latino youth. Furthermore, for LYLWH, not having knowledge of HIV/AIDS can impact HIV testing and linkage to care. In addition, without proper knowledge of the course of HIV infection and AIDS, unintentional HIV transmission is more likely to occur, as well as reinfection for HIV.

Interpersonal-Level Factors Influencing the HIV Epidemic

Interpersonal-level factors refers to those relationships in the immediate environment in which the individual operates. The relationships individuals hold with their peers, their families, and their significant others can influence their vulnerability across the continuum of care for HIV. For YLWH, another important relationship is with their healthcare providers, inclusive of the medical doctor, nurse practitioner, psychologist, and case manager. These relationships can be protective or pose challenges when considering the continuum of care.

The relationships youths have in this microsystem can put them at increased risk for HIV. For example, in 2011, the most common mode of HIV transmission for Latinos in the United States was through sexual contact with a man for both men and women, followed by injection-drug use (CDC, 2011). Harper and colleagues (2002) found that Mexican American young women are at heightened risk for HIV acquisition, in part due to engaging in sex with older partners who may or may not be aware of their HIV status.

Parental relationships are important considerations when exploring HIV-related risk. Parental monitoring is an important predictor for multiple protective factors such as higher academic achievement, maintaining less deviant peer relationships, and engaging in less risky sexual behaviors. In an ecodevelopmental model developed for Latino adolescents, Pantin, Schwartz, Sullivan, Prado, and Szapocznik (2004) posited that a stronger mesosystemic connection between parents and other important microsystems (e.g., school and peers) generates a greater protective effect (Pantin, Schwartz, Sullivan, Prado, and Szapocznik,

2004). Moreover, some mesosystemic processes, such as parental monitoring of adolescent social activities, directly protect against adolescent unsafe sexual behavior (Miller, McCoy, Olson, & Wallace, 1986). One concern among Latino immigrant youth is that they are far less likely than their native-born counterparts to be living in a home with their parents (Pew Hispanic Center, 2009). For example, just over one third (38%) of the first generation are living with a parent, compared with 72% of second-generation Latino youths. Although, researchers need more data to better understand the living arrangements of immigrant Latino youth, living with nonrelatives may pose additional risks for these youth, as they are away from their usual sources of support.

Community-Level Factors Influencing the HIV Epidemic

Community-level factors are factors such as neighborhood, education, poverty, social norms, and employment services that can indirectly put individuals at risk for HIV. In addition to community-level factors, healthcare systems in these communities can influence the HIV epidemic among the Latino community. According the U.S. Census, 31% of Latino youth live in poverty (Ramirez & de la Cruz, 2003). Poverty links with a sense of powerlessness and resignation that can further impede one's ability to focus on health and healthcare needs (National Council of La Raza, 2006). However, it is also worthwhile to note that poverty can also yield protest and political action to address the societal issues inherent in society (Epstein, 1991). Zierler et al. (2000) examined AIDS incidence in Massachusetts in relation to economic deprivation by examining census-block data along with HIV-incidence data, stratified by sex and by neighborhood

measures of economic position for the total, Black, Latino, and White populations. This study demonstrated high population density and poverty as significant correlates for increased AIDS cases in African American and Latino communities (Zierler et al., 2000). Multiple factors align with poverty that contribute to further marginalization including lack of transportation, unstable childcare, and inflexible hours in low-paying jobs (National Council of La Raza, 2006). Additional research would more fully delineate how best to intervene to ameliorate health disparities for HIV-positive individuals (Lightfoot, 2012).

Structural-Level Factors Influencing the HIV Epidemic

In addition to the individual-, interpersonal-, and community-level factors that promote HIV transmission in the Latino community, many complex structural-level factors contribute to the HIV/AIDS epidemic in the U.S. Latino community. It is important to examine how the distribution of power, money, and resources affects these health outcomes. Macroeconomic and social forces, including racism, sexism, and homophobia, underpin the HIV/AIDS epidemic. Although the Latino community is extremely diverse, its members share common factors that may place them at increased risk of HIV/AIDS: structural-level discrimination and stigma against people living with HIV, marginalized status, and limited access to care (Kaiser Family Foundation, 2007).

The historical legal limitations for immigrants living with HIV can also place undue stress on immigrants seeking health services in the United States. Prior to 2008, an immigrant with a confirmed HIV diagnosis faced the possibility of being restricted from permanent legal residency and Medicaid benefits under

the U.S. color of law code 42 CFR §34.2, (National Council of La Raza, 2006). Section 212(a)(1)(A)(i) of the Immigration and Nationality Act restricted admission to the United States for any foreign national who had been diagnosed with certain illnesses. On November 2, 2009, the Department of Health and Human Services removed HIV infection from the list of illnesses that make a foreign national inadmissible. Following January 4, 2010, HIV is no longer medical grounds for inadmissibility, and all cases delayed because of HIV infection were decided according to the new rule.

In addition, prior to 2008, HIV was considered “a communicable disease of public health significance”: HIV-positive individuals were barred from obtaining Lawful Permanent Resident (LPR) status without a special waiver. LPR status means that a foreign national could remain in the United States permanently and work indefinitely as long as he or she did not violate certain criminal or immigration laws. Generally, an applicant must have close U.S.-citizen or LPR family members to qualify for a waiver and must demonstrate possession of private health insurance. Since the United States lifted the travel ban for PLWH, those who qualify for a green card who are applying for permanent residence in the United States do not have to take an HIV test as part of the application process. Positive HIV status alone is no longer a reason to deny a green card or immigrant visa. In addition, with consent, a person, regardless of immigration status, may be tested and treated for HIV as part of their medical care, and no information is shared with immigration authorities. Although the government has lifted the travel ban and HIV-related restrictions on immigration, more recent immigrants,

who may not be English-language dominant, may remain wary of revealing their HIV status.

Although these laws have been repealed as of 2010, real structural barriers may impede Spanish-language-dominant immigrant Latinos from seeking HIV-related services, including fear of exclusion, risk of deportation if undocumented, or fear of intimidation from law-enforcement agencies (Dang, Giordano, Kim, 2012; Cunningham et al., 2000). Dang, Giordano, and Kim (2012) conducted a qualitative study in Houston, TX to better understand the structural barriers facing undocumented Latinos living with HIV and found that fear of deportation deterred them from seeking medical care. Cunningham and colleagues (2000), examining factors associated with long-term survival from hospitalizations for HIV infection, found that Latino immigrants reported fear of immigration as a deterrent for seeking HIV care. These data suggest that fear of deportation has important implications for delaying or foregoing HIV treatment among undocumented individuals, particularly when deportation can result in complete loss of HIV care. Limited research discerns more recent data on how these historical legal barriers can impact healthcare-service.

Federal funding for HIV/AIDS has increased significantly over the course of the epidemic, rising by \$5 billion (or 21%) since 2008. Increased spending on mandatory domestic care and treatment programs drove this growth, as more people live with HIV/AIDS in the United States. The government funded the Ryan White Comprehensive AIDS Resources Emergency Act, the largest HIV-specific discretionary grant program in the United States and third largest source

of funding for HIV care, at \$2.5 billion in the budget for 2013, with the majority of funds being allocated to the AIDS Drug Assistance Program for HIV-related drug expenses. In the current public healthcare system and with the increasing prevalence of chronic conditions and longer life spans, an even greater need exists for residential and community-based health-related services designed to minimize loss of function and keep people out of long-term institutional settings (CDC, 2008). These community-based residential and health-related services keep long-term healthcare costs down for people living with chronic conditions. However, even with these systems, pockets of people (such as minorities and young adults) have no proper or sufficient healthcare coverage. For example, approximately 4 million adolescents, aged 10–18, lack health insurance, but an estimated 65% of them are eligible for, but not enrolled in, Medicaid/Children’s Health Insurance Program. Adolescents lacking healthcare insurance or with gaps in coverage have worse access to needed health services, and half of uninsured adolescents have at least one unmet health need.

With the growing number of YLWH in the United States, adolescent-specific primary-care services need to offer appropriate and effective care to youth (Lemos, Harper, & Cellar, 2011). Engagement in medical care is necessary for YLWH to improve medical outcomes (i.e., viral load suppression and long-term survival), psychological outcomes (i.e., psychosocial functioning and quality of life), and public-health outcomes (i.e., reduced viral transmission to others through sexual contact and reduced mother-to-child transmission; Department of Health and Human Services, 2011). The following section reviews the U.S.

National HIV/AIDS Strategy and the Affordable Care Act, enacted during the Obama administration.

In July 2010, the Obama administration released a U.S. National HIV/AIDS Strategy, which represents an effort to refocus national attention on ending the domestic HIV epidemic. The strategy introduces key goals intended to identify a small number of action steps to focus and align efforts across federal, state, local, and tribal levels. Key goals include reducing HIV-related incidence, increasing access to care, and optimizing health outcomes. The United States initially succeeded in reducing new HIV infections from 130,000 per year in the 1980s to 56,000 in the 1990s, but overall HIV incidence in the United States has remained stable for more than a decade. Although HIV has remained stable or decreased in other populations, it continues to increase among MSM. One key aspect of the National HIV/AIDS Strategy is to intensify HIV-transmission-prevention efforts in communities where HIV is most heavily concentrated. The National Strategy identifies gay and bisexual men, Black Americans, Latinos, and substance users as the primary focus for HIV prevention efforts. The HIV/AIDS strategy has specific recommended action steps and targets to reach goals. For example, one primary goal is to reduce the annual incidence of HIV by 25% by 2015. Another target specific to Latinos involves increasing access to care, specifically increasing the proportion of HIV-diagnosed Latinos with undetectable viral load by 20%.

Limited or unavailable access to care is a major concern, given the current healthcare system in the United States. In addition to the National HIV/AIDS

Strategy, focused specifically on HIV/AIDS, in 2010, the Obama administration passed the Affordable Care Act (ACA), which aims to improve access to care for many uninsured individuals and to promote healthcare. The goal of the ACA is to improve access to health coverage for everyone and to protect consumers from abusive insurance company practices. Becoming operational in 2015, the ACA aims to implement a series of changes that would improve access to health insurance and remove healthcare barriers. The ACA increases access to healthcare by ending lifetime caps, making healthcare more affordable, increasing coverage for young adults, mandating coverage of preexisting conditions (including HIV/AIDS), and requiring the provision of no-cost preventive benefits. Although the law was passed in 2010, the timeline for the provisions extended to 2015. As of 2012, uninsured persons with preexisting conditions had access to coverage, patients had access to free preventive services, and insurance companies could no longer deny coverage to children with preexisting conditions.

According to the National Center for Health Statistics (2011), 2.5 million more Americans under the age of 26 gained coverage through their parents' health insurance plans, thereby increasing coverage among young adults. One important exception to this Act is that it excludes access to care for and plans for undocumented persons. Access to care will continue to be a concern for these individuals. It remains unknown how mixed-status families, those that have undocumented immigrants as well as legal residents or U.S. citizens, will be able to access the right plans for various household members. It is possible that children or adolescents are citizens but their parents are undocumented. In that

case, the children are eligible for healthcare or Medicaid, based on their qualification, but their parents could not receive benefits. Another potential source of care for undocumented persons is community-based medical clinics that serve those who cannot afford care. The ACA does include additional funding for these clinics.

Given concerns about funding for services for undocumented persons, little extant research described how these new laws would impact access to and engagement in care. Currently, major concerns exist about the extent to which immigrants, particularly unauthorized immigrants, impact or burden the already fragile U.S. healthcare system (Derose et al., 2007). Concerns frequently center on uncompensated care costs, often cited as a reason to limit immigration to the United States. Patients incur uncompensated care costs when they receive healthcare services for providers do not receive insurance or other payments: hospitals, healthcare providers and public-health entities absorb uncompensated care costs (Gans, 2006). If health entities are responsible for uncompensated care costs, they may limit the availability of health services or reduce care for those who cannot pay or provide health insurance. Because a significant number of Latino immigrants lack health insurance, stakeholders know little about how these concerns about costs can impact immigrants seeking health services. A dearth of research exists on these enacted laws, such as the ACA, and their impact on immigrants already receiving care. With regards to LYLWH, researchers must understand how these policies will impact engagement in care because of the need for routine medical care to maintain optimal health.

Cultural Factors That Impact the HIV Epidemic

Several Latino-specific cultural norms contribute to the heightened risk for HIV transmission. Culture refers to peoples' shared meanings, including people with similar life experiences and understandings (Barker, 2000). Often groups have shared historic, linguistic, social, and political contexts with a common label, such as an ethnicity or nationality (Barker, 2000). Although Latinos are a diverse group from different racial and ethnic backgrounds, some common cultural norms may promote HIV-risk behaviors. Cultural norms regarding traditional gender roles and a culture of silence surrounding sex further inhibit HIV-prevention education. Traditional gender roles such as *machismo* and *marianismo* emphasize traditional husband and wife roles that discourage open discussion of sex before marriage, homosexuality, and equality in sexual relationships (Amaro & Raj, 2000; Maldonado, 1999; Mason, Marks, Simoni, Ruiz, & Richardson, 1995). This lack of open discussion regarding sexuality promotes stigma toward HIV/AIDS; lesbian, gay, bisexual, transgender and queer people (LGBTQ); and HIV-prevention efforts. The stigma toward LGBTQ people further promotes a culture of duality in which Latino youth may feel forced to adhere to traditional roles while coming to terms with their "hidden" sexuality (Maldonado, 1999; Mason et al., 1995).

Researchers attributed increased risk for HIV among Latinos to a host of sociocultural factors including length of stay in the United States (Denner, Organista, Dupree & Thrush, 2005; Ehrlich, Organista & Oman, 2007; Organista, Carrillo, & Ayala, 2004; Sanchez et al., 2012). According to Organista et al.

(2004), global migratory systems play a key role in the geographic spread of HIV, due to mobility factors associated with being away from home for extended periods of time, with family interruptions, and with the potential for an increased number of sexual partners, short term and long term. These differences are particularly salient when comparing foreign-born to U.S.-born Latinos (Rodríguez, Bustamante, & Ang, 2009). Research among a sample of migrant workers of Latino origin who had been in the United States for about 12 years found high levels of injection-drug use, MSM, and sex with commercial sex workers, compared to more recent Latino migrant-worker samples (Denner et al., 2005). The factors contributing to higher levels of risky behaviors among the longer staying sample may relate to the factors found in a study conducted by Ehrlich et al. (2007). Their findings suggested that although a majority of the male migrants in their sample had primary partners back home, these migrant workers still reported being sexually active in the U.S.

Despite growing evidence of a Latino paradox in which recent immigrants tend to have lower rates of HIV infection, their HIV behavioral risk increases as their time in the United States increases. Thus, although more recent immigrants arrive healthier in the United States, their risk for acquiring HIV increases as their time in the United States increases. In a recent study, Espinoza et al. (2012) found that HIV was highest among foreign-born Latino immigrants when compared to U.S.-born Latinos. Several researchers found that immigrants are younger, more likely to present with indicators of more advanced HIV disease, have lower CD4

(a glycoprotein) counts, and more likely are hospitalized at time of diagnosis than U.S.-born patients (Espinoza et al., 2012; Levy et al., 2006).

Acculturation status also plays a critical role in Latino youths' ability to negotiate safer sex practices (National Council of La Raza, 2006; Villarruel, Jemmott, Jemmott, & Ronis, 2004). Acculturation is the process of adaptation in which immigrants alter their attitudes, beliefs, and behaviors to resemble those of the host society in which they reside (Marin, Tschann, Gomez, & Kegeles, 1993). Despite widespread agreement about the role of acculturation and HIV risk (Organista et al., 2004), the direction and influence of this relationship is unclear for HIV-risk. Villarruel et al. (2004) found that more-acculturated Latino youth reported increased sense of control over their sexual health and disease-prevention practices compared to less-acculturated youth. A study by Marin et al. (1993) examined differences in and correlates of condom use among Latino men and women and non-Latino men and women. They found that HIV-related behaviors and attitudes strongly aligned with gender, ethnic group, and level of acculturation. Specifically, Spanish-speaking women were less knowledgeable about HIV and less like to carry condoms, compared to White women.

Flaskerud, Uman. Lara, Romero, and Taka (1996) examined the sexual practices, attitudes and knowledge related to HIV transmission in low-income Latina women residing in Los Angeles and found that traditional Latino sexual values can serve as a protective force when compared to the sexual practices among Latina women who were highly acculturated to U.S. culture. The relationship between HIV risk and acculturation is unclear because less

acculturated women report less sexual contact and experiences, but also less condom use and less reports of negotiated safer sex. This behavior may increase their risk because less acculturated Latino men are more likely to report more sexual partners and are also less likely to use condoms. In summary, the role of acculturation and its relationship to HIV cannot be ignored. Overall, the level of acculturation is an important consideration for health-access research because particular challenges may accrue related to traditional Latino cultural values that those developing socioecological interventions need to include or address. Research also has challenged the role of acculturation as an underlying tenant driving health inequalities and has suggested that discrimination and poverty may play a larger role in the health inequalities experienced by Latinos than the role of acculturation (Viruell-Fuentes, 2007).

Another contributing factor is the limited availability of culturally relevant and accessible information about HIV/AIDS or comprehensive sexual education in the Latino community. The sexual culture of the Latino community differs strikingly from that of the United States. This contrast creates a dramatically different perception of HIV risk and protective behaviors. In the United States, the focus is heavily skewed toward individual-level behaviors such as rationalization, disclosure, and open negotiation. For example, Carrillo's (2002) 2-year ethnographic research on Mexican men and women and the sexual culture there demonstrated a greater fluidity of sexual ideologies and flexibility in defining categories of sexual identity that mixes traditional gender classifications with contemporary classifications of hetero-, bi- and homosexuality. From this

perspective, a sexual culture termed *sexual silence* affords sexual-diversity tolerance but not discussion. Although this practice offers a complicated set of strategies that allow for avoidance of sexual topics, it also allows for some veiled communication about sexual topics (Carrillo, 2002).

In Mexico, people integrate such HIV-protective behaviors as condom use into the culturally influenced ways in which Mexicans prefer to have sex. For example, Carrillo (2002) found that some Mexican men and women wove HIV prevention into seduction, spontaneity, and sexual passion, which did not require any type of discussion and was mainly guided by body communication. This contrasts starkly with some key strategies comprising U.S. HIV-prevention and -intervention messaging. Thus, a greater need exists to understand the relationship between cultural constructions and norms regarding sexual activity, and HIV-prevention research among Latinos in the United States (Organista et al., 2004).

Finally, religion and spirituality impart cultural values in the Latino community. The majority of Latinos identify as Catholic or Christian. Although an individual's religion can be seen as individual, for Latinos, many core cultural values stem from their religious affiliation or upbringing. These religious and spiritual beliefs can influence how PLWH engage in care. For example, Martinez, Lemos, and Hosek (2012) explored the stressors and supports for a subset of newly diagnosed LYLWH. For these youth, religion and spirituality served as a source of support to address their HIV status. For Spanish-speaking LYLWH, the concept of religion played an important role in how they perceived their health

outcomes after the initial diagnosis. For these youth, their connection to their religion was a source of support in making sense of their diagnosis. In addition, their beliefs aligned with their decision to seek medical care. Researchers offered specific recommendations for how to address issues of culture in primary and secondary HIV-risk-reduction programs (Harper, 2007) that may also be applicable to engagement in care programs for racial or ethnic minority YLWH. However, additional research would aid in understanding the role of these values for engagement in care.

Socioecological Influences on Continuum of Care for LYLWH

The following section describes the socioecological factors influencing YLWHs' engagement in care across the continuum of HIV care. The concept of adherence for PLWH has expanded beyond adherence to ART to include adherence to clinical care, commonly referenced as engagement in care (Cheever, 2007; Mugavero et al., 2009). The U.S. Health Resources and Services Administration has operationalized a continuum of engagement ranging from those who are not aware of their HIV status through individuals who are fully engaged in HIV care (see Figure 2). This continuum focuses on key steps in the HIV process that impact overall engagement in care, including HIV testing, linkage, retention, ART adherence, and reengagement for those who are lost to follow-up (Ulett et al., 2009). The goal of engagement across the continuum of care is to achieve optimal treatment outcomes through early HIV diagnosis, optimal linkage and retention in HIV care, sufficient use of ART, and adherence to HIV care. Incomplete engagement in care means late HIV diagnosis,

suboptimal linkage and retention in HIV care, insufficient use of ART, or insufficient adherence to HIV care. The factors affecting YLWHs' engagement in care group in five areas: testing, linkage to care, engagement in care, medication adherence, and retention in care.

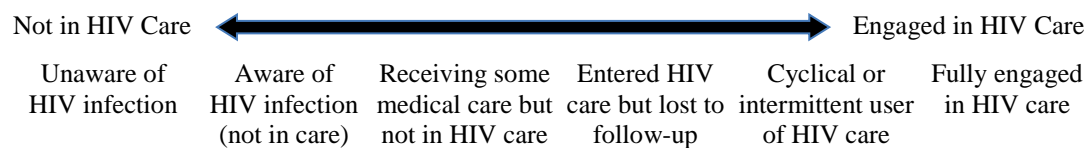


Figure 2. Health Resources and Services Administration continuum of HIV care describing the spectrum of engagement in HIV care.

Source: “The Spectrum of Engagement in HIV Care and its Relevance to Test-and-Treat Strategies for Prevention of HIV Infection,” by E. M. Gardner, M. P. McLees, J. F. Steiner, C. del Rio, & W. J. Berman, 2011, *Clinical Infectious Diseases*, 52, p. 794.

Factors Influencing HIV Testing

The CDC (2006) recommends routine HIV testing as part of regular medical care for all persons aged 13–64 years and the Academy of Pediatrics Committee on Pediatric AIDS (2011) recommends testing for all youths aged 16–18 years and all sexually active youths regardless of age. People who are infected with HIV and unaware of it are unable to take advantage of therapies that can keep them healthy and extend their lives; those who are unaware do not have the knowledge to protect their sex or drug-use partners from becoming infected (CDC, 2006). Knowing whether one is positive or negative for HIV confers great benefits in healthy decision making.

One barrier to HIV testing is irregular access to healthcare. Latinos' access to healthcare is a concern because it can reduce access to HIV testing, lead to late diagnosis of HIV, and limit access to proper treatment. Using cross-sectional data from the 2007 Pew Hispanic Center/Robert Wood Johnson Foundation Hispanic Healthcare Survey, a nationally representative telephone survey of 4,013 Latino adults, Rodríguez et al. (2009) compared U.S.-born Latinos with foreign-born Latino citizens, foreign-born Latino permanent residents, and undocumented Latinos on different healthcare factors. The researchers found differences in the perceived quality of care, use of preventive care, and usual source of care, based on U.S. nativity and immigration status (Rodríguez et al., 2009). They found that undocumented Latinos were less likely to have a usual source of care, received less preventive care, and perceived care to be of lower quality compared to their

foreign-born and U.S.-citizen counterparts. This is a concern because this impedes regular access to HIV testing.

In addition, DuBard and Gizlice (2008) examined data from 45,076 Latino adults from the Behavioral Risk Factor Surveillance data system. They compared 25 health indicators between Spanish-speaking Latinos and English-speaking Latinos. Although certain chronic diseases were lower among Spanish-speaking Latinos, they reported far worse access to care (55% vs. 23% uninsured and 58% vs. 29% without a personal doctor) and received less preventive care. These disparities in access to care extend to Latino youth. U.S.-born children with noncitizen or naturalized parents have lower rates of health insurance (public and private) than U.S.-born children with U.S.-born parents (Derose, Escarce, & Lurie, 2007). These youth and children did not have a regular source of care and did not have a physician or dental visit in the past year (Derose et al., 2007). These disparities extend specifically to HIV-testing patterns among Latino youth. According to the CDC (2011), Latino youth are less likely to report having a routine HIV test in the past compared to African American students, despite reporting higher prevalence of sexual behaviors.

Factors Influencing HIV Linkage to Care

HIV linkage to care refers to successful initiation of timely HIV care after initial diagnosis (Gardner et al., 2011). However, failure to initiate timely HIV care after diagnosis is common. Longer delays in linkage with medical care align with greater likelihood of progression to AIDS by CD4-cell criteria (Gardner et al., 2011). Researchers demonstrated a need to improve linkage to care, as only

75% of PLWH link to care within 3–6 months of diagnosis and 80–90% link successfully 3 to 5 years after diagnosis (Gardner et al., 2011). Serious gaps exist in the linkage to care system as nearly a quarter of newly diagnosed individuals do not successfully link to care.

One subgroup among Latinos identified as experiencing linkage to care barriers are the Latino foreign-born PLWH. Few studies exist on documented immigrants living with HIV, but evidence suggests a lack of sufficient HIV/AIDS knowledge, increased HIV/AIDS stigma, language barriers, and confidentiality concerns that may impact receipt or uptake of timely HIV care (Rhodes, Hergenrather, Wilkin, et al., 2008; Shedlin & Shulman L, 2004). Specifically, undocumented HIV-infected Latinos are more likely to enter HIV care with advanced AIDS than are documented Latinos, Whites, and Blacks (Poon et al., 2010). Qualitative data from 22 undocumented Latinos living with HIV revealed that a majority of these received their diagnosis at public hospitals after seeking emergency care for advanced or severe symptoms (Dang et al., 2011). The 1986 Emergency Medicaid Treatment and Active Labor Act guarantees emergency care for undocumented individuals. However, they may face certain hurdles in linking to chronic HIV care after hospital discharge. Undocumented individuals with low literacy and linguistic barriers may have difficulty completing forms required for access and may feel overwhelmed navigating healthcare systems (Dang et al., 2011). Additionally, such perceptual barriers as misconceptions about deportation risks and lack of awareness about available HIV services contribute to delayed HIV diagnosis and late linkage to HIV primary care.

Factors Influencing HIV Engagement in Care

As a result of medical advancements and interventions in early detection and treatment of HIV, PLWH are now living longer. Attention has now shifted to managing HIV as a chronic disease (Uphold & Mkanta, 2005). Strong evidence shows that engagement in care links to improved medical outcomes for PLWH (Giordano et al., 2007; Heckman et al., 2004; Mugavero et al., 2007, 2009). Thus, increased focus ensures that PLWH engage in medical care early after learning about their HIV diagnosis. In general, engagement in care is difficult to define because of the continuum of services that PLWH may need: home care, rehabilitation services, mental health programs, and nursing home care, all in addition to the need for HIV-specific care (Uphold & Mkanta, 2005).

Although engagement in care is difficult to ascertain because of the scope of services for an individual living with HIV, between 20% and 40% of PLWH fail to attend a clinic visit within 3 to 6 months of receiving their HIV diagnosis (Mugavero et al., 2007). Delays in receiving HIV-related care, such as missing a medical appointment during the 1st year of diagnosis, increase the odds of mortality when compared to those who attend all their HIV-related care appointment (Mugavero et al., 2009). Multiple diagnoses further complicate engagement in care, including comorbidity with mental health and substance-use disorders. These factors serve as additional barriers to PLWH receiving continuous medical care (Hosek et al., 2002; Murphy, Wilson, Durako, Muenz, & Belzer, 2001), thereby negatively influencing adherence to medical care, including medications and doctor visits. According to a study by Gardner et al.

(2011), of the more than 1 million people living with HIV/AIDS in the U.S., 20% do not know their HIV status, 40% have not seen an HIV primary-care doctor, 60% do not regularly see their doctor, and 80% have not achieved recommended viral-load suppression. It is important to note that research has suggested that these rates of engagement across the continuum of care may be underestimated by approximately 10% due to other factors that may mask true engagement in care such as out-migration from the state, unknown or undocumented deaths, and lack of full reporting in some of the reporting jurisdictions (Rowan, Johnson, Thrun et al., 2012). One reason could be that clinical practice and guidelines have changed regarding recommendations for clinic engagement for PLWH (CDC, 2014). The recommendation for continued engagement shifted from one visit every 3 months to one visit every 6 months for PLWH who have good immunologic function, excellent adherence, and sustained virologic control. This change in visit recommendations can result in underreporting of actual engagement if the 3 month marker is used to assess engagement in care (CDC, 2014). Despite these limitations, the issue of engagement in care remains an important consideration for curbing the HIV epidemic in the United States. Despite the medical advances and interventions to identify and treat individuals living with HIV, multiple challenges persist to engaging PLWH, resulting in delays in identification and treatment for HIV and comorbid mental health or physical health conditions that may impact their overall health.

Additionally, these delays in care increase PLWH odds of transmitting HIV/AIDS to others by engaging in unsafe sex with uncontrolled viral loads

(Kalichman et al., 2001). In addition to the physical progression of the disease, Latino males are least likely to disclose their status to family members or significant others, thus limiting their access to social-support networks that can promote engagement in care or adherence to medications (Kalichman et al., 2003; Mason et al., 1995). Research on adults patterns of engagement in care suggest Latino males have increased risk for falling out of care. Limited data exists for Latinas living with HIV.

Factors Influencing Medication Adherence

HIV-infected individuals who engage in care have four main barriers to successful treatment with antiretroviral medications: delay or failure to initiate therapy, lack of persistence with therapy, poor adherence to therapy, and viral resistance to antiretroviral medication (Gardner et al., 2011). Gardner et al. (2011) estimated that 80% of in-care HIV-infected individuals in the United States should be receiving antiretroviral therapy but that 25% of these individuals are not receiving therapy.

Specific to HIV medication adherence, a systematic review of barriers to adherence to HIV treatment (Mills et al., 2006) revealed that fear of disclosure, forgetfulness, a poor understanding of treatment benefits, complicated regimens, and being away from their medications were consistent barriers to HIV-medication adherence across developed and developing nations. In addition, psychosocial barriers to adherence among YLWH pertain to mental health issues such as depression, concerns about stigma, fear of disclosing their HIV status through medications, and using other substances, in particular marijuana (Hosek,

Harper, & Domanico, 2005; Murphy et al., 2001; Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007). A complex set of factors, ranging from individual-level factors to socioecological factors, impact the ability to maintain optimal HIV-medication adherence. For Latino immigrants, especially those who are Spanish-language dominant, these barriers to care may carry important significance due to great differences in healthcare systems and requisites between the United States and their home countries. Learning to navigate these systems can be an emotional and time-intensive challenge that may hinder access to important healthcare services. Spanish-language dominance marks a particularly vulnerable subpopulation of U.S. Latinos for which access to care and use of preventive care are more difficult than for English-speaking Latinos.

Factors Influencing Retention in Care

Retention in care plays an important role in maintaining optimal health for PLWH. Numerous studies have documented high rates of attrition within the first year after enrollment in HIV care, and poor retention has linked with ART receipt and adherence (Giordano et al., 2007; Mugavero et al., 2009; Ulett et al., 2009). The HIV Cost and Services Utilization Study, a nationally representative study of PLWH receiving regular or ongoing medical care for HIV infection, found that Latinos were more likely to report postponing medical care due to factors as simple as lack of transportation (Cunningham et al., 1999; Shapiro et al., 1999).

Although researchers lack data about access to regular medical care for LYLWH, Sarmiento and colleagues (2005) conducted a cross-sectional analysis of data from Latino adolescents in Wave I of the National Longitudinal

Adolescent Health Study to explore routine care patterns among Latino immigrant adolescents. First-generation immigrants who had lived in the United States more than 5 years were less likely to receive routine physical care than third-generation immigrants (39.0% vs. 54.9%). Magnus et al. (2010) explored the characteristics associated with retention among adolescent African American and Latino HIV-positive men. They found that adolescent Latino HIV-positive men were at increased risk of falling out of care compared to African Americans and other MSM. Recent data focusing on YLWH, suggests that patterns of retention may differ from those of adults. For example, one research study sponsored by the Health Resources and Services Administration examining the continuum of care among YLWH, only young men, demonstrated that linkage and long-term retention in care was significantly higher among Latino participants (96.2%), compared to African American participants (79.9%; Hightow-Weidman, Jones, et al., 2011). Thus, examining the protective factors that promote engagement in care among LYLWH can guide best practices to promote higher engagement in care among YLWH in general.

HIV-Related Interventions for Latinos and Latino Youth

Given the growing concern about HIV among Latinos, it is important to examine the scholarly literature regarding interventions that target Latino youth, including those who are at risk for infection and those who are living with HIV. Most of these HIV-related interventions focus on HIV prevention. For example, one comprehensive system-wide literature review yielded important information on the state of the art for interventions targeting male and female Latino

adolescents. Cardoza, Documet, Fryer, Gold, and Butler (2012) conducted a literature review of sexual-health-behavior interventions, including HIV/AIDS interventions, for U.S. Latino adolescents, with articles published between 1993 and 2011. They found that 15 of the 68 articles specifically addressed Latino adolescents. Based on targeted outcomes, of the 15 interventions, 60% reduced risky sexual behavior; 53% demonstrated changes in attitudes, beliefs, and perceptions about sexual health and sexually transmitted infections (STIs), including HIV/AIDs; 33% increased sexual-health knowledge; and 20% increased skills-based learning. Only one intervention measured and demonstrated a reduction of STI and pregnancy rates among participants. For this literature review, the researchers then classified interventions based on the socioecological levels of influence on sexual behavior. The majority of the interventions focused on individual-level change including knowledge, attitudes, beliefs, perceptions, and intentions. The scholars then analyzed interpersonal-level change, targeting friendships, peer-group activities, sexual partners, parental involvement, parent–child communication, and family cohesion. None of the interventions focused on community-level influences such as social cohesion, social-support groups, school-based programs, community-based organizations, or community lay-health work. Finally, none of the interventions focused on societal/policy levels of influences such as culture, language, immigration laws, school-based sexual-health-education policy, or access to healthcare, including contraceptive care.

Of the HIV prevention interventions, five major strengths emerged in the Latino adolescent sexual-health research agenda (Cardoza et al., 2012). First,

interventions addressed the most critical issues in adolescent sexual health among Latino adolescents including STIs and HIV. Second, interventions' problem-solving approach aimed at different socioecological levels to effect change in Latino adolescents' negative sexual-health outcomes. For example, although some interventions targeted change in individuals' perceptions, attitudes, and knowledge about sexual health, other interventions targeted interpersonal-relationship skills that affect sexual behavior and HIV-risk behavior. Third, interventions used different strategies (e.g., lectures, discussions, role playing, and home visits) and settings (e.g., schools, neighborhood streets, and health clinics) to deliver sexual-health messages to adolescents. These strategies often developed using participatory empowerment approaches. For example, Harper, Bangi, Sanchez, Doll, and Pedraza (2006, 2009) used a participatory empowerment approach to tailor a sexual-health-promotion program to best meet the needs of young Latinas at risk for unplanned pregnancy, HIV, and other sexually transmitted infections. Through process evaluation of the sociocultural and contextual factors impacting Latina adolescents, the team modified several aspects of the program targeting concerns present at multiple system levels, including individual-, agency-, and neighborhood- or community-based factors. Specifically, they were able to address concerns related to teen pregnancy, age-discordant sexual relationships, and gang affiliation or involvement. Using the concept of "subverting culture" (Ortiz, Serrano-Garcia, & Torres-Burgos, 2000), the authors asserted that healthcare personnel should not use culture as a vehicle

for further oppression, and that interventions must include a critical examination of cultural aspects that promote and impede prevention efforts.

A final strength was the diversity of U.S. geographical locations where researchers conducted the interventions, which included the cities with some of the largest concentrations of Latinos (e.g., Miami, FL; Chicago, IL; Los Angeles, CA; and Houston, TX). The prominence patterns of Latino ethnic groups vary greatly by location, suggesting that the needs of these diverse groups may also vary depending on geographic location. For example, Latinos in the southwest region of the United States are predominantly of Mexican descent, whereas those in the northeast region of the United States are predominantly of Caribbean descent. Having geographically, culturally, and linguistically tailored programs allows for greater reach and understanding of these youths' needs. The fifth strength of these studies overall was that they used a variety of evaluation modalities including qualitative and quantitative evaluation methods.

Cardoza et al. (2012) also noted numerous weaknesses in the research conducted to impact Latino adolescents' sexual health. One major weakness was the paucity of behavioral interventions that specifically targeted and promoted Latino adolescent sexual health. Of the 68 interventions identified, only 15 specifically targeted Latino youth, suggesting a need for the development of targeted interventions for these youth, given the sexual health-related disparities facing these youth. Another weakness was the low percentage of interventions for Latino adolescents that addressed sexual-health problems from a socioecological approach, targeting multiple levels of influence. In this review, only three studies

employed or described a sociocultural framework for the development of the interventions. The majority of interventions focused on STI and HIV/AIDS prevention at the individual level. Furthermore, interventions, for the most part, targeted young women, with less attention focused on the young men's role in a sexual relationship, as well as other levels of influence that determine the health of female adolescents. With the highest teen pregnancy and birth rates among all ethnic minority groups, Latino male and female adolescents require interventions that are proven effective in reducing pregnancy in adolescence, and that incorporate multiple levels of the socioecological framework. Furthermore, unplanned pregnancy is an indicator of having unprotected sexual intercourse, which increases the risk for HIV transmission.

Scant literature focused on interventions for YLWH, even less so for LYLWH. Murphy et al. (2001) published psychosocial findings from the Reaching for Excellence in Adolescent Care and Health study, the first large-scale disease-progression study of behaviorally infected YLWH. In this sample, only 41% of youth reported full adherence to highly active antiretroviral therapy. Youth depression strongly aligned with nonadherence; however, no relationship emerged between social support and adherence.

For interventions, Rotheram-Borus et al. (2001) developed a 23-session group-based intervention for use with behaviorally HIV-infected youth. Together Learning Choices (TLC, previously referred to as Teens Linked to Care) is a small-group intervention designed for youth and young adults living with HIV. TLC consists of two modules: Stay Healthy and Act Safe. The Stay Healthy

module consists of 12 sessions to promote positive health behaviors. The Act Safe module consists of 11 sessions to increase self-protection and other-protection motivation to change behavior and to reduce substance use and unprotected sex acts.

In all, 257 youth participated in the intervention trial (mean age = 21, 72% male, 64% ethnic minority). TLC participants were significantly more likely to report no sexual risk pattern and significantly lower percentages of unprotected vaginal and anal sex acts than the control group ($p < .05$) at 3 months after the Act Safe module. Youth who participated in this intervention, compared to those in the control condition, reported increased social support, positive lifestyle changes, and active coping. It is important to note, however, that more than 25% of participants attended less than half the required sessions (Rotheram-Borus et al., 2001). Additionally, the researchers suggested the need to identify alternative formats to deliver interventions (Rotheram-Borus et al., 2001).

Choosing Life: Empowerment, Actions, Results (CLEAR), an offshoot of TLC, is a three-module intervention delivered in individual sessions to substance-using YLWH (Rotheram-Borus et al., 2004). Each of the three modules consists of six sessions focused on different target behaviors. Module 1 focuses on improving youths' physical health, including the use of and adherence to antiretroviral medication, implementing new daily routines to stay healthy, and coping with their serostatus. Module 2 aims to reduce unprotected sex acts and substance use through the identification of situations that elicit risky behavior. Module 3 aims to reduce emotional distress and to increase participants' quality.

Participants in the efficacy trial were 175 YLWH (median age = 23, 78% male). At 15 months postbaseline, participants who received the CLEAR intervention reported significantly greater increases in the proportion of protected sex acts with all sex partners ($p < .01$) and proportion of protected sex acts with HIV-seronegative partners ($p < .05$) compared to wait-list control participants. However, other targeted outcomes, including substance use, HIV-medication adherence, health behaviors, and emotional distress, did not significantly improve through the intervention.

Markham, Shegog, Leonard, Bui, and Paul (2009) completed a pilot test of +CLICK, an individual, web-based application designed to enhance sexual-risk reduction skills among perinatally infected youth (YLWH who were infected during pregnancy and delivery). +CLICK targets four behaviors: choosing not to have sex, disclosing HIV status to a potential sex partner, using condoms correctly and consistently, and using an effective method of birth control along with condoms. Completing the pilot study were 32 HIV-positive youth (mean age = 17.8, 62.5% female, 68.8% African American). Short-term psychosocial outcomes indicated a significant increase in condom use self-efficacy ($p = .008$) and positive trends toward importance ($p = .067$) and self-efficacy ($p = .071$) for waiting before having sex. Acceptability and feasibility ratings were high.

Of the several published youth-specific adherence studies, several used directly observed therapy (Glickman, Walsh, Valkenburg, Mangat, & Marcinak, 2007; Parsons et al., 2006; Purdy et al., 2008) and one used medication scheduling (i.e., reduction to once-daily dosing) as the intervention. One

behavioral counseling intervention (the Therapeutic Regimens Enhancing Adherence in Teens program; Rogers, Miller, Murphy, Tanney, & Fortune, 2001) evaluated an 8-week program involving medication education through videotapes, booklets, and audiotapes. Only 18 of 112 participants completed the program. Of those who completed, two thirds initiated antiretroviral therapy and half self-reported adherence “most” to “all of the time” (Rogers et al., 2001). Lyon and colleagues (2003) used a family-group approach, recruiting 30 pairs of HIV-infected youth and a family member to engage in 12 weeks of education sessions in a group-psychotherapy format. Of participants, 91% reported increased adherence and most showed improvement in CD4 counts (Lyon et al., 2003). Finally, Naar-King and colleagues (2009) tested Healthy Choices, a four-session motivation-enhancement program combining motivational interviewing with cognitive-behavioral strategies such as decisional balance and goal setting to improve adherence. The intervention did not significantly improve viral load immediately posttreatment, but improvements in viral load were significant at 6 months postbaseline compared to multidisciplinary specialty care alone. Only 50% of youth attended all sessions and changes in viral load were not maintained at 9 months (Naar-King et al., 2009).

Hosek et al. (2011) developed an intervention to build behavioral skills to assist newly diagnosed youth with psychosocial adjustment to living with HIV. The researchers developed the intervention, Adolescents Coping, Connecting, Empowering and Protecting Together (Project ACCEPT), based on qualitative data gathered from a previous exploratory study (Hosek et al., 2008). Hosek et al.

(2008) conducted focus groups and individual interviews with medical and mental-health providers, as well as case managers, regarding the intervention needs of youths (aged 16–24) newly diagnosed with HIV. The researchers then conducted focus groups with HIV-positive youth from three sites (Chicago, IL; Bronx, NY; and San Juan, PR) to identify the challenges, strengths, and areas needing support or assistance associated with receiving an HIV diagnosis. Hosek et al. (2011) used these data to guide the development of an intervention manual.

The disability-stress-coping model (Wallander & Varni, 1995) undergirds the Project ACCEPT intervention, which incorporates skill-building activities guided by social-cognitive theory (Bandura, 1986). The Project ACCEPT intervention consists of a combination of individual and group sessions, which allows for more intensive individualized attention as well as group support. Youth first participate in two individual sessions, followed by nine group sessions, and end with one additional individual session.

In general, outcomes were in the expected direction, with some differences between genders. HIV knowledge increased across both time periods for the overall sample, with an effect size of .52 at the 3-month follow-up. Depressive symptoms also improved for male participants, with the largest decrease occurring directly following the intervention. However, female depressive symptoms did not demonstrate an improvement ($d = .03$ and $.20$, at postintervention and 3-month follow-up, respectively). Self-efficacy for disclosure of HIV status demonstrated a small improvement for the entire sample, with the largest effect occurring postintervention ($d = .12$). Self-efficacy related to

sexual discussions improved across both time periods for women, but demonstrated a slight decrease at the 3-month follow-up for male participants. Although the study was feasible (with 84% attending more than six sessions) and acceptable, the need persists to further examine how these types of interventions impact engagement in care for YLWH.

Finally, in 2005, the Health Research and Services Administration created the YMSM of Color Initiative to design and test novel interventions to engage and retain YMSM of color who are HIV positive. In particular, the organizations developed two case-management interventions for young men living with HIV to improve linkage and retention in care. Wohl et al. (2011) developed an intensive psychosocial case-management program (2 months of weekly visits followed by 22 monthly visits) targeting young Latino and African American MSM who were either newly diagnosed or sporadically in HIV primary care. Of the 61 participants enrolled into the study, 78% reported critical or immediate need for supplemental services such as stable housing, substance-abuse treatment, or mental health services. After 6 months, 70% of participants were in care, and retention rates among intermittent users of HIV primary care increased from 7 to 73%.

In another study, Hightow-Weidman, Smith, Valera, Matthews, and Lyons (2011) designed Strength Through Youth Livin' Empowered (STYLE) to address the previously unmet needs of this population by providing an array of services above and beyond the standard of care. These services included a peer outreach worker, a case manager, and members of the research staff who formed a

medical–social-support network for the youth, created weekly support-group meetings, and made themselves available by text or telephone to assist with appointment scheduling or to answer medical questions. Over a 3-year period, 81 men were either newly diagnosed or reengaged in care. Overall, the program retained 63% of the cohort in clinical care, defined as attending at least one medical visit every 4 months. Results from the longitudinal analysis of whether someone attended a clinic visit shows that the odds ratio for STYLE is 2.58 (95% CI 1.34–4.98) compared to the years predating the STYLE cohort. In summary, these data suggests that YLWH have critical needs that need to be addressed in addition to the immediate care and retention for HIV medical care. Through intensive psychosocial approaches, data demonstrated that clinic-based interventions have the ability to stabilize and retain YLWH in consistent care.

Research on HIV care continuum has increased dramatically from 2011 to 2015 (Greenberg, Purcell, Gordon, et al., 2015). This research has primarily focused on the descriptive/epidemiological studies, assessing and modeling the impact of interventions and monitoring quality of care (Greenberg et al., 2015). One point of contention in the HIV literature is which point of intervention will yield the greatest impact on minimizing the HIV epidemic in the U.S. For example, of the studies discussed in this literature review, the majority of the studies take place in clinical settings. These studies also have a primarily behavioral component, which are guided by underlying determinants of care such as improving engagement in care by addressing information about HIV, behavioral skills to adhere to medication or disclose to significant others. These

studies have demonstrated limited effectiveness and difficulty with effects being sustained over time. Thus, researchers that focus on social determinants of HIV argue that such interventions are limited because they do not address the underlying issues that can negatively affect engagement in care such as poverty, discrimination and other social determinants of HIV (Greenberg, Purcell, Gorden et al., 2015). It is important to recognize that interventions that focus on structural issues such as stigma, unstable housing, and poverty are lacking in the current literature. However there is a need to further explore such interventions to assess the degree of influence these factors have on engagement in HIV care as there is debate that these factors have greater influence than behavioral factors.

Rationale

In summary, most research with PLWH suggested behavioral, interpersonal, community, societal, and cultural factors influence engagement across the continuum of care. In addition, despite biomedical advances in the treatment and prevention of HIV, youth require supports to sufficiently address the epidemic. With the success of ART, HIV is now seen as a chronic illness, and focus is now on promoting engagement across the continuum of HIV medical care. Gardner et al. (2011) suggested that improvement in the entire continuum of engagement in care will require healthcare professionals to engage in test-and-treat strategies to substantially increase the proportion of persons with undetectable viral loads. Given the paucity of research exploring the process of engagement in care for LYLWH, researchers must examine the facilitators and

challenges, to better understand engagement across the continuum of care for this group.

Attention to LYLWH is necessary from a socioecological model because the vulnerabilities experienced by this group pose a significant challenge to conducting health-related research, due to low rates of patient enrollment, engagement in healthcare, and adherence to research or clinical protocols. Healthcare service providers at community-based agencies and medical-care centers are poised to make important contributions in health research, due to their knowledge, experiences, and ability to connect members of this community (geographically and socially) with health services. Critical to their role is the existing trust they have established in the community; a common challenge for researchers. Therefore, this study explored the perceptions of providers about the health-related facilitators and challenges that LYLWH experience in their healthcare settings and communities.

For this study, I used a qualitative data-collection approach comprised of in-depth individual interviews with providers serving LYLWH, to explore the factors that impact their engagement in care across the continuum of care. The implications of this research are that the collected data extends the theoretical understanding of engagement in care across the continuum of care for Latino HIV-positive youth in HIV care settings. Thus, practitioners can better understand the facilitators and challenges for potentially disempowered youth to obtain regular and ongoing medical care and to engage in healthcare research. Practitioners also can better design, deliver, and engage the appropriate personnel

to empower LYLWH with the skills to improve engagement in care for this hard-to-reach population.

The actual perceptions and lived experience of LYLWH and their engagement in care have been neglected in the existing literature. The vast majority of studies and theories relating to YLWH have looked at the challenges experienced by YLWH, with very few studies examining the facilitators that promote engagement in care across the continuum of care. Understanding the experiences described through the perspective of providers yielded important information on the specific contexts with which these youth must contend to remain engaged in care. The qualitative focus of this study was on the perceptions of healthcare providers who actively engage in the provision of care for YLWH. Although U.S. physicians may have a biological, clinical view of illness and health based on a scientific medical paradigm, which may differ from their low-income Latino patients' health and illness views, their insights can provide guidance on necessary interventions to improve engagement in care (Penn, Kar, Kramer, Skinner, & Zambrana, 1995). In previous studies of supportive agents for PLWH, researchers identified healthcare providers as crucial sources of emotional, instrumental, and informational support (George et al., 2009; Hosek et al., 2008).

Understanding the provider's perspectives can be helpful in forming interventions that can reduce the socioecological challenges experienced by LYLWH and build on their assets and strengths. In addition, the care of YLWH requires that practitioners are aware of all their physiologic and psychosocial developmental issues. Researchers have not extensively explored the care of

LYLWH in the literature, although HIV-infected Latino youth represent a significant proportion of youth with HIV. This study reflects the agency and voice of the healthcare providers themselves, to add a reflective and personal meaning to the existing literature about engagement in care for YLWH.

Furthermore, service providers need to be involved from the beginning of intervention development to assist with the adaptation of services: to make them more accessible, acceptable, and youth friendly. Service providers often work in settings in which they may be unable to deliver risk-reduction or culturally appropriate care for these youth. Thus, understanding their perspectives will contribute significantly to the development and implementation of interventions or healthcare models of care for these youth of interest.

Focus on Theoretical Foundation

In the current study, I aimed to better understand providers' perspectives on the experiences of LYLWH by exploring the challenges, strengths, and needed areas of support/assistance associated with engagement in care across the continuum of care. The Hosek et al. (2008) model of psychosocial adjustment for newly diagnosed youth guided the data collection and analysis for this study. Hosek et al. (2008) developed this model of psychosocial adjustment with elements of Bronfenbrenner's (1986) ecological-systems theory of human development and the Kazak et al. (1995) social-ecological model of chronically ill children. In the Kazak et al. (1995) model, the microsystem extends to include the disease itself, placing demands on the individual and the family. The mesosystem considers the interactions between caregivers and hospitals as well as

the healthcare team. The exosystem primarily considers the parents' or caregivers' social networks and the extent to which the disease impacts those networks.

Finally, the macrosystem includes laws and policies that may directly impact the care and services available to children with pediatric illness.

I used the socioecological model developed by Hosek et al. (2008) to gain a broader understanding of the unique needs and supports of LYLWH. Hosek et al. (2008) identified similarities and differences in the experiences of adolescents and young adults living with HIV when compared to the Kazak et al. (1995) model of other chronically ill youth. For example, similar to the Kazak et al. (1995) model, the microsystem includes the disease itself because many youth experience the demands and stressors of the illness directly. In contrast, although the mesosystem in Kazak's model considers interactions between caregivers and hospitals, as well as the healthcare team, this consideration did not hold up as well in Hosek and colleagues' (2008) model because most youth were directly responsible for their disease management and did not have the traditional family caregivers who may be present with other chronic childhood illnesses. Other mesosystemic influences that appeared unique to this population included the school-peer and family-partner interactions and relationships.

For children with other chronic illness, the exosystem primarily assesses parents' or caregivers' social networks and the extent to which the disease impacts those networks (Kazak et al., 1995). For YLWH, the same type of influence on the social networks of the family members or caregivers was not as common because many families were unaware of the youth's HIV status.

Although participants did not speak about it directly, it is possible that once they disclosed their status to family or caregivers, they may have received some differential treatment in the extended family structure; several participants reported cases where previous relatives with HIV had been shunned by the family network. Another unique aspect of the exosystem for HIV-positive youth is their experience with media and the presence of misinformation and misconceptions surrounding the HIV disease and AIDS. Finally, compared to youth with other chronic illnesses, the macrosystem of YLWH may include increased experiences with stress on the societal level, due to the highly stigmatized nature of HIV. Additionally, whereas the macrosystem includes laws and policies that may directly impact the care and services available to children with pediatric illness, YLWH often perceived violation of these laws, particularly as they related to confidentiality and privacy.

A need exists to explore the unique challenges experienced by Latino LYLWH using a qualitative methodology, given that this subset of the population may experience unique socioecological differences in challenges and facilitators. For example, at the individual-level, acculturation is an important determinant of health. However, the degree to which acculturation is independent of other social determinants of health such as poverty and discrimination is a point of contention among researchers (Viruell-Fuentes, 2007). In addition, researchers must consider the influence of socioeconomic, socioecological, and other community factors on health status when discussing factors involving engagement in care for HIV health services (Organista et al., 2004).

Although the Hosek et al. (2008) socioecological framework provides unique insight on the facilitators and challenges of psychosocial adjustment for YLWH, the current study also incorporated the macrolevel influence of the healthcare system and the policy factors influencing engagement in HIV medical care. Mugavero et al. (2011) proposed a socioecological framework that described the salient healthcare system and policy factors that influence engagement in HIV medical care. Mugavero et al. (2011) used the socioecological perspective to outline the complex interplay of individual, relationship, community, healthcare system, and policy factors that influence the processes of engagement in care. This perspective is unique because it explores the specific challenges and facilitators to engagement in care in the U.S. healthcare system. Furthermore, given the magnitude of macro-level factors impacting LYLWH, a large proportion of YLWH may encounter policy-level challenges that are unique to this population. For example, with the passing of the ACA, approximately 22% of all Latino youth aged 16 to 25, who are undocumented immigrants, will be excluded from the health-exchange component and from Medicaid. Thus this dissertation also sought to incorporate the role of the macrolevel components of U.S. healthcare policies that influence engagement across the continuum of care (see Figure 3).

Research Questions

1. How do **individual-level factors or characteristics** (coping strategies, competencies, etc.) impact the continuum of care for LYLWH?
 - a. How do individual-level factors impact HIV testing?

- b. How do individual-level factors impact linkage to care?
 - c. How do individual-level factors impact receipt of HIV care?
 - d. How do individual-level factors impact retention in care?
 - e. How do individual-level factors impact sufficient use of ART?
2. How do **interpersonal-level factors** (relationships with parents, friends, and providers) impact the continuum of care for LYLWH?
- a. How do interpersonal-level factors impact HIV testing?
 - b. How do interpersonal-level factors impact linkage to care?
 - c. How do interpersonal-level factors impact receipt of HIV care?
 - d. How do interpersonal-level factors impact retention in care?
 - e. How do interpersonal-level factors impact sufficient use of ART?
3. How do **clinic-level factors** (setting-related factors) impact the continuum of care for LYLWH?
- a. How do clinic-level factors impact HIV testing?
 - b. How do clinic-level factors impact linkage to care?
 - c. How do clinic-level factors impact receipt of HIV care?
 - d. How do clinic-level factors impact retention in care?
 - e. How do clinic-level factors impact sufficient use of ART?
4. How do **policy-level factors** (HIV-specific and immigration policies) impact the continuum of care for LYLWH?
- a. How do policy-level factors impact HIV testing?
 - b. How do policy-level factors impact linkage to care?
 - c. How do policy-level factors impact receipt of HIV care?

- d. How do policy-level factors impact retention in care?
 - e. How do policy-level factors impact sufficient use of ART?
5. How do **sociocultural factors** (cultural values and stigma) impact the continuum of care for LYLWH?
- a. How do sociocultural factors impact HIV testing?
 - b. How do sociocultural factors impact linkage to care?
 - c. How do sociocultural factors impact receipt of HIV care?
 - d. How do sociocultural factors impact retention in care?
 - e. How do sociocultural factors impact sufficient use of ART?

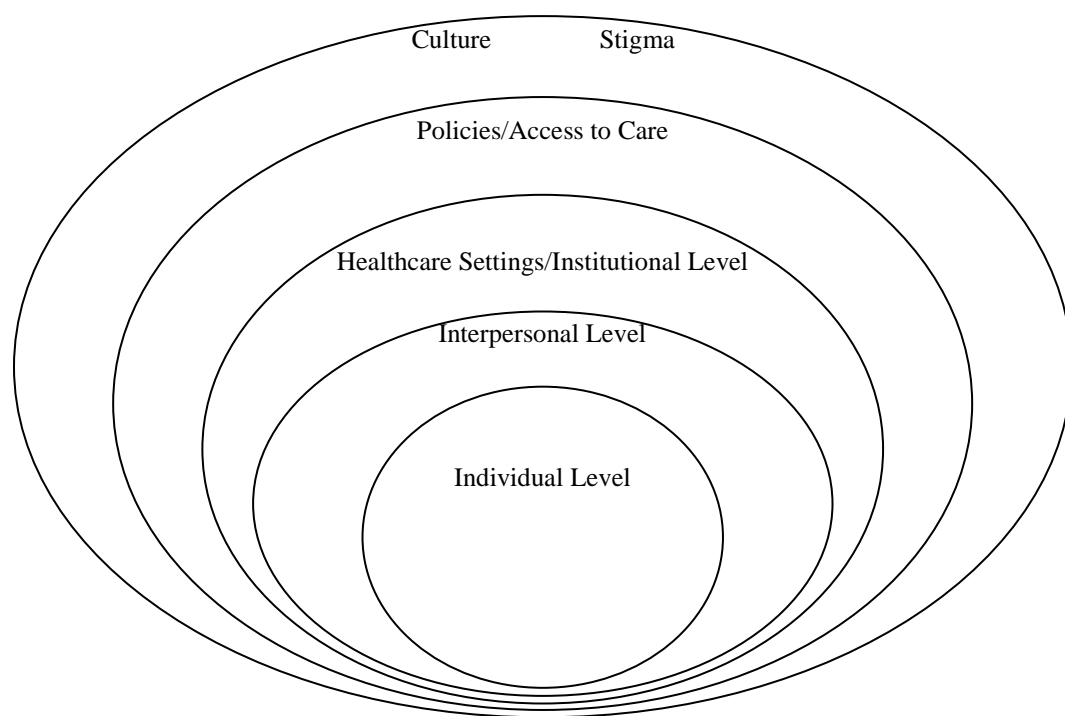


Figure 3. A socioecological framework exploring the complex interplay of individual, relationship, community, healthcare, and policy factors that influence the processes of engagement in care for Latino youth living with HIV.

CHAPTER II

METHOD

I implemented a qualitative methodology using a socioecological framework to explore the facilitators and challenges to engagement in care across the continuum of care for LYLWH. I recruited participants through a purposive sample of providers working with LYLWH. I conducted 26 provider interviews with clinical providers, mental health providers, case managers, or other direct care staff with at least 1 year of experience working with HIV-positive youth, attempting to interview at least one from each category of selected medical provider or community sites. All study participants provided oral informed consent to be screened for eligibility and to participate in the study.

Participants

A total of 26 providers participated in these interviews. Providers represented each of the selected provider categories from four geographical areas. Table 1 shows a descriptive overview of participant demographics. Participants in this study had an average of 10.46 ($SD = 9.69$) years working with YLWH. Participants worked in a variety of settings representing AIDS Serving Community-Based Organizations, LGBTQ Community-Based Centers, University-based Hospital Systems, and Local Government Hospital Systems. Participants worked in settings that served a range of youth. Some providers served two Latino youth whereas others, served 400 youth. See Table 1 for more descriptive overview of the population served by the participants. Participants discussed different motivations for working with LYLWH. Some providers

worked with Latino youth due to the geographical make up of the population they served, whereas, others explicitly chose to work with LYLWH due to their own personal connections with HIV, LGBTQ-concerns, or minority-identity.

Table 1

Demographic Characteristics of Providers

Geographic location	Service provider type			Total
	Clinical health care provider	Direct services/case manager	Mental health care provider	
Chicago	1	5	2	8
Los Angeles Area	1	4	2	7
Florida Area	1	3	1	5
New York City	4	1	1	6
Total	7	13	6	26

Sample-Size Justification

Sandelowski (1995) notes that “a common misconception about sampling in qualitative research is that numbers are unimportant in ensuring the adequacy of a sampling strategy,” however, I took the stance that justification for sample size should be determined by representativeness of the population of interest as noted below. Patton (2001) argues that no rules exist for sample size in qualitative inquiry; thus, for this dissertation study I conducted a total of 26 qualitative interviews. As Lincoln and Guba (1985) recommended, data collection may cease when saturation is reached. After conducting 22 interviews, I elicited relatively few new themes, but, data analysis continued to meet the suggested number of participants from each of the geographic areas.

I used a combination of purposive sampling strategies to obtain a variety of providers for this study. I used purposive-sampling recruitment strategy to invite healthcare providers with various degrees of experience working with LYLWH. I contacted healthcare providers such as clinic directors by e-mail and Listservs, asking them to circulate the study-information sheet to providers in their healthcare institutions or organizations. This circulated flier included some key information to help identify the interested providers' levels of comfort and experience with LYLWH. The goal of this purposive-sampling strategy for this study was to select those with these experiences and to provide a balanced representation of experiences with youth across the continuum of care. I focused on these three levels of healthcare service providers for this study:

1. *Medical care providers*: primary-care physicians, nurse practitioners, physician assistants, HIV-care residents, or HIV specialists
2. *Case managers*: social work case managers, case managers, or registered nurse case managers
3. *Mental health providers*: psychologists, social workers, or psychiatrists

In anticipation of potential difficulty in recruiting participants who represented all three of these levels, especially medical-care providers, I implemented specific recruitment efforts tailored to these hard to reach groups. This was a dedicated attempt to afford depth and scope to the emerging data and final analysis. After receiving Institutional Review Board (IRB) approval to recruit through multiple Listservs, I circulated Calls for Participation

announcements (flyers, e-mails) through professional Listservs such as the Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN), the Hispanic Health-Serving Professional Institutions Network (HSHPS), Society for Adolescent Health & Medicine Listerv, and the Community-Based Participatory Research Listserv (CBPR), among others. Although I approached other agencies to distribute the fliers, I included only those who agreed to share the flier.

The ATN is a cooperative agreement among 14 clinical sites, investigators, and the National Institutes of Health. Established in March of 2001, the ATN develops and implements a wide array of interventions aimed at improving the health and reducing the HIV risk of U.S. adolescents. Its mission includes community-based primary prevention, as well as clinical management of HIV-infected adolescents. The 14 clinical sites are geographically and demographically diverse to reflect the populations most impacted by the epidemic locally.

HSHPS is a member-based organization that currently consists of 22 medical schools and six schools of public health across the United States. HSHPS provides services such as training opportunities for students, educators, and professionals. HSHPS addresses the health disparities that exist in the Latino community and acts as the unifying voice in bringing about a solution to the Latino health crisis in the United States. The Society for Adolescent Health & Medicine is a multidisciplinary organization committed to improving the physical and psychosocial health and well-being of all adolescents through advocacy, clinical care, health promotion, health service delivery, professional development, and research. Finally, the CBPR e-mail community serves the growing network of

people involved and interested in CBPR and other types of community-academic research partnerships.

Recruitment Procedures

Audiotaped provider interviews (either by phone or face-to-face) took place with clinical providers, mental health providers, case managers, and other pertinent staff from each of the four sites (for a total target of 26 interviews). The selected geographic sites were Chicago, Los Angeles, Miami, and New York City. The geographic locations are located in states with the highest numbers of Latinos, which include California, Texas, Florida, New York, Arizona, Illinois, New Jersey, Colorado, New Mexico, and Georgia. Additionally, each of these regions has a disproportionate burden of HIV, inclusive of LYLWH.

Initially, I obtained a stratified-sampling list of all key expert medical personnel from each of the four geographic sites from publicly-available sites, such as the ATN website directory, or from selected community-based partners. The ATN coordination team then sent out the recruitment flier on my behalf to the selected providers. I then screened interested expert medical personnel to determine eligibility to participate in the study. To be eligible for this study, participants had to be professional staff including clinical providers, mental health providers, case managers at a medical center, or a community-based medical site providing HIV care services with a minimum of at least 1 year of experience working with LYLWH. Potential participants were ineligible for this study if they did not provide direct healthcare services to LYLWH. I conducted initial screening telephone calls with personnel from each site to introduce them to the

study and to confirm that these individuals had at least 1 year of experience working with YLWH, and determine which eligible staff members would be most appropriate for the interviews (based on direct clinical experience, availability, etc.). I was attentive during the recruitment process to maintain a somewhat balanced representation of the three provider categories (i.e., clinical provider, mental health provider, and case manager). Additionally, I was mindful during recruitment to contact providers who worked directly with monolingual or bilingual Spanish-speaking clients. I gave providers the option of having the interview conducted in Spanish or English, and indicated that I would conduct all Spanish interviews; however, I completed all interviews in English.

Any interested participant was given an opportunity to screen for eligibility for the study. Many interested providers recruited from the e-mail Listserv approach self-reported that they no longer provided direct services to LYLWH or were not in the selected geographical areas, according to their e-mail disclosure. For those that responded, using a purposive-sampling approach, I obtained at least one additional expert healthcare provider who works directly with women or works directly with monolingual Spanish-speaking LYLWH. This modified purposive respondent-driven sampling consisted of allowing participants to refer me to other participants through the distribution of information letters to at least three other healthcare providers who work with the desired population of interest. Respondent-driven sampling allowed an opportunity to access vulnerable and more impenetrable social groupings, or when proxies such as providers helped access these vulnerable populations. Respondent-driven sampling is ideal

for reaching a target population, particularly during the qualitative-interview phase (Hendricks, Blanken, & Adriaans, 1992). Researchers can use respondent-driven sampling to make inferences about a population of individuals who are difficult to reach through common methods, such as random-sampling methods (Faugier & Sergeant, 1997; Snijders, 1992). Although healthcare providers are not generally seen as vulnerable populations, providers who serve LYLWH may be harder to reach than providers serving the general population because these youth may not be receiving services in traditional healthcare settings. Because foreign-born residents use less funding from public insurers (such as Medicare and Medicaid), a pattern that is even more pronounced for undocumented immigrants, Latinos may be more likely to access services in atypical private medical settings. Atypical settings include individual-practice providers or community-based health centers. For this study, I employed a modified version of the respondent-driven sampling technique because the population of interest, in this case providers, are not the vulnerable population of interest. This means that this technique supplemented the purposive-sampling strategy used to reach other providers caring for LYLWH in other unique settings. This approach yielded providers from atypical settings such as small community-based organizations (CBOs) providing services in suburban areas where predominantly recent immigrant populations live.

Obtaining Consent

After obtaining IRB approval from DePaul University's Office of Research Service, I distributed the flier to potential participants (see Appendix B).

To determine eligibility, potential participants provided informed consent and answered a series of eligibility questions. After confirming the interested potential participant's eligibility, either I set up a meeting with the potential participant to obtain consent and conduct the interview for the study, or I proceeded to obtain consent and conduct the interview. I collected no personal information from these providers other than basic demographic and professional-experience data. Thus I obtained an exemption from the documented informed consent from the IRB under Code of Regulations, specifically, 45 CFR 46.117(c)(a):

An IRB may waive the requirement for the investigator to obtain a signed consent form for some or all of the subjects if it finds ... that the research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context. (part 45)

Because participants had no more than a minimal risk of harm, the interview collected information addressing professional opinion and knowledge and required no personally sensitive information.

I conducted all interviews in English. In addition, I verbally reviewed the consent form with participants prior to the initiation of the individual interview. The consent form stated that the individual interviews would be digitally recorded and transcribed. After reviewing the consent form, I obtained verbal informed consent from the participant. Prior to the scheduled interview call, I e-mailed a copy of the consent form and the semistructured interview guide or distributed them to participants for review during the call. The interview guide included a

definition and figure describing Gardner's continuum of HIV care for participants to review.

Data Collection

For this study, I elicited perceptions of providers serving Latino youth through individual-interview methodology (Creswell, 1998). I employed a semistructured interview guide to generate responses from participants. A semistructured interview guide steered the discussion as well as allowing flexibility in which topics and subjects of interest were explored. Therefore, the semistructured interview guide provided the ability to explore, probe, and ask questions that expanded and illuminated areas of interest or that required further exploration (Patton, 2001). The advantage of having an interview guide was the ability to share questions with healthcare providers before the interview, to maximize the limited time available with these individuals. It also allowed for making the interviews more systematic and comprehensive by delimiting the issues to be explored. In contrast to a structured interview guide, the semistructured interview guide also allowed for exploration of new subjects that were not covered in the framework of the interview guide. Thus, I was able to explore topics related to the subject at hand that were important to respondents and that I could incorporate into the analysis of the captured data.

Quality Assurance

After each interview, I conducted an immediate postinterview reflection to record detailed observations about the interview in the interviewer assessment (see Appendix C). I recorded when the interviews took place, under what

conditions, any immediate reflections pertinent to the content of interest, and any other information relevant to understanding the context for interpreting and making sense of the data (Patton, 2001). Conducting this reflection and elaboration was essential to ensure the data obtained are useful, reliable, and authentic. Therefore, these interviewer assessments took place immediately after the completion of the interview to allow for such reflections. I scheduled interviews so that sufficient time was available afterward for data clarification, elaboration, and evaluation. I wrote down ideas that emerged following an interview in the reflective journal and marked them as emergent field-based notes to review further during the data-analysis phase. For example, issues relevant to cultural values arose during the interviews, thus, I was able to note the distinctive tone in which providers discussed elements of *familialismo* and *respeto* when they talked about the challenges and facilitators that were unique to the LYLWH in their clinics.

I obtained all qualitative interview data via audiotaped individual interviews. Audiotapes were transcribed under my supervision by a professional transcription company. I reviewed a select number of audiotapes and transcripts, using a random spot-check system to ensure transcripts were accurate. I devised a random spot-check system whereby I reviewed 10% of all transcription work ($n = 3$ interviews) for accuracy (Sobo, 2009). Because the three randomly selected transcripts were accurate, I assumed the rest of the rest of the interviews would be accurate. This process eliminated the need to organize a full review, or to retranscribe. To improve accuracy of the data, I had interviews transcribed as they

were collected, rather than waiting until all data were collected. By listening to the tapes, I was able to have some flexibility in clarifying information, if necessary. Additionally, through this process, I identified any malfunctioning equipment or audio quality prior to conducting additional interviews. Doing so allowed me to paraphrase or take notes from memory if necessary (Sobo, 2009). I analyzed the data using matrices and networks to identify emerging themes, using paper and pencil as well as Excel software.

Ethical Considerations

Interviews impact people because of the directed, reflective process in which participants engage. Participants in this study may learn something about themselves and the views they hold toward LYLWH. Although the possibility existed that the interviews would induce transformative change for participants, it is hard to anticipate the impact these interviews had on the individuals being interviewed (Patton, 2001). Given that I did not ask service providers to consider their own experiences of living with HIV, it is unlikely that the service providers experienced emotional distress during these interviews.

Another important ethical consideration encompasses maintaining participants' confidentiality. One way to maintain confidentiality was to minimize collection of identifying information. I collected and stored demographic data and eligibility criteria in a safe location and assigned participants a random identification number; the completed forms will remain in locked cabinets. Data are stored in a locked database with only my access. Additionally, any contact information collected from participants is kept separately from

demographic and eligibility forms. I used contact information solely to contact participants during the study period for study-related purposes and to distribute the results booklet to participants who expressed interest. Additionally, I reminded participants that all patient-related information should remain confidential. If participants wished to provide illustrative cases of patients, I reminded them to use aliases to protect confidentiality.

Participants completed contact-information forms so I could contact them for participation in the qualitative interview, the interview to verify themes, or to distribute a published report on the findings. After completing the study interviews, participants received a \$20 Amazon gift e-card, sent to the participant's e-mail address.

Measures

Semistructured interview guide. I developed a semistructured interview guide for this study. Building on previous work that examined barriers and facilitators to engagement in care for YLWH (Hosek, Harper, Lemos, & Martinez, 2008), the interview protocol addressed social and ecological factors that may impact engagement in care across the continuum of care. The interviews included questions about providers' perspectives on the barriers and facilitators for engagement in care through a socioecological lens.

Peers reviewed this interview guide for any necessary changes in the appropriateness and clarity of the language. Other adjustments to the interview protocol included when the language was unclear or if there were any culturally relevant words that were more appropriate, once interviews started with the

targeted population. The university IRB approved the semistructured interview instrument. The full semistructured interview guide is attached as Appendix D.

The goal of the interview guide was to identify different factors impacting the continuum of care at the individual (intrapersonal), interpersonal (microsystem), community (exosystem), and sociocultural and policy (macrosystem) levels. Specific to each section of the continuum of care, I first asked participants to differentiate between the different stages across the continuum of care (i.e., awareness of HIV infection, receipt of some HIV care, entered but lost to follow-up, cyclical or intermittent user of HIV care, and fully engaged in care). The interview also covered the following primary topics:

- (a) assessing to what extent LYLWH received different levels of care,
- (b) descriptions of communities and areas where LYLWH live and work, as well as a description of challenges and struggles associated with HIV in these communities;
- (c) descriptions of personally useful approaches to improve engagement in care across the continuum of care for LYLWH.

I worked to obtain unique challenges across the continuum of care, but participants did not always differentiate specific challenges across the continuum of care, and tended to focus on the broader term of engagement in care, as in retention to medical services or medication. When participants differentiated across the continuum of care, I provide their responses. In general, providers discussed challenges across the continuum of care as a whole; therefore, I discussed specific factors along the continuum only as they were highlighted by the providers (i.e., HIV testing or HIV-medication adherence).

Reflective journal. The last form of data was maintaining a reflective journal and field notes. The journal allowed me to describe feelings about conducting research in this area of study. According to Morrow and Smith (2000), the use of a reflective journal adds rigor to qualitative inquiry, as the investigator is able to record reactions, assumptions, expectations, and biases about the research process.

CHAPTER III

ANALYSIS AND RESULTS

As I sought to learn about the range of ecological factors that influence engagement across the continuum of HIV care, I used a psychological phenomenological framework (Creswell et al., 2007; Patton, 2001).

Phenomenology specifically focuses on describing what a given group of participants have in common as they experience a particular phenomenon, and is an inductive analytic approach that allows the patterns, themes, and categories of analysis to emerge from the data (Creswell et al., 2007; Patton, 2001).

Phenomenology differs from other approaches to qualitative inquiry in that the primary focus is on identifying elements of a particular phenomenon by describing both *what* the phenomenon is and *how* a particular group of people experiences it (Creswell, 2012). Researchers then present these data through textual descriptions of the phenomena based on summaries of the experiences described by respondents. The composite descriptions offer an explanation of the underlying structure that exists across the respondents' experiences (Creswell et al., 2007).

This method allowed me to learn about the sociocultural behaviors, language, roles, and interactions in a culture-sharing group, and to focus on individual and shared experiences and meanings given to those experiences, as described by the providers working directly with LYLWH. Although my analysis relied predominantly on a phenomenological inductive approach that was guided by the data, I also employed aspects of deductive analysis that considered the

guiding developmental theoretical framework: the socioecological framework (Bronfenbrenner, 1986). This latter deductive influence took the form of the creation of initial a priori codes that represented the primary systems presented in Bronfenbrenner's (1986) socioecological framework, demonstrated to influence engagement in care for adolescents (i.e., individual, microsystem, exosystem, and macrosystem), as well as one additional code for individual characteristics (intrapersonal factors). Individual characteristics are typically situated at the core of the socioecological framework's nested interconnected systems. This combination of analytic strategies allowed me to conduct a phenomenological analysis that was directly guided by the data (inductive), but also was influenced by existing adolescent research and theory through the use of a priori codes based on Bronfenbrenner's socioecological framework (deductive).

Data coding and analysis was an iterative and interactive process. I identified consistent patterns in meaning, concepts, and themes across all interviews (Creswell et al., 2007; Miles & Huberman, 1994), and created data matrices as visual representations of the findings. I discussed coding and analytic activities during peer team meetings, and resolved discrepancies in coding and interpretation through consensus. Given the phenomenological framework that guided data collection and analysis, I took steps to assure that different voices were represented and that conceptual "outliers" were not silenced by the average or dominant perspective, by presenting all voiced themes instead of only those that were endorsed by a majority of participants (Creswell et al., 2007). Finally, I conducted a modified member-checking process with five providers who

participated in individual interviews. Member check-in respondents generally confirmed the findings reflected in their experiences working with LYLWH. One respondent commented that the cultural values surprised him in a way that he was not expecting because he was able to perceive how his experiences were influenced by specific Latino cultural values he had not previously encountered in his profession. The member checking process was helpful because it yielded a sense of completeness that the analysis process accurately captured the experiences of the providers in working with LYLWH. I reviewed the emerging themes and subthemes to confirm credibility of the findings and alignment with the lived experiences of an LYLWH.

Analysis

The data-analysis process for this study took place in four major stages. The first stage, essential to the psychological phenomenological approach to analysis, is bracketing or *epoche* (Creswell, 1998) of previous experiences that may bias researchers in the analysis and interpretation process. The second stage involves the development and organization of codes. These codes transform and organize the raw transcripts into analyzable pieces of text. The third stage is data comparison. In the data-comparison stage, cross-case analysis takes place. The fourth stage is the data-verification stage, in which researchers use techniques such as peer debriefing, member checking, and consensus coding to ascertain the credibility of research findings. Because of the interactive nature of qualitative data analysis, these stages are not necessarily discrete or sequential in nature; some stages, such as the peer debriefing and consensus coding, take place

throughout the implementation of the study. Thus, the information generated from one stage often informs or refines information from another. For example, feedback received during member checking could lead to the generation of new codes, which could lead to additional data comparison. A detailed description of each stage, its purpose, and an example of how it was used in the study follows.

Bracketing of Experiences

As mentioned previously, the central tenet of the phenomenological approach is to understand the meaning or essence of an experience from the perspective of those who are familiar with the experience. According to researchers, bracketing of experiences is what differentiates phenomenological approach from grounded theory (Crotty, 1996). This process allows researchers to examine their own prejudices in order to “bracket” or put them to one side throughout the research process. Bracketing can be done prior to the research, during the data collection and through the analysis of the interviews (Dowling, 2007). To be most effective, researchers must do their best to bracket any previous experiences related to the phenomenon under study. The purpose of this bracketing is to elucidate any internal biases held by researchers to guarantee that any themes discovered validly represent the data, rather than the researcher’s preconceived notions. Bracketing also presents an opportunity for researchers to engage in self-reflection and acknowledge personal reasons for pursuing the particular phenomenon under study. Lincoln and Guba (1985) suggested a similar approach, using a reflexive journal, as a way to ensure internal validity. To that end, I engaged in a reflection of my sociohistoric background, the development of

my views on racial/ethnic health disparities, and my motivation to pursue this line of inquiry.

I am a 33-year old, heterosexual Latina female. I grew up in a working-class family in Chicago with both of my parents until the age of 14, when my parents divorced and I subsequently lived with my mother. I have lived in Chicago in predominantly Latino and secondarily African American neighborhoods. My school environments from the beginning until my graduation from high school were overwhelmingly dominated by Latinos and African Americans of similar socioeconomic backgrounds attending inner-city public schools. This environment contrasted with my college environment at an urban public university in Chicago, where the setting was strikingly diverse. The differences between the expectations that my high school environment placed on its students and the expectations that the respective high school environments of many of my college peers placed on them was unexpected. My education at an urban public school, which often aimed to provide students with a technical education or a community college degree, and the adjustment to university-level expectations, also had a deep impact on my view of life as a Latina. I believe my experiences during these formative years in two very different cultural environments profoundly shaped my ideas on race, privilege, and oppression in the United States.

My parents' working-class experiences strongly influenced my perspectives on the role of health disparities in access to care. My parents were fortunate to work in companies that allowed them to provide the family with

healthcare insurance. I was unaware of the privilege of having access to healthcare insurance until I was in high school. For the most part, when we were hurt as young children, we were able to visit the doctor and able to have access to preventive care. In high school I realized that not all of my friends or peers had this luxury. Many of my peers often had to miss an entire day or days of school to wait in the waiting rooms of public hospitals or often shared stories of having sick parents who were unable to access healthcare services due to their immigration status or their fear of the medical system.

As I got older, I realized how much of a sacrifice it was for my parents to be able to provide us with healthcare insurance. As the rates of healthcare insurance escalated, many employers chose to pass the costs to their employees; now, my mother pays more than 50% of her gross monthly income to be able to afford healthcare insurance. It is with these personal experiences that I have come to realize that healthcare disparities exist in the U.S. healthcare system.

The roots of my interests in HIV among Latinos living with HIV stem from my strong belief in equality. I have been working in HIV research since 2004. Through this work, I have become aware of the socioecological forces that continue to drive the spread of the epidemic among youth, among African Americans, among Latinos, and among gay and bisexual men and women. Young gay and bisexual men aged 13–29 comprise less than 1% of the U.S. population but account for 27% of all new infections. Black young men especially contract AIDS, experiencing a shocking 48% increase in the number of new HIV infections between 2006 and 2009. Yet, despite these alarming infection rates, the

response to HIV/AIDS among young gay and bisexual men has not been proportionately adequate. Allocation of prevention, research, and other resources to focus on gay men overall, or young men in particular, has never equaled their proportion of the epidemic; in fact, it has been severely negligent. Negative experiences and other barriers to accessing healthcare have left too many young men, mostly of color, estranged from the services and institutions that could support healthy sexual, physical, and emotional development. Family rejection, social isolation, homophobia, and absent legal protections have perpetuated a cycle of homelessness, unemployment, substance use, and poverty among the most vulnerable.

My current research positions have allowed for me to better understand how structural inequalities and stigma continue to influence the spread of HIV in the United States. The African American and Latino youth I have worked with have shared stories about how they were infected or affected with HIV and described the impact that HIV has had on their lives and their intimate relationships. Many youth became infected because they did not feel free to be who they were and were not sufficiently empowered over their own sexuality, or simply were uneducated about sexual health issues or HIV. The stigma associated with HIV and being gay are also strong drivers that influence the silence around these issues. These sociocultural factors have impacted how young people decide to test, access, and remain engaged in HIV. I recognize inherent strengths and sources of resilience that youth possess and employ to overcome many of these inequalities. These inherent strengths and sources of resilience have allowed many

marginalized youth to thrive and overcome these challenges. In my research experience, I know that for some youth, receiving an HIV diagnoses was a wakeup call to make positive lifestyle changes. For others, the diagnosis presented an opportunity to recognize their worth as an individual and to appreciate their supportive others. Oftentimes, the relationships they have with their healthcare team are among the most stable and influential relationships they have formed.

Coding

Codes are labels for assigning units of meaning to pieces of data (Miles & Huberman, 1994). In this case, pieces of data were units of text from the interview transcripts. The process of coding was a four-step process consisting of (a) a complete reading of all of the transcribed interviews, (b) content analysis, (c) thematic analysis, and (d) coding refinement.

Reviewing Interviews

I read through all collected data once before attempting any coding. I conducted this complete reading of all interviews to ensure a general understanding of each participant's overall experience related to engagement in care across the continuum of care, as articulated in the interview, and as a first step in forming an understanding of the data as a whole. Additionally, I noted any initial impressions in the margins. This provided me with a familiarity of the depth and breadth of the data.

Content Analysis

The next step in the coding procedure was the content analysis. Content analysis involves coding all parts of the transcripts broadly to identify all ideas or concepts mentioned that are relevant to the research questions posed. All content related to a participant's conceptualizations of engagement in care across the continuum of care were coded (Miles & Huberman, 1994). After the completion of content analysis, I conducted analysis of relevant themes.

Thematic Analysis

Thematic analysis was the next step of the coding procedure. Thematic analysis involved searching across the data set to find repeated patterns of themes and concepts identified during the content-analysis procedure. Once completed, I assigned thematic codes that reflect specific phenomena related to the research questions (Miles & Huberman, 1994; Patton, 2001). Specifically regarding the study, as an example, a code of "BARRIERS/ACCESS" was assigned to barriers that providers described about accessing healthcare services.

Coding Refinement

The fourth step involved coding refinement. Coding refinement involves the identification of subsets of codes that may exist in themes identified through thematic analysis. Building on the previous example, the code "BARRIERS/ACCESS-males" was used to delineate barriers to access to care that participants believe are inappropriate for men specifically. Additionally, I identified any emergent codes that came from the data. I repeated this process

repeated until all relevant subthemes that emerged from the data were represented (Miles & Huberman, 1994).

Data Comparison

Once the thematic-analysis process was complete and codes were clarified through coding refinement, I conducted cross-case analysis. Essentially, this involved examining themes, patterns, and relationships across cases to see if these findings were consistent across members of the sample (Miles & Huberman, 1994). According to Miles and Huberman (1994), the two main reasons researchers conduct cross-case analyses are to enhance the generalizability of the findings and to enhance the understanding and explanation of the results. For example, if one of the results emerged that particular participants were adamant about low socioeconomic status being the primary barrier for engagement in care, cross-case analysis allowed the researcher to see if this was consistent across all of participants, or only a subset. If this finding emerged from only a few participants, I examined consistent patterns across that subset to see what underlying mechanisms could exist to account for this phenomenon.

Data Verification

As with all research, steps must be taken to ensure that findings are accurate representations of the data and that the story that emerges is, in fact, the one that best represents the experiences of participants. I established credibility of findings in the study in three main ways: through the processes of peer debriefing, member checking, and consensus coding.

Peer debriefing took place throughout the analysis process, from beginning to end. Peer debriefing involved the periodic relaying of information about study methodology, data, and results to a “disinterested” peer to minimize potential bias that can occur from being submerged in the data (Lincoln & Guba, 1985). The peer not only provided feedback, but also helped me explore neglected avenues of inquiry and alternative explanations for results, if warranted by the data. Additionally, the peer debriefer served as an understanding colleague with whom I could speak honestly about any frustrations regarding the process. For this study, members of my research team, all doctoral candidates experienced in qualitative research, served as peer debriefers. We discussed ongoing struggles related to this dissertation project as well as to their own research studies.

Consensus coding is the process by which experienced coders code transcripts separately, then come together to compare and contrast results. The coders address differences in coding through discussion and explanation of the rationale behind each coder’s particular analysis. This process continues until coders reach consensus. A modified process of consensus coding took place for this study: I gave members of the aforementioned research team pieces of transcript (instead of the entire transcript) that I coded and asked them to review and examine this text to see if they would code it in a similar way. This process allowed me to benefit from the elicitation of a variety of informed viewpoints during the coding and interpretation phase of analysis.

Lincoln and Guba (1985) argued that member checking is the most important technique for establishing credibility. Member checking is the process

by which researchers verify data interpretations and conclusions by informants as accurate representations of their realities and experiences. In this study I shared results of the analysis with a small number of individual participants to elicit feedback. I conducted member checking once analysis was complete, as this allowed informants to comment on large themes and main relationships.

Regarding member checking, I shared the results with at least one participant from each of the previously identified geographically stratified occupational categories, for a total of five participants who completed the member-checking process. Based on member checking agreement with the outline of the results, I had greater confidence that the results of the analysis accurately reflected the phenomenon under study; thus, I conducted no additional analysis.

Results

The results of this qualitative study should provide a description of providers' perspectives of facilitators and barriers for engagement in care across the continuum of HIV care of LYLWH. In addition results should elicit an understanding as to the impact that individual, interpersonal, and sociocultural factors have on engagement in care for these youth. Results from this study could serve to inform individual, group, and policy-level interventions that seek to promote engagement of care for LYLWH.

Case Summaries of Individual Participants

For the following section, I present a brief case summary for each participant with notable background information from the individual interviews. I randomly assigned participant-identification numbers such that each participant

had their own unique number, used to track the interviews throughout the study. As presented in the description of the analysis, I created holistic case summaries to orient the reader to the diversity of the sample for this study. In this section, participants are presented by their pseudonym, their professional title, as reported in the qualitative interview, and their city of residence/practice. With regard to their motivation for working with LYLWH, at the onset of the interview, I asked participants to describe their motivations for working with PLWH and for working with the Latino community. Participants provided insight on the number of LYLWH they served along with the gender breakdown and primary language dominance (English or Spanish) of their clients but they did not provide ethnic or generational status indicators of their client population. I describe these stories below in the case summaries. I present all demographic description, case summaries, and other professional information using the self-reported data and labels from respondents; thus, they may not match the previously established definitions provided in this dissertation. For example, providers who self-identified as Hispanic were given that label, and providers who used a variation of the terms gay, bisexual, or transgender (GBT) or LGBT were used as they provided. Furthermore, providers responded to questions about the population they served in percentages of their clients or actual client numbers and was reported accordingly. The term bilingual refers to one's ability to use both English and Spanish languages. Table 1 illustrates the demographic characteristics of the providers in this study.

01, Dr. Lawrence French, Adolescent Medicine, Miami

Lawrence is an adolescent/pediatric physician with over 30 years of experience practicing medicine at a university-based health system. His involvement in HIV/AIDS stemmed from “being in the right place at the right time” in the 1980s when HIV/AIDS became an increasingly common sexually transmitted infection among adolescents. His work with Latino youth is reflective of the demographic characteristics of Miami-Dade County and the population accessing the services at his clinical site. Currently, he serves 20 LYLWH, the majority of whom are bilingual.

02, Dr. Barry Michaels, Adolescent Medicine, Los Angeles

Barry is an adolescent medicine doctor with 27 years of clinical experience at a university-based health system. He started working in HIV/AIDS while completing a fellowship. His expertise in the field then solidified his career in HIV. He began working with Latino youth primarily as a result of the local demographics reflecting a Latino majority; thereby being a population that is “hard to avoid.” Currently, he serves approximately 60 to 70 LYLWH, of which only two are monolingual Spanish-speaking youth, 50% are bilingual, and the remainder are monolingual English-speaking youth.

03, Dr. Patricia Verde, Psychiatrist, Chicago

Patricia is a psychiatrist with 12 years of experience practicing medicine in a publicly-funded multidisciplinary institution. Her involvement in HIV/AIDS stemmed from her early exposure to people living with HIV while pursuing arts, theater and living in New York City. Her passion for HIV/AIDs was influenced

by witnessing firsthand the disenfranchised and stigmatized communities affected by HIV/AIDS in New York and Peru. Currently, she serves 10 LYLWH, the majority of whom are primarily bilingual clients.

04, Mr. Gabriel Busto, Case Manager, Los Angeles

Gabriel is a case manager for a small community-based organization. He became involved in the HIV/AIDS field after witnessing gay friends living and dying from HIV/AIDS. He then sought to make this his career work. Living in Los Angeles, he identifies as Latino and was thus motivated to work with his community. He currently works with approximately 10 young men, the majority of whom are bilingual speakers.

05, Mr. Luis Lopez, Case Manager, Chicago

Luis is a case manager working at a publicly funded institution. Currently, he serves about 10 LYLWH, eight of whom are Spanish-speaking monolingual LYLWH and the remainder are bilingual. The majority of his clients are young men, and he works with one young woman. He started in the HIV field as a volunteer because of the lack of services available for Latinos in the 1980s. He then moved toward working with Latino youth when he noticed a lack of services for youth. As a result, he built a career trying to engage Latino youth in HIV/AIDS education and awareness.

06, Dr. Henry Garcia, Psychologist, Chicago

Henry is a clinical psychologist working at publicly funded institution providing mental health services to PLWH. He became involved in HIV work because of the professional connections and his strong interest in working with

multidisciplinary teams. His work with LYLWH reflects the population that the institution serves. In addition, as a bilingual clinical psychologist, he has worked in the field for 8 years and has worked with approximately 400 Latino youth, of which 50 were strictly monolingual Spanish-language speaking.

07, Dr. Julio Medrano, Pediatrician, Chicago

Julio is a pediatrician working at a publicly-funded institution providing direct HIV care. He became involved in HIV work in the early 1990s when he was approached to work with a small group of youth who were hemophiliacs with HIV. Soon thereafter he began working with youth living with HIV who were behaviorally infected. As a bilingual provider, he has been eager to serve monolingual Spanish speaking youth because of the lack of services available for those youth. In addition, he aims to serve as a role model for inner city youth who may not have exposure to minority healthcare professionals. In the early 1990s he started his clinical practice with about 32 youth, which has now expanded to serve about 273 youth living with HIV.

08, Mr. Manny Perez, Medical and Supportive Case Manager, Chicago

Manny is a case manager of 3 years. He has been volunteering in HIV-related work but was not employed in the field until he found an HIV-related opportunity that allowed him to use his bilingual skills and maximize his ability to build rapport with people. Because of his work and his bilingual skills, he works primarily with many Latino youth. He currently works with five LYLWH, all young men, of whom two are monolingual Spanish-speaking and the remainder are bilingual LYLWH.

09, Ms. Gracie Rodriguez-Smith, Community Linkage Coordinator, Chicago

Gracie works as a community liaison, employed to bridge the Latino community with academic researchers and community partners. She also served as the national project director for a multisite study focused on testing HIV testing and linkage-to-care efforts for Latino youth aged 12–24. Her interest in working with Latino youth stems from her personal experience as a teenage mother along with experiencing the loss of a family member who presumably died from AIDS complications. She became frustrated at the lack of discussion around sex and sexuality in the Latino community and, thus, pursued a career in the HIV/AIDS field.

10, Ms. Lisa Woods, Nurse Practitioner, Bronx

Lisa is a nurse practitioner at an adolescent-specific university-based health clinic. She currently serves about 60 LYLWH, of which five are monolingual Spanish-speaking LYLWH, five are monolingual English-speaking LYLWH, and the remainder are bilingual-speaking LYLWH. Her work in HIV stems from her passion for social justice and work with the LGBTQ community, along with a passion for the dynamic and fascinating field of HIV. Her work with the Latino community stems from working in a community that is predominantly Latino and her enjoyment of working with a “fun” community.

11, Ms. Laura Martinez, Social Worker, Bronx

Laura is a trained social worker and the head of the peer-education program at an adolescent-focused HIV clinic. Her work in HIV stems from her personal motivation to work with others and her academic interest in sexuality.

Her work with the Latino community stems from her own roots as well as her upbringing in the Bronx community. Her clinic currently serves 130 youth living with HIV of whom, she estimates, 75% are of Latino descent. She estimates that the vast majority are monolingual English-speaking and very few are bilingual or monolingual Spanish-speaking LYLWH.

12. Ms. Janet Brady, Clinical Nurse, Bronx

Janet is a clinical research nurse at an adolescent program and service provider for sexually transmitted disease/HIV treatments for PLWH. She currently serves 20 LYLWH. Her work in HIV stems from her interest in LGBTQ health along with her own identification as a lesbian. Her work with the Latino community has been circumstantial, due to the clinic being in a predominantly Latino community.

13. Mr. Fabian Bruno, Community Outreach Worker, Chicago

Fabian is an HIV testing counselor/community outreach worker for an LGBT-specific community-based agency. His professional career in HIV-related services stemmed from a “kinda outta the blue” HIV testing visit, followed by his interest in applying to a posted job announcement that eventually led to his work in the HIV/AIDS field. As a native Spanish-speaking bilingual Latino, he posits he was hired to work there because of his language skills and the high-demand for bilingual healthcare professionals. He currently works directly with six LYLWH, four bilingual, one monolingual Spanish-speaker, and one monolingual English-speaker.

14. Mr. Pedro Perez, Health Educator, Chicago

Pedro is a health educator working primarily with GBT and queer men, conducting outreach or HIV risk-reduction education. He became interested in HIV work from his own personal experiences with HIV testing. Although he is Latino, his main motivation for working with Latino youth is to ensure that everyone gets an HIV test and education regardless of sex or sexual orientation. He serves 10 LYLWH, of whom one is primarily monolingual Spanish-speaking, four are bilingual, and the remainder are primarily English-speaking LYLWH.

15. Mr. Jose Torres, Social Worker, Bronx

Jose is a social worker. He became involved in the HIV/AIDS field as a PLWH for the past 8 years. He became involved with the Latino community because he identifies as Hispanic. He currently serves approximately 20 bilingual LYLWH.

16. Ms. Emily Bustamante, Clinical Researcher, Tampa/Bronx

Emily is a clinical researcher involved in the implementation of behavioral interventions with YLWH. She became involved in HIV/AIDS while completing a fellowship at an HIV/AIDS adolescent clinical site. She became passionate about working in this challenging field as a way to promote access to education. Her work with LYLWH stems from her own Latina background as well as interest in working with the Latino community and Latino youth. She currently works in a setting in which approximately 50% of YLWH are LYLWH, and of the LYLWH, 40% are monolingual Spanish-speaking, with slightly more young women than young men (55% and 45%, respectively).

17, Mr. Richard Rodriguez, Linkage-To-Care Counselor, Los Angeles

Richard works in research as a linkage-to-care counselor. When he was young, he started in the HIV/AIDS field as a volunteer for an empowerment group, motivated to work in the field as he identified a high need for HIV supportive services. Furthermore, he was motivated to work in the Latino community because of his own cultural connection and understanding of the intersectionality of culture and sexual orientation. He felt a strong connection specifically toward working with the Latino gay community, a group with which he closely identifies. He serves approximately 50 LYLWH, the majority of whom are bilingual and approximately four or five are monolingual English-speaking LYLWH. By gender, 40 are young men and the remainder of his clients are transgendered women.

18, Mr. Ismael Patricio, Case Manager, Los Angeles

Ismael is a case manager at an adolescent HIV/AIDS clinic. His current caseload includes nine LYLWH: seven are young men and 2 are young women. Of the LYLWH, six are bilingual and three are monolingual English speakers. His interest in HIV stems from his own self-identification as queer, working in the LGBTQ center, which then exposed him to the challenges these youth faced. His interest in working with Latino youth results from his own connection with the Latino community, resulting from his own “Brown identity.”

19, Dr. Alicia Fernandez, Infectious Disease Doctor, New York City

Alicia is an infectious-disease specialist and medical director of an adolescent AIDS program. Her interest in HIV/AIDS stemmed from her

infectious-disease fellowship training. Her cultural connection to her Dominican roots also motivated her to work binationally and maintain a close connection with her community through her HIV/AIDS service. Currently, she serves approximately 75 LYLWH. Approximately three are monolingual Spanish-speaking LYLWH and the remainder are bilingual LYLWH.

20. Mr. Gustavo Sanchez, Outreach/Prevention Program Manager, Los Angeles

Gustavo is a health outreach and prevention program manager at an AIDS service center. He became interested in the HIV/AIDS field while completing a master's thesis on MSM. His thesis also influenced his decision to work with Latino youth as many of the interviews were conducted with adolescents. Annually, he serves approximately 700 youth providing HIV testing services. The majority of HIV testing recipients are bilingual LYLWH with only a few being monolingual English-speaking LYLWH.

21. Mr. Byron Travis, Health Educator, Miami

Byron works in the field of prevention at a local LGBT community agency. He became involved in HIV prevention services as a former client of the agency and was hired because of his ability to relate to youth. His work with Latino youth stems from the demographics of Miami where there is a large Latino population. Because of his prevention work in HIV, annually, he provides services to approximately 900 Latino youth. He estimates approximately 100 of those are monolingual Spanish-speaking.

22, Ms. Wanda Martinez, Therapist, Los Angeles

Wanda is a therapist at an HIV clinic that offers comprehensive HIV services for clients. Her clinic serves approximately 300 clients, of whom 15% identify as Latino. Of those, a majority of clients are bilingual-speaking youth, and only about 6% of the youth are either monolingual English (3%) or Spanish speakers (3%). The majority of the LYLWH are young men; only one is a young woman. She initially became involved in HIV because of her experience working with survivors of sexual assault and domestic violence. She saw the overlapping experiences of trauma among PLWH and remained in that field after her internship experience.

23, Mr. Sam Frank, Executive Director/Psychologist, Miami

Sam is an executive director for a Latino-focused LGBT CBO. The majority of services are impromptu services or social-planning activities for youth living with as well as those who are not living with HIV. His CBO population is primarily cisgender men and transgender men and women. He became interested in HIV work in the mid-1990s because of personal experiences related to knowing others with HIV. His interest in working with the Latino community stems from his focus on working with disenfranchised populations and the need to address services for LGBT people in the Latino community. His organization serves approximately 200 Latino youth across the spectrum of the continuum of HIV care. He considers 20% of his Latino youths to be monolingual Spanish-speakers, 30% to be monolingual English-speakers, and the remainder to be bilingual youth.

24, Dr. Cristina Ramirez, Infectious Disease Specialist, Florida

Cristina is an infectious-disease specialist and director of a tuberculosis clinic. She started working in HIV after working in a laboratory setting, then expanding into HIV clinical care, and has been involved in that field for the past 10 years. Although she is bilingual, her work with the Latino community results from her own primary Spanish-language dominant skill set coupled with working in a community that reflects a large Latino population. Although her clientele is not necessarily Spanish-language dominant, many prefer Spanish rather than English during the clinic visit. In general, she currently serves 20 LYLWH, of whom only two are Spanish-language monolingual, approximately four are English-language monolingual, and the remainder are bilingual. Her clinic population is about evenly divided between young men and young women.

25, Mr. Mark Brown, LTC counselor, Miami

Mark is a Linkage-to-Care (LTC) and HIV-testing counselor at a community-based organization. After being a recipient of the services at the CBO, he was offered a position providing HIV-testing services. His work with Latino youth is reflective of the demographic characteristics of the Miami epidemic primarily affecting Latino and Black LGBT youth. He estimated that in a year he reaches approximately 300 Latino youth; of those, approximately 40 are LYLWH. Among the LYLWH, all are either monolingual English-speaking or bilingual and all are young men.

26. Ms. Myra Smith, Health Educator, Miami

Ms. Myra Smith is a health educator at a community-based organization in Miami. As a young person, she enjoys working with other youth to educate them on HIV prevention. She works with Latino youth primarily because they are part of the client population her organization serves. All her clients are English-speaking young men and women.

Summary of Qualitative Data Analysis

The results regarding multiple ecological factors that influenced participants' engagement across the continuum of HIV are presented here. Given theoretical grounding in Bronfenbrenner's (1986) socioecological framework, I organized the findings regarding factors impacting the continuum of HIV into thematic areas related to the following systems of influence: intrapersonal (individual) factors, interpersonal (microsystem) factors, community (exosystem) factors, and sociocultural/policy (macrosystem) factors. In the following section, I present themes using these specific socioecological levels, and describe themes that emerged across the continuum of care (i.e., becoming aware of HIV infection, receiving some HIV care, entering HIV care but being lost to follow-up, using HIV care cyclically or intermittently, and being fully engaged in HIV care). I provide the general themes in Figure 4. I discuss general themes and subthemes in greater detail in the last section of results, where I provide excerpts of qualitative interview text to illustrate overarching themes. As with Bronfenbrenner's (1986) socioecological framework, I view the various systemic influences as occurring through bidirectional interactional processes between individuals and their

environments, and recognize the interconnectedness of each system and its consequent interaction with the individual. Thus, although I categorized some specific factors into a particular system in the model, they also may assert their influence through interactions with other factors in connected systems.

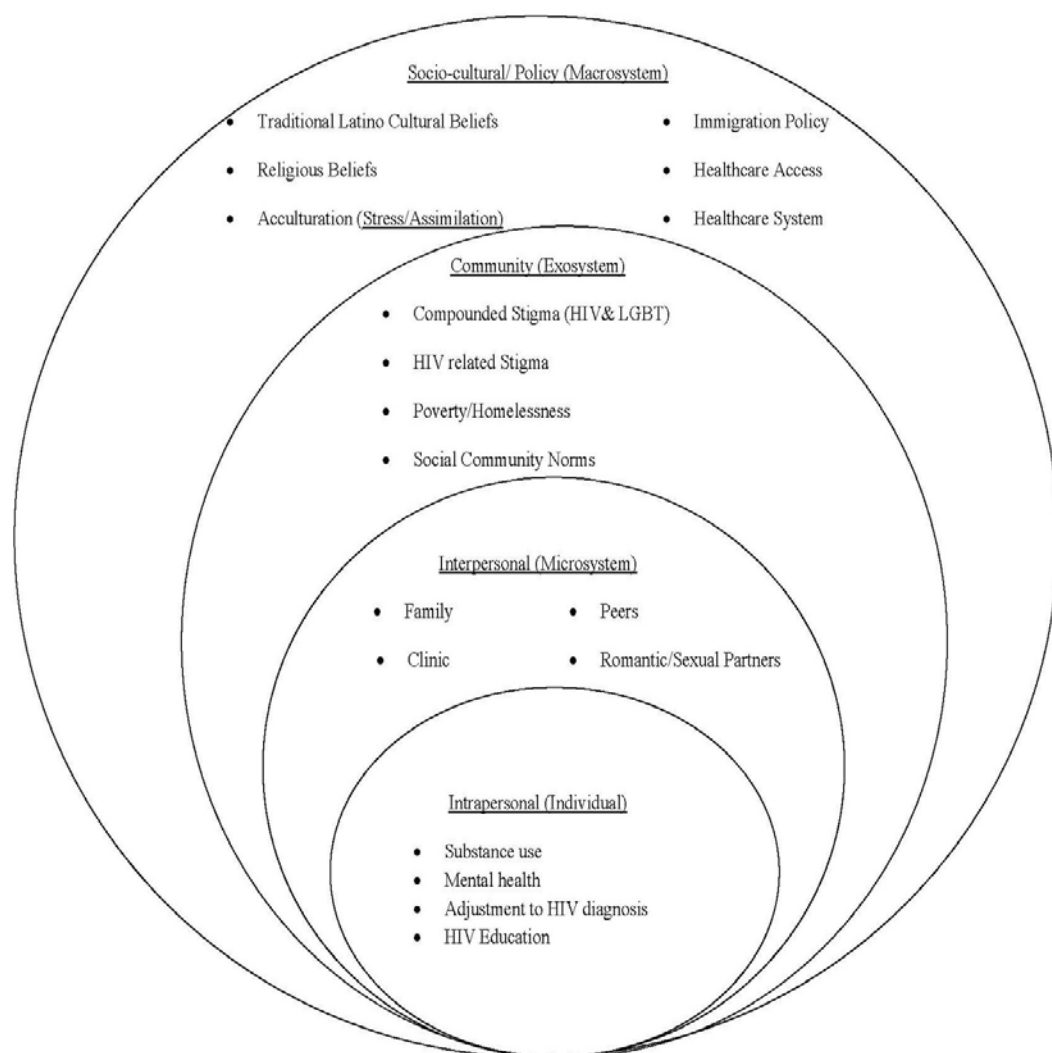


Figure 4. General themes for qualitative interview analysis.

Although I asked providers to identify challenges specific to LYLWH, providers often discussed challenges relevant to general YLWH, not just Latino youth. If providers highlighted specific challenges or nuanced differences for LYLWH, then I present these in the text as such. Thus, throughout the results section, I make reference to Latino/Hispanic and specific ethnic diversity, where specified. I used these different terms to signify Latino as a shared identity. In addition, I use the term *undocumented* to refer to people who are living in the United States without U.S. documentation such as U.S. citizenship, a green card, or a valid visa. I did not ask participants to describe the ethnic background of their Latino population; therefore, I did not examine ethnic differences in this study. However, the geographic selection of the populations for this study represent a variety of Latino subpopulations; thus, I explored differences pertaining to regions the providers serve to determine any nuanced differences by region, when appropriate. Finally, I used different terms to signify LGBTQ as a shared identity for nonheterosexual individuals, which is akin to the “gay community,” as described by sexual-orientation identity-development theories (Cass, 1989). The term GBT, however, describes the specific sexual-orientation identity of the participant, which may consist of a different gay community than encapsulated in LGBTQ or gay community. As a result, I use the terms differentially to refer to the larger gay community (LGBTQ) and the community and identity specific to the participant (GBT). I did not use the term lesbian in the description of individual participants, as none of the providers described issues specifically ascribed to lesbian or bisexual women. Issues addressed by providers along the

LGBT identity spectrum were specific to cisgender men and transgender women living with HIV.

Individual (Intrapersonal)

Providers discussed multiple individual-level factors or characteristics that impact engagement in care for LYLWH. Individual-level factors generally refer to the biological and personal-history factors that influence HIV acquisition and disease progression, including such factors as age, education, income, substance use, HIV knowledge, perceptions of risk and use of healthcare services (Mugavero et al., 2011; Poundstone et al., 2004). For this study, providers discussed a myriad of factors that impact the continuum of care for YLWH, specific to adolescent issues. Themes specific to LYLWH included mental health issues, substance use, adjustment to HIV diagnosis, and HIV education.

Mental health. Mental health issues such as psychological disorders including depression, anxiety, or trauma make youth vulnerable to leaving care for services across the continuum of care, including adherence to medications. Two primary concerns emerged regarding mental health by providers: the impact of psychological disorders on functioning and the effect of untreated trauma resulting from sexual abuse.

Impact of psychological disorders on functioning. Providers asserted that untreated mental health issues or disorders posed a significant challenge to maintaining engagement in care for many reasons, including the impact of the symptoms of the psychological disorder on the youth's life, because these symptoms impair functioning. Thus, these symptoms may result in youth not

prioritizing their health when addressing untreated or unaddressed mental health issues or other related concerns. In particular, mood and anxiety disorders seem to affect engagement across the continuum of care, as youth are less likely to prioritize their sexual or physical health if the mental health issues they are experiencing include suicidal ideation, guilt, self-loathing, persistent worry, or tension. They may also choose to avoid getting HIV care because attending to their diagnosis triggers or reinforces these symptoms. Furthermore, they may choose to stop taking HIV medications because the medications serve as a reminder of their life-long HIV diagnosis. Although a large percentage of YLWH experience psychological disorders, providers described the rate of untreated psychological disorders, particularly depression, in their clinical settings, as seemingly higher among Latinos compared to other youth they treated in their clinics.

Now a lot of Latino youth don't have those issues [mental health, substance use, internalized homophobia] but the percentage that do, you know, that, at least for those that are HIV infected, is reasonably large and does impact, you know obviously, you know, ah, somebody who does get an HIV positive test, those same factors may make it – them resistant to wanting to access care. They may access care and not continue in care, they may become not adherent, and you know, they're all interrelated to those, you know, individual factors. I think the challenge is, of these kind of more individual level factors. ... So if you have

depression, or you have a history of trauma or abuse it's so much harder accessing [services] at all levels. (Dr. Barry Michaels)

Well maybe mental health. I think they're dealing with a lot of depression or anxiety. They've had emotional problems, if they had psychiatric care before they even became positive. And this just adds on top of it. So I think a lot of that can factor in. (Mr. Gabriel Gusto)

Effects of untreated trauma. Another psychological distress providers discussed was untreated trauma from experiencing sexual abuse or experiencing other traumatic events. These untreated mental health and psychological trauma-related issues make it particularly difficult for youth to consider HIV testing and prevention strategies. Society attaches stigma to sexual abuse, particularly if it stems from family members and if it occurs during childhood, so youth are not able to properly seek out services. One provider described this as an “ugly” epidemic that is not going to get the attention it deserves in our society because it makes people uncomfortable. Oftentimes, this discomfort results in youth trying to cope with these psychological traumas without any external or professional assistance. In addition, providers discussed how, at times, young men can become confused, especially as they try to address how the sexual abuse relates to their sexual orientation.

I'm not going to [say] that it's not, and especially I would say that one particular cycle that is particularly bad in Hispanic culture is childhood sexual abuse. And when there has been childhood sexual abuse, like in the

father or the uncle, and it's been a homosexual sexual abuse, it just ends up creating a whole dynamic of confusion. (Dr. Patricia Verde)

Actually all of those four experienced a lot of trauma in their childhood. I would guess that the mental health stuff came into play first, and then it started with substances and then they were diagnosed with HIV. So, yeah I guess that's the order of things. (Mr. Ismael Patricio)

Substance use. Substance use among Latino youth was commonly reported by providers. Perhaps, as a result of these untreated psychological disorders or psychological traumas, providers also observed that Latino youth report heavier substance use than other racial/ethnic patients in their clinics. In addition, providers asserted that Latinos tend to report more varied substance use that extends beyond the typical alcohol or marijuana use reported among other youth at their clinics. Latino youth were more often involved in actively using other street drugs or hard drugs such as cocaine, heroin, ecstasy, and methamphetamines. These drugs often become significant barriers to accessing HIV care because, according to providers, the priorities for youth then shift from self-care to “focusing on their immediate needs and not the long-term HIV needs.” Many providers hypothesized that youth often turn to these drugs to cope with underlying conditions such as depression, isolation, or feelings of not belonging. In addition, for many providers the issue of substance abuse was often confounded with other issues such as untreated mental health issues, acculturation stress, or homelessness.

It could be a coping mechanism (for HIV) but it usually—the substance use precedes their HIV diagnosis. So it might a coping mechanism to adjust for being Latino in a majority culture, not being able to fit in, suffering from depression perhaps, or living in poverty, having dropped out of school—which is another issue for our youth. (Dr. Julio Medrano)

But also a lot of it is their sobriety—So it's the alcohol, it's the, it's the pot, and the other recreational drugs that they are—most of them are not continually but occasionally, go into —we have a couple that are constant usage but there some that are occasionally fall back to old behaviors ... and then they fall out of care. They don't come to their appointments, they don't answer their phone at all. You know, all those kinds of stuff. (Mr. Gabriel Gusto)

Adjustment to HIV diagnosis. Providers also cited youths' adjustment to their HIV diagnosis as an important contributor to ongoing engagement to care for LYLWH. Adjustment to an HIV diagnosis means the ability to integrate their diagnosis into their life specifically in how they cope with the illness and how they make meaning of their illness. Making meaning can include the degree to which they acknowledge their diagnosis. Providers discussed challenges with adjustment to HIV diagnosis and psychosocial adjustment as a facilitator for engagement in care.

Challenges with adjustment to HIV diagnosis. Providers acknowledged that many LYLWH struggle to accept their HIV status. The adjustment

experience for LYLWH appears to be affected by multiple factors that are socioculturally and developmentally influenced. Providers described specific barriers to psychosocial adjustment to their HIV diagnosis such as internalized homophobia among GBT youth, mental health issues, or maintaining secrecy about their HIV status. For example, Richard stated “I guess another challenge and its pretty knowledgeable is homophobia and self-hatred” when discussing barriers to engagement in care. The overwhelming majority of providers recognized that internalized homophobia among gay and bisexual youth often interfered with their engagement in care because HIV care created a reminder of their gay and bisexual identity, with which they had not yet come fully to terms. Thus, Latino gay and bisexual youth living with HIV avoid care or fall out of care.

Challenges with psychosocial adjustment to an HIV diagnosis can produce significant barriers to engagement across the continuum of care. LYLWH may experience a period of denial of their HIV status that prevents them from seeking or staying in care. For YLWH, acknowledging their HIV status forces them to deal with mortality, their sexuality, and their concerns about financial stability. Providers discussed that young women living with HIV tend to mourn their HIV-negative life, focusing instead on their inability to maintain “normal” relationships or have children, which, in turn, causes greater difficulty in adjusting to their HIV diagnosis. One factor that seemed specific to young Latina women is a heightened sense of shame about having acquired HIV. Thus, oftentimes, LYLWH who have not successfully adjusted to their HIV diagnosis focus on avoidant-focused coping mechanisms such as avoiding HIV care, substance abuse,

and isolating themselves from social support to avoid rejection. Avoidance coping can inhibit adjustment to diagnosis because as one provider noted, “They don’t develop an HIV identity.”

I think it is stigma. And I think for youth there’s an element of, “It’s not going to happen to me. Like I’m not gonna get sick,” or “I don’t really have HIV” or “I know I did that test, and it’s really not positive.” This kind of magical thinking slash, you know, lack of — the invincibility kind of thing. (Ms. Lisa Woods)

It’s a huge factor in heterosexual women. Heterosexual—now we don’t see many Latina heterosexual women with HIV in our particular community—but we see some. But in that community, that whole shame factor is huge and often leads to nonadherence to care, and nonadherence to medication, and then you know —lots of depression, you know, and sometimes substance abuse, but less so—More depression and just withdrawal from life and care. (Dr. Barry Michaels)

Psychosocial adjustment as a facilitator for engagement in care.

Psychosocial adjustment serves as an important facilitator for engagement in care across the continuum of care for LYLWH. According to providers, Latino youth who successfully adjust to their HIV diagnosis better engage in care across the continuum. Specifically, they are more adherent to their medical visits and to their medications. Youth who are able to successfully adjust to their HIV diagnosis have a healthy sense of their own identity, have a profound spiritual connection,

and demonstrate general resilience in their own lives. Having a healthy sense of their own identity means that these youth are able to integrate HIV into their life without feeling that HIV defines them overall. As one case manager stated, “They’ve come to terms (with their status), and they know it’s not going to be easy, but they’re willing to like — tackle it on.” In general, this was a reference to these youth taking the necessary steps to attend their medical appointments or adhere to their medications.

Youth who have profound spiritual connections are better able to integrate meaning into their diagnosis rather than placing guilt or blame on themselves for acquiring HIV, which can result in Latino youth taking a proactive stance toward engaging in their HIV care. Dr. Medrano noted, “There’s a sense of spiritualism among these youths, a sense of religiosity that also helps them in dealing with their illness” A nurse practitioner noted, “I’ve think I’ve seen specifically with Latino youth, I think faith does play a part and again for some people that gets in the way, and for some that’s stronger—spirituality, I guess.” One psychiatrist noted religion provided youth with a sense of purpose “and this could be somewhat Catholic is that you have to sort of do God’s work.”

Furthermore, providers also described a general sense of resilience among most youth who have been successful in adjusting to their diagnosis despite the multiple challenges they face in their lives. Providers described this resilience as stemming from facing life challenges successfully and seeing HIV as another one of these challenges to confront. Latino youth who are resilient tend to have an optimistic outlook about being able to manage the disease, and therefore are more

willing to engage in care on a routine basis, as well as take their medications on a regular basis. “They are resilient. I think that resilience comes in many times from those other hurdles that they have to encounter and live through make them very resilience in due time, do what they need to do” (Dr. Alicia Fernandez).

I would venture to say that a lot of these young guys, they have better problem-solving skills than we think. They’re able to survive. And though we see their intermittent adherence to treatment or intermittent engagement as failures ... from a medical standpoint, looking at it from a survival standpoint, it’s pretty extraordinary. It really is. The fact that they can manage to, you know ... having no money, having no this ... having no support, they’re able to get somewhere, either through school or find a safe place to live. (Dr. Patricia Verde)

HIV education. Providers discussed the importance of HIV education as facilitators who promote continued engagement across the continuum of care. Providers acknowledged the importance of general education and its impact on engagement in care and, in particular, to adherence to HIV medication. First, providers acknowledged that having a base level of general education allows YLWH to understand the importance of medication and the HIV lifecycle. Secondly, the receipt and comprehension of HIV education seems to be relevant to ensure participant commitment to ongoing and regular HIV care.

According to providers, with education, YLWH are better able to understand and evaluate HIV-related information and apply it to their lives. They are better able to grasp the concepts of what it means to have a diagnosis that is

not symptomatic. In addition, YLWH who have acquired critical-thinking skills are also able to be active problem solvers in overcoming challenges in their adherence to appointments or medications. For example, if they are having trouble with transportation, they can talk to their case manager and try to come up with a solution for the transportation issue. However, providers stated that many LYLWH do not have the basic general knowledge to understand or make sense of their HIV infection. “And they’re not sassy about HIV information. I mean they might know some stuff but some of it’s like they learn it from other people. So some is not” (Mr. Luis Lopez).

So I think those, that’s really the biggest things that I see, ah ... and just the education, education around HIV and what does it mean. So they’re less likely, um, if they don’t really know about HIV, they’re less likely to seek services, because they don’t know where, you know, they don’t know what resources are available. (Ms. Wanda Martinez)

Interpersonal (Microsystem)

Providers discussed multiple interpersonal factors that can affect engagement in care for LYLWH. Interpersonal factors refer to those relationships in the immediate environment in which the individual is operating. The relationships individuals hold with their families, peers, and romantic or sexual partners can influence their engagement across the continuum of care for HIV. A unique relationship specific to YLWH is their relationship with their healthcare clinics, inclusive of the healthcare providers, nurse practitioners, psychologists, and front-line staff members such as the receptionist or medical assistants.

Providers offered insight on how these relationships can be protective or pose challenges when considering engagement in care for LYLWH. Specifically, providers discussed the systematic impacts of family, providers, and the one-on-one relationships with peers and romantic or sexual partners.

Family. The most prominent microsystem for LYLWH was that of birth family and the relationships between members of their families. Family dynamics and experiences played an important role in determining the degree of engagement in care for LYLWH. Family-related stressors and facilitators include disclosure of HIV status, family reactions to youth's sexuality, and family involvement in their clinical care.

Disclosure of HIV status. An underlying sense of tension stemmed from youth struggling with disclosing to their family members. Disclosure to family members often created a sense of despair or anxiety for youth as they thought about the possible consequences stemming from disclosing their HIV status to their family members. Often youth discussed their fear of rejection, allegiance to family members, and concerns about family members' reactions as hindrances to disclosing to family members. According to providers, LYLWH who did not disclose to family members struggled with adherence to medications or care more than those who had disclosed to at least one member.

Well, the challenges is that many times they don't want their parents to know ... and one of the reasons are that they're not, some of the parents are not involved in their lives. Or their separated: some are in Mexico ...

or some of them are turned away because of their sexual orientation. (Mr. Luis Lopez)

I don't think so. It's, yeah, it's something that happens a lot. I think a really honest and close relationship with a parental figure ... that's something that often gets in the way. Um, because they feel like they have to keep it a secret from their parents specially. (Dr. Henry Garcia)

Family reactions to youth's sexuality. Rejection or tension surrounding the youth's sexuality was a significant barrier for LYLWH. As youth were struggling with their own sexuality, if parents were aware of their youth's sexuality, youth were also addressing their family's reaction to their sexuality. Thus, having parents who did not accept their youth's sexual orientation resulted in the youth perceiving themselves as "dirty." In families where these tensions were present, providers described trying to engage youth as challenging. Many providers believed that when youth were not accepted at home due to their sexual orientation, they did not prioritize their own health care. Although it was not common that these youth became homeless, they were living in psychologically straining households but often did not see leaving the household as an option, due to a sense of allegiance to their family. Many of these youth felt trapped, living in a home where their sexual orientation was not completely accepted or supported. Dr. French offered, "Like, maybe their Anglo, is what the non-Hispanic Whites are called and the various Black communities sometimes it seems like it's a little easier or the youth to acknowledge their sexuality and be ok in their families."

Or they don't want to admit that their child has HIV/AIDS or they don't want to admit that their child is gay or they have a problem with it and those cases it's really hard to engage the youth in care because they you know just don't have the family support. (Ms. Janet Brady)

One of the specific relationship dynamics that providers described with Latino families of LYLWH is the provision of conditional support for their HIV diagnosis, particularly for GBT youth. Conditional support involves parents or family members supporting LYLWH through their HIV diagnosis, care, and treatment, despite not fully accepting their son's GBT identity. Providers acknowledged that even provision of conditional family support was helpful to maintain engagement in care for LYLWH. Dr. French said, "That's huge, because then it's not a secret from the parents, and then the parents' relationship with their child around HIV is more just the health aspect, rather than also including the, um, social aspect of sexuality."

That's a family member that supports them, even if they don't, I see this the most in Latino youth—even if they don't—even if their mom is so not okay with the fact that they're gay. They're—they love their son and they want to make sure their son gets absolutely the best medical care for their HIV possible you know, then that makes a huge difference. I definitely see that in the Latino youth more than in the other youth that we serve. (Ms. Lisa Woods)

Family involvement in their clinical care. One significant facilitator was that when families were involved in the care, adherence to medication and care improved for the LYLWH. After youth disclosed to family members, engaging

family members as part of the healthcare team was generally beneficial for providers and for LYLWH. Once youth link to care, family members can serve as supportive others to assist LYLWH to remain engaged in their care. Providers can communicate concerns about adherence or general health to the family members, with permission of the youth, to promote supportive environments at home.

You know, you know, I would just say that specific within the Latino community, there is a very strong and resilient connection to family members and often that actually is a strength. You know, you know, obviously the two main communities are African American and Latino in terms who we serve and who is impacted by HIV. And, often the ... that familial side is actually a strength. Again it's not universal and not all, you know, African American kids don't have supportive families, but just in general, you know, that's a cultural factor, that's actually helpful for our Latino youth. (Dr. Barry Michaels)

You know one ... hands down, one of the facilitators are support, support, support. I mean if they come from a family that they have been able to say they're gay and were accepted, I mean even if it's just one sibling, or one uncle or one aunt, or whomever. I mean it is just extraordinary how just having one family member on your team can just be a total ... it's just a game changer. (Dr. Patricia Verde)

Clinic. Another prominent microsystem for LYLWH pertained to the relationship dynamics youth maintained with healthcare staff members at the clinics. In this clinic system, many factors contributed to youth's ongoing

engagement in care. Specifically, providers discussed the role of provider–patient communication style, trust, and attention to meeting the needs of LYLWH.

Provider–patient communication style. Providers also discussed the critical importance of provider–patient communication. Providers in this study defined important providers as “somebody from the team that can establish a connection with the youth and help them through the process.” Because this interaction with the healthcare team is so important, one dynamic that inhibits engagement in care is provider–patient communication style. Provider–patient communication style can inhibit engagement when working with YLWH, not just LYLWH, as the manner in which providers engage youth can negatively affect their desire to come to their appointments. In particular, providers who do not engage with their patients, typically by adopting a hierarchical approach with their clients, will have a harder time with retention over time. According to participant providers, providers who do not listen to their patients, make patients feel rushed, or do not ensure that participant feels heard can impact retention over time. In addition, using a hierarchical approach can be intimidating for patients. Thus patients may not freely express challenges with their adherence to medications or medical appointments. If youth do not feel heard, they may withdraw from care because they do not feel appreciated or understood.

Another thing to touch on is front line staff is also ridiculously important.

You know, that’s the first person they come in contact with. That’s the first person in the waiting room they come in contact with. If it’s unfriendly , if it’s not youth friendly, if it’s not information in Spanish and

English of people who don't speak English, all of these things are a big turn off to a young people. They say, "well they are not welcoming me so it's like why should I be here?" (Mr. Jose Torres)

Alternatively, providers highlighted some important elements of supportive provider-patient communication. Most importantly, staff members must demonstrate genuine interest in the youth in order to form relationships with them. Generally, providers recommended having bilingual and diverse staff members facilitate communication rather than having to rely on translators or family members. Another important strategy is taking time to know participants and to make them feel welcome.

Inviting them to tell their stories ... in a nonjudgmental way and very honest and matter of fact setting and approach, you know where you can talk one to one. Obviously, if they're dominant in one language, Spanish say, then speaking the language is a big help. (Dr. Henry Garcia)

We have long-term service providers. ... I think the personal experience for most youth would be like, "Oh, this is nice. If I need somebody who speaks Spanish," we have that, you know, access. "If I want somebody, you know, who is gay, GLBT" ... we have lots of staff here who are GLBT who they can connect with, so I think we've really try to provide a really nice, kind of, youth-friendly, you know, experience for them. Generally I think that's, you know, seen as a positive. (Dr. Barry Michaels)

Trust. Providers discussed that Latino youth, in general, did not trust providers or the healthcare system to openly discuss HIV-related information. As one health educator noted, “they have to feel that trust, or they won’t come back.” Oftentimes, providers described having to spend significant amounts of time building trust with LYLWH and Latino communities. Youth are not always aware of the disclosure policies, or that these policies vary by state; thus, LYLWH tend to be afraid that they will have to disclose sensitive information to a parent to access testing services or care and treatment. Providers discussed LYLWH as hesitant to discuss any challenges to safer-sex practices or adherence to medication with providers or outreach staff. Usually, those patients did not trust providers to discuss any challenges to adherence to medications or safer-sex strategies because they were concerned about confidentiality.

For example, a psychologist noted the following “I think there’s distrust of organizations, especially public ones, especially now with increasing concerns about privacy, and the political climate that’s very anti-immigration, closing the borders, trying to find ways to kicking people out.” Another reason for not trusting providers was that participants felt “shamed” for not following service providers’ prescriptions or recommendations. Providers also acknowledged that Latino youth distrusted community-based and healthcare organizations to a greater extent than other racial or ethnic groups in their clinics, due to the mainly larger systemic issues such as concerns with confidentiality about documentation status or general distrust of government. Finally, trust also pertains to the trust youth have in the actual HIV-related treatments. For example, a case manager

stated, “The second distrust will be the actual treatment. They don’t think the treatment is gonna work.” Distrust was particularly challenging for providers because it impeded their ability to solve problems with LYLWH to better address their challenges or provide supportive services.

You know developing a level of trust with the provider. I often see patients who are going through the continuum of care and when we try to ... they age out. We only serve to about 24 and they age out and when we try to refer them to the adult-care services, sometimes their adherence and retention drop off because they don’t feel comfortable starting a new process all over again with a new provider, telling them their stories all over again. They haven’t built the rapport with that provider, so definitely a challenge there. (Ms. Janet Brady)

Definitely is ah—it’s a team of people, professionals. When working with my clients, I always make sure that I touch base with who, who do they feel comfortable discussing their personal issues. Um, if they tell me they didn’t have anyone they’re able to trust with, you know, letting them know that they’re positive, you know, I—I validate that—try and see who else can they, you know, how open are they with talking to their doctor? Do they have a mental health provider? That’s a big, a big, plus, um, because if they don’t have a support system, ah, at home, it’s imperative that they have someone they can talk to. So definitely mental health has to be involved, at least in the beginning. (Mr. Manny Perez)

Attention to meeting the needs of LYLWH. Providers discussed the importance of paying attention to meeting the needs of LYLWH to promote engagement across the continuum of care. To meet their needs, providers discussed providing developmentally appropriate service delivery along with a “one-stop” shop for healthcare services.

Developmentally appropriate service delivery was another important consideration for meeting the needs of LYLWH. Providers discussed that Latino youth often struggled with having to choose between receiving services that are sensitive to the needs of Latinos or receiving services at adolescent-specific clinics. As one provider stated,

there are other Spanish clinics that are run by English people or are clinics that are comfortable for monolingual and bilingual populations. But the uniqueness of the service that I supervise is the fact that it’s really an adolescent service, adolescent, you know, being teenagers and young adults both.

In providing developmentally appropriate service delivery, providers specifically discussed issues around flexibility and inclusion of peer navigators as facilitators for promoting engagement in care for LYLWH. Flexibility in clinic schedules, such as offering evening and weekend hours, is extremely important for working with LYLWH. Primarily having strict business hours or time restrictions can be perceived as a barrier for LYLWH to remain engaged in care. Having hours that are flexible and varying throughout the day are important tools that sites can implement to promote acceptability of services for LYLWH. Furthermore,

allowing extra flexibility in appointment times to see youth is an important part of meeting the needs of adolescents that is not commonly factored in adult clinics for PLWH. “We’re not an emergency hospital, sitting here, we’re a clinic ... open during daytime hours, a, you know. So they’re not aware of the system and how it works. How much prep time they need” (Mr. Gabriel Busto).

But I know when we were ... earlier this year ... sorry it’s the new year ... in 2013 we were having a lot of problems with people not being able to get tested because they don’t have documentation. We were trying to explain to the testers ... hey they are youth ... they haven’t gotten their IDs or State IDs. ... Can they use the school IDs? ... and they were giving them a really hard time because they didn’t have documentation. (Mr. Mark Brown)

For many providers, having peer navigators on site provided an opportunity to deliver developmentally appropriate health care. For sites that have peer navigators, this is particularly helpful to promote engagement in care during the linkage to care processes and ongoing engagement. Peer buddies can provide emotional support as the newly engaged youth are able to identify with similar others who are open about living with HIV. In addition, peer buddies can provide informational support to help youth transition and navigate the healthcare process. “We find that individuals who actually come to some of the group meetings and they establish root and connections with the other patients they are often more adherent and more engaged” (Ms. Janet Brady).

Definitely, I know that one of the things that I really like about the system is that many of the clinics have their peer—peer system. They have their peer navigators, which that helps a lot cause they have someone there, that's going to help transition the first session. (Mr. Manny Perez)

The final aspect of attention to meeting the needs of LYLWH involved adopting “one-stop shop” models for delivering comprehensive services. Providers described effective programming for LYLWH as clinics that offer a comprehensive set of programs to address the complex and multiple needs of LYLWH. According to providers, clinics that offer comprehensive services such as a wide variety of social services may do better at engaging LYLWH over time because they can get a variety of their needs met and provide opportunities to enhance their overall life. Providers discussed how multidisciplinary team approaches are better suited for working with LYLWH. In addition, specific models of care should be interdisciplinary, include case management, mental health, medical health, and nursing.

You know, so to have, and I'm not necessarily just talking like Latino, um, staff members, but also African American and just a, like, diverse staff so that, um, so that I think that the patients can connect with staff people or staff members. I think that's important. Also like the clinic where I'm at, uh, we have sort of a system that has, like, every service a patient can possible need, ah, throughout their care. So we have a nutritionist, a psychiatrist, mental health providers, case managers, eligibility specialists. Um, you name it, we have it there, so I think that structure has been really

helpful in retaining patients because all of our clients have to come, they can come there and they can get all of the sort of services. ... It's like a one stop shop. So really it's helpful because you have clients come maybe once, twice a week sometimes, so they get to know the staff. (Ms. Wanda Martinez)

Peers. For LYLWH, peers have a unique role in helping navigate the HIV diagnosis. Oftentimes, LYLWH first disclose to their peers. Youth can practice disclosing their HIV status to supportive peers. For some youth, peers also help them navigate the healthcare system. However, LYLWH also reported being apprehensive of their friends and fearing that their disclosure to peers would result in widespread gossip regarding their HIV status. One Linkage to Care coordinator stated, "it's harder to test Latinos, being Latino and being part of the (gay) community, looking at it, like, well, how they are not going to gossip like a *chismoso* or *chismosa*." One other concern providers expressed regarding the role of peers is that peers often engage in the same risky behaviors that may either affect engagement in care or increase the likelihood of disengagement, due to drug or alcohol use. As one participant noted, "A lot of times going with their friends, going out. Definitely that's ... also if they like to party, that will impact their medication adherence too."

Well we talked a little bit about parent, and we talked about roommates and boyfriends. With regards to friends, there's still a lot of, especially for the recent immigrants, there's still a lot of myths about HIV transmission. You know, you can only get it if you were the bottom. Therefore, if I find

out my friend is HIV positive, it must mean he's a slutty bottom, so therefore I stigmatize him. (Mr. Sam Frank)

And with friends, I think with friends it can go both ways really, 'cause friends can be great resources. We have kids who have brought their friends into the clinic to get care because they are HIV positive, or to get tested. So, I see that a lot and that's really, I think that's really encouraging. And then, with providers, I would say I don't see it here so much but I would imagine that ... um ... maybe there's an amount of fear of confidentiality, or maybe there are places where kids go and they feel like they are not culturally understood and they wouldn't want to go back there. (Mr. Ismael Patricio)

Romantic/sexual partners. In general, providers acknowledged that sexual partners played a significant role for LYLWH. Providers tended to describe these dynamics as being stressful for LYLWH. Many attributed this stress to the developmental nature of sexual relationships in adolescence, where sexual partners tend not be part of long-term relationships or partnerships. Providers acknowledged that this stress was common among adolescents, as they were more likely to be in short-term but significant relationships. These relationships were important for engagement in care because different points in relationships with sexual partners can be conducive to specific stressors that may affect engagement in care. For example, initiation of relationships may cause disclosure concerns, as youth have to think about disclosing their HIV status to their new sexual partner.

When relationships dissolve, this is another cause for concern for youth and can trigger a downward spiral that leads youth to withdraw from care. Furthermore, certain types of power dynamics in sexual relationships can affect whether youth engage in care. For example, one provider discussed an experience in which an LYLWH was in a relationship with an older male who was not open to him getting HIV care and prevented the LYLWH from taking his HIV medications. Furthermore, when LYLWH have not disclosed to a sexual partner, they may be reluctant to engage in care out of fear that their sexual partner will find out about their HIV status and their concurrent sexual relationships.

Yeah, for sure ... uh ... I think the relationships that they have with their partner, uh ... um, I see a lot. ... I guess I talk about the patients that have, that happen to be gay, and those that I have that are not, that are heterosexual. So, because it is different, um, so like if we have a patient that has a girlfriend, like is a male that has a girlfriend, then what impacts is their fear of "Okay well if I cheated on her then I don't want to find out if I'm HIV positive or if I am HIV positive, I can't go to my appointment just because she's gonna find out like that I'm going to these appointment and she's gonna start questioning." I think that impacts sort of adherence.

(Ms. Wanda Martinez)

Friends, we've had a lot of boyfriend problems. They, they break up, they meet someone new they disclose, it causes big craziness in their relationship and then they go back to the drug use. And they don't go to

their appointment. We have those factors in, the new boyfriend ... whoever their partner is, affecting their care, basically. (Mr. Gabriel Gusto)

Community (Exosystem)

Providers shared insight on the community-level factors that impact engagement across the continuum of care for LYLWH. Providers described the communities that most LYLWH lived in as urban, lower-income neighborhoods. One central description from providers is that LYLWH tend to live in segregated neighborhoods. In some urban centers, segregation is marked by a pronounced Spanish-language dominance. However, the specific segregation may vary depending on the racial/ethnic makeup of the dominant Latino community. For example, a community in Florida may be comprised more of mixed-race residents due to the Afro-Caribbean influence from residents of Cuban or Dominican ethnicity. However other states, such as California, may be characterized less by mixed-race variability and more by within-ethnic differentiation (regional or tribal differences), due to the largely Mexican community residing there. Gaining insight into some community descriptors allows for greater insight to community-level factors that providers described as challenges for engagement in care. Pertaining to community-level factors impacting engagement in care for LYLWH, providers discussed the role of compounded stigma surrounding HIV and LGBT issues, along with HIV-related stigma, poverty/unstable housing, and social-community norms.

Compounded stigma. First, providers generally described the compounded stigma in the community where YLWH reside regarding how HIV and LGBT affected engagement in care. Compounded refers to the coexisting stigma toward both of these factors. Providers acknowledged that communities where compounded stigma was present, LYLWH are less forthcoming in seeking care in their communities. Thus, youth likely seek out services in areas that are not in their community to maintain anonymity and minimize the unintentional disclosure of any of these issues. For example, youth receive negative messages about being GBT in their communities, such as their schools or neighborhoods, and thus, will avoid seeking services at an agency that is LGBT-specific. The stigma in the communities may also inhibit whether youth seek psychosocial services for mental health issues or for substance use because they are not fully ready to address or treat these other conditions.

And then there's all the other sort of, um, stigma that are mixed in with homophobia, which I think it's very powerful. Well it's powerful in all communities. It's powerful in the African American community too, um, that you know, I mean, many Latinos have told me, okay it's fine if you're gay, just don't get HIV, and then, so, um, and, and, and, those youth who've told that to me have had a harder time getting into care. (Ms. Lisa Woods)

I'm not entirely sure because there are some patients that I thought were and it turns out they are actually not because they are very open about it, some of them are very obviously open about it in the clinic, but then some

of them don't want the community to know at all. That's another thing, too, is some of them that come to the clinic are very open about it because they receive services right here in the community. But there are some patients ... Latino Patients that choose not to come to clinics in the Bronx and they will go to Collin-Lorde or they will go to [Gay Men's Health Crisis] because they don't want the community to know about it. They don't want to be spotted. (Ms. Janet Brady)

HIV stigma. HIV stigma is another factor that contributed independently to engagement in care for LYLWH. Providers acknowledged a strong sense of cultural pride in many of these predominantly Latino communities and that this cultural pride promotes a sense of tight-knit community. However, this closeness also presents a challenge for engagement across the continuum of care for LYLWH. Primarily, these tight-knit communities can inadvertently make LYLWH more afraid to access services because HIV is highly stigmatized in that community. One provider noted, "Oh [HIV stigma is] the biggest that they are fearing and are avoiding. So, it's number one, top of the list." Thus, community members may be more aware of who accesses what services at these designated clinics, who is believed to be living with HIV, and perhaps, people living with HIV experienced being ostracized from the community. These types of casual conversations in these tight-knit communities may make youth resist getting tested for HIV and following up with their medical appointments.

I think community is an interesting one and it can—a lot of our youth are born and raised in the Bronx and a lot of our youth still live in the Bronx

and there's very strong senses of community neighborhoods here and I think that, um, that's sometimes hard—harder than it is helpful specifically when it comes to HIV because of stigma. (Ms. Lisa Woods)

Well I can't really go anywhere in my neighborhood because people are going to see me coming out of this place and assume I have HIV and the closest place to them is in the city; they have to take a train to go over there all the time. (Mr. Jose Torres)

Poverty. Providers for the most part described the communities that many of LYLWH lived in as experiencing high rates of poverty. Community poverty related to lack of supportive services such as reliable transportation. In addition, community poverty contributed to disparity in the types of services available for LYLWH, which reflected the socioeconomic issues affecting these communities. For example, LYLWH often noted the lack of investment in the facilities residing in their communities compared to the facilities in more affluent communities. Some providers felt these disparities, at some level, disengaged youth from receiving ongoing care at facilities in their communities. Among youth experiencing extreme poverty, major concerns centered around having stable housing and meeting basic life needs in addition to living in these high-poverty communities. For youth in these situations, securing basic life needs prevailed over their need to obtain regular healthcare. For these youth, healthcare services conflicted with their ability to secure low-skilled jobs that frequently do not offer sick time, vacation time, or paid time off. LYLWH were specifically vulnerable to

this because many of them felt a pronounced level of commitment to financially contributing to their households. Ms. Brady opined, “Well on a community level I guess it’s poverty, access to adequate care, access to adequate housing. There is stigma around HIV/AIDS and homosexuality. There is high levels of drug abuse, umm, you know.”

Latino low income, Latino individual and youth are dealing with other things in life that become sort of codemands, if you will, that make it difficult for people to stay in ... linked to care. You know, not having health insurance, I think, high unemployment, all effect individual’s engagement in care. (Mr. Gustavo Sanchez)

Unstable housing. Providers acknowledged that a major challenge for some Latino youth’s ability to engage in regular care stemmed from experiencing unstable housing situations. Many LYLWH struggled to meet their basic life needs. LYLWH either lacked food or housing security. Unstable housing was a concerning issue, particularly for GBT-identified LYLWH. In general, providers felt that homelessness was not as prevalent among LYLWH, but unstable-housing situations affected youths’ ability to engage across the continuum of HIV care. Transient homelessness, or unstable housing, was more common among GBT LYLWH because they were able to stay with extended family members or friends, despite not having a stable or permanent place to stay. For other youth, they may not be homeless but they focus on securing their own private place because they feel unwelcomed or unsafe in their families’ homes, which places significant pressure on youth to obtain alternative housing.

Right, homelessness is a huge issue. Homelessness is probably like ... you know ... if we could house these guys, girls and boys on the street, who have been turn out from their families ... we would take care of, really I mean ... that alone, just food, clothing, and shelter ... would provide so much stability for them. It would be an extraordinary thing. You would still have all the other issues of them feeling rejected, the issues of being gay, the issues of being closeted, I mean you would have all those other stigma issues, but just that structural issue alone of youth homelessness is really problematic. (Dr. Patricia Verde)

And so the ones that are homeless tend to be, um, to stay in the clinic, are less likely to be in the clinics. They're less likely to be adherent but because of the same issue, because they're not stable anywhere. (Ms. Wanda Martinez)

Social community norms. The social norms surrounding different behaviors also affected engagement in care for many of the LYLWH. Specifically, providers discussed gay=community norms and street culture/community norms as facilitators or challenges affecting engagement in care. Gay community social norms surrounding HIV can serve as facilitators or challenges for engagement in care. For example, if the gay community in a particular region promoted open discussion and HIV testing and treatment, residents experienced less secrecy about seeking HIV services. For example, providers perceived San Francisco or New York gay communities as being more open about HIV, where HIV was more

openly discussed and thus stigma was not as prevalent because people were more willing to seek out HIV services. Other gay communities were not as open, perpetuating the secrecy surrounding HIV, because members did not want to discuss HIV for fear of tarnishing their reputation. Another social norm centered on attraction and desirability. Providers acknowledged the challenge of engaging some youth in care because attending to their HIV interfered with their desirability in the gay community. After receiving an HIV diagnosis, these youth perceived it as a potential threat to their sense of being healthy, invincible, and desirable in a gay community that was not openly discussing HIV.

I mean you could—there's a stigma in the gay community that still exists in Los Angeles and this is the land of models and dancers and actors and singers. You know, Beverly Hills, and everybody's you, so it's different from San Francisco or San Diego. People are more out about their status in San Francisco or even San Diego. LA has a different vibe to it as far as community goes. I think it's what gets these guys to keep their status a secret. (Mr. Gabriel Gusto)

And I would say there's a lot of crossover by White MSM, their same age range or not, ah, who are very attracted to Latinos. So that's, for many of them, their identity is very much focused on that. Um, lots of Facebook selfie's with 134 "Likes." And if I was to generalize, I would say that when they enter into care it makes their HIV status very real. And they feel a great deal of shame, stigma, imminent mortality, loss of youth, loss

of attractiveness, loss of desirability. So I guess, and I'm just speculating based on actions I see, I guess that might be why some delay in care or fall out in care for any excuse they can find. (Mr. Sam Frank)

Providers also discussed social norms pertaining to street culture/community that affect engagement in care. Social norms for gang membership and involvement may impede a youth's ability to remain engaged in care. Gang membership may provide an outlet for some youth to be part of a group that may not have social support at their homes. For others, LYLWH may join gangs to ascribe to heterosexual norms in their communities. Thus, the gangs then expect them to display a "macho" lifestyle. Providers described experiences in which youth try to maintain a "macho" appearance, not just in the way they dressed, but in overall demeanor, to minimize being bullied by neighbors or other community members. Involvement undergoes specific socialization regarding expectations involving sexual behaviors, illicit substance use or trade, along with participation in planned or unplanned violent acts (such as fights in a night club or a targeted revenge attack). Gang membership can deter engagement in care because youth may have other activities they prioritize over regular engagement in care. In addition, providers speculated that LYLWH involved in gangs tend to resist care more than others due to fears that their HIV or GBT identity will be uncovered, putting them at risk for violence from fellow gang members. Furthermore, being in a gang can complicate where youth are able to receive services. One provider stated, "but I know they have to get out of their community. And that itself was a barrier ... especially if they were gang bangers were afraid

to leave their neighborhood because of gang crossings.” Dr. Garcia averred, “It’s the kids that are more Americanized Latinos, those are the ones that fall out of care. They’re the ones that don’t take their meds. They’re the ones that drop out of school. They’re the ones joining gangs.”

Some of the youth, male youth, are gang members and in that culture of gang culture there is a sense of always being masculine, always being strong, having multiple sexual partners, and it’s hard for these young men, many who acquired HIV as a result of same-sex activity, to be able to disclose that, and that hinders my ability to provide good medical care, when youth withhold information. (Dr. Julio Medrano)

Another social norm deemed particularly harmful for engagement in care was the street illicit-drug culture for some youth. The reason it was concerning for some providers was that this street drug culture centered around heavy illicit-drug use usually involving club drug-use binges with drugs such as ecstasy, date-rape drugs, and methamphetamines. When youth were on drug binges, usually lasting weeks at a time, they would certainly fall out of care and become less adherent to their HIV-medications. After the binges, youth would return to care, but usually for something other than HIV-related care. For example, if they need assistance for housing or needed to seek social services, they would reconnect with the agency. The hardest part of this street culture is that, just like gang membership, it was very difficult to leave the street drug culture, once youth were part of it initially.

If you're unlucky, you may get picked up by a different crowd, more on the drug-scene crowd, and those young guys tend to live like in ... they do live, like, in houses, um, but they have a lot of really ... I think that culturally it's a culture. It's a culture of unprotective sex, drug use, um ... a lot behaviors that I think people would just say it's extremely dangerous behavior. Extremely dangerous behavior. I mean, I'm not saying dangerous behavior in terms of HIV transmission, because you can have unprotected sex in like bathhouses and all these other things. But I'm saying they're very, just very dangerous because they could die. I mean they use so much drugs that they literally could die. So that's one issue. So it's a high risk of death. Um, and then, the other thing is to leave that culture is really hard. And I had a couple people who have fallen in and out of care over years in this culture. (Dr. Patricia Verde)

Sociocultural/Policy-Level Factors (Macrosystem)

The macrosystem comprises sociocultural and policy-level factors. First, I discuss sociocultural factors; then I focus on policy-level factors separately. Sociocultural factors relate to social and cultural factors that affect engagement across the continuum of care for LYLWH. As previously stated, according to Barker (2000), culture refers to peoples' shared meanings, including people with similar life experiences and understandings. Often these groups have shared historic, linguistic, social, and political contexts, with a common label, such as an ethnicity or nationality (Barker, 2000). For LYLWH, strong Latino cultural

factors can affect engagement across the continuum of care. Sociocultural factors include traditional Latino cultural beliefs, religious beliefs, and acculturation.

Traditional Latino cultural beliefs. It is important to note that not all Latinos share all these cultural values, but the general sense is that they affect engagement for a significant portion of the LYLWH in some manner, across the urban areas explored for this study. Of note, providers discussed the cultural values related to *machismo*, *familialismo*, *respeto*, and *cultural views of health* as factors affecting engagement across the continuum of care for LYLWH. It is important to acknowledge that aspects of these values are part of society. In general, the providers described these as having a greater degree of influence among LYLWH than among other youth they work with in their clinics.

Machismo. Specifically, providers discussed the role of *machismo* and its' influence on LYLWH's acceptance of their GBT identity; *machismo* may negatively affect engagement in care for these youth. This continuum of GBT-identity acceptance further complicates their ability to accept their HIV diagnosis. *Machismo*, and its' female counterpart, *marianismo*, refer to acceptance of gender roles that emphasize traditional husband and wife roles and may implicitly or explicitly discourage open discussion regarding sex, homosexuality, and equality in sexual relationships. Providers generally believed that LYLWH and Latino youth, in general, experienced greater difficulty discussing sex and their sexual behaviors with providers than those of other ethnicities. Their hesitation was not specific merely to talking about risk behaviors, but was a prevailing discomfort surrounding sex. Culturally, researchers reference this discomfort as a "culture of

sexual silence” (Carrillo, 2012) which may stem from sexual repression and expected control over one’s sexual desires in relation to one’s ascribed gender roles. For providers, this was a specific challenge, given that the majority acquired HIV through unprotected intercourse. Thus, not being able to discuss risk factors with LYLWH in an open and nonjudgmental manner may impede genuine skill-building discussions or opportunities.

But it is a barrier. It is a barrier because culturally some of them don’t feel comfortable being identified as an MSM or gay, or even bi at some points. ... I would say even talking about it. Not even just the label, just talking about the things that they do. (Mr. Luis Lopez)

Well, I mean , I guess it depends. There’s a lot of—within the Latino community there’s a lot of *machismo* still involved. There’s still a lot of, you know, if the client is gay, there’s still a lot stigma definitely. ... It’s just all ... I want to say it’s just the culture [laughter]. But, you know, I guess *machismo* is like one of the biggest ones.” (Mr. Manny Perez)

Familialismo. Another challenging dynamic that providers often discussed surrounded the degree of allegiance to family and the household. Due to the strong emphasis on family, Latinos experience a strong sense of responsibility in caretaking, as one psychiatrist noted, “but it’s this worry that they’re still in a caretaking role for all these other people.” Caretaking means different things for young men and women. For young women living with HIV, their children often played an important role in their engagement in care and served as a facilitator

and a challenge at different points in their lives. For example, during pregnancy, adherence to routine care and medications was relatively high, primarily motivated by reducing the likelihood of transmitting HIV to their child. However, as the children grew and became a competing priority, oftentimes mothers would forego their own health needs to attend to their children's needs. This affects adherence because they may not have childcare to attend medical appointments or may forego medication due to competing priorities if they disrupt their well-being in the short-term. Young men are usually considered an important financial provider to the family household. Youth often felt the urge to contribute financially to support the household. Thus, youth often took jobs that did not offer flexibility in their schedules or hours. This challenged youth to come in for regular care, as their schedules often conflicted with clinic hours. Thus, having to maintain a job is a significant stressor for these youth. With the majority of the low-skilled jobs, young men must sometimes choose between attending their medical appointments or going to work. Thus, family caretaking concerns can hinder youths' ability to fully engage in care.

Oftentimes they become pregnant, which adds to their burden of having to care for their HIV because now they not only have to worry about what to do with the pregnancy. If they should carry the pregnancy to term, they to worry about their children, often to the exclusion of their own health. And when their children become a priority, they begin to miss their clinic appointments. They begin to be more noncompliant, nonadherent to their medications. (Dr. Julio Medrano)

Yeah, I mean, and things like feeling an allegiance to family sometimes, I think, where they feel ... I'm talking more about the young adults the 18–24 year olds. A lot of them work and help to support family, and contribute to the household, so they feel like there's other responsibilities, particularly for the men. They feel like they [have] to work and keep going so they tend to prioritize that over their health care, and so they only seek health care until they're really sick sometimes. (Dr. Henry Garcia)

Respeto. Providers acknowledged *respeto* as a factor that influenced engagement in care across the continuum of care for LYLWH. *Respeto*, loosely translated into respect, is a cultural value that often emphasizes respect for elders and respect for hierarchical relationships. In this sense, providers may have difficulty forming relationships with LYLWH because of the relationship style that *respeto* promotes between the provider and youth. In this sense, youth may conform to a more didactic relationship with their providers. According to one provider, they “feel embarrassed to be honest with the physician ... going against doctor's advice.” They may not feel comfortable asking clarifying questions of providers if they do not understand a particular issue. Providers described this discomfort as a potential challenge for engagement because youth may feel a sense of shame when they do not understand information, leading them to avoid engagement so as not to disappoint the provider. In addition, adherence to medication may be problematic because LYLWH may be hesitant to discuss

nonadherence or complications with side effects, again sensing that not following doctors' orders may be seen as disrespectful.

So they (hospital providers) ask closed-ended questions like “You understand everything I’m saying?” and um, “You’re taking all your pills on time, right?” and the clients will say yes, even if they don’t understand everything they’re saying because of the cultural norm of *respeto*. (Mr. Sam Frank)

But from my experiences thinking about the Latino culture, it’s a hierarchical culture where adults know what is right or appropriate and youth don’t. So in light of that, when we talk about Latino youth engaging in care, you’re asking them to do the complete opposite of what they’re told by their family, in their home settings, and in their school setting—which is to be empowered; to take an active stance in your healthcare. (Ms. Gracie Rodriguez-Smith)

In contrast, this sense of *respeto* also related to better adherence to their appointments and medications, especially among immigrant LYLWH. *Respeto* motivated youth to remain adherent to their appointments as they were following doctors' orders despite other challenges in their lives.

I think immigrants come here and they struggle to survive, so they’re working. They understand their priorities. I don’t want to miss my appointment because it cost me \$200 dollars a day to come here, so I can’t afford to be missing work and walking—waltzing in as a walk-in. They

don't have that luxury. So they really, really appreciate the time that we give them. (Dr. Henry Garcia)

Cultural views of health. Another challenge in working with LYLWH from providers' perspectives is that the cultural notion of health is generally defined as the lack of illness or symptoms. One provider noted, in "the Latino culture, we promote this idea that if you feel good, you don't need to take medication." This cultural view of health can be particularly challenging for those with HIV because PLWH can be asymptomatic. Yet, PLWH still must maintain ongoing regular care. Thus, if feeling unwell or having symptoms aligns with receiving health care, then youth may forego care when they are feeling healthy.

And generally, this is not just an HIV thing, but Latinos tend to go to the doctor when they are very sick. They don't believe in prevention, you know, like testing, check-ups, and all of that. They wait until something is very serious for them to go to the doctor. And they don't see the need.

And that's something that's cultural, like, you know, like that's how they grew up. ... It's a financial thing, but it's also cultural. Like their perception of disease is, or infection is related to being very sick. (Mr.

Luis Lopez)

Well, definitely knowing their status is one of the major factors. I know that within the Latino community, I've noticed that, true to our culture, people don't seek out testing or anything ... you know, going to the doctor

or medical assistance, unless they know they're ill or they know something is going on. (Mr. Manny Perez)

Furthermore, the general distrust of modern medicine may be rooted in the cultural use of holistic or alternative approaches. Latino families may hold higher regard for these approaches for enhancing overall health, including curing HIV. For example, several providers noted that families often held firmly to the belief that someone could be cured of HIV through the work of God. This was particularly true when youth maintained undetectable viral loads for a long time. Although holistic approaches did not entirely deter engagement in care, they could hinder engagement because LYLWH may not bring up these approaches with their providers out of fear or respect. Dr. Ramirez said, "I also have experience here so sometimes there's some kind of folkloric medication or things that you need to be aware that you know that they're going on in the community even if they're not necessarily medically proven." Providers acknowledged that having these conversations were important because, oftentimes, some holistic approaches may diminish the efficacy of the actual treatment therapies.

Culture's huge for Latino families ya know, there's religious beliefs, there's, you know, there's some Hispanics where their parents don't believe in modern day medicine. ... They believe in more holistic approaches and you know with HIV, you know ... medicines are important, but if you have families that are not welcoming to actually using them, then you have to understand that, as a culture, how do we

embrace both what they are bringing to the table and what we know needs to happen as far as medication. (Mr. Jose Torres)

Religious beliefs. Many providers felt that the cultural emphasis on religion and the closely related socially conservative views of regarding marriage and heterosexual relationships often indirectly impacted youths' ability to accept their own HIV diagnosis. Providers described a heightened sense of struggle because Latino youth grew up in traditionally religious households or communities. Providers speculated that the cultural values associated with Latino Christian religion often emphasized guilt and punishment, which translated to youth as HIV being a punishment for their GBT-identity. Thus, youth tend to struggle more in accepting their diagnosis because the punishment was something they deserved for acting out according to the religious values they experienced in their upbringing. As one provider stated, "many of them don't want to be gay." This belief that HIV was a punishment, then, reinforced their sense of *fatalismo* because this was God's will or punishment for their behaviors.

So it's very hard to reconcile them with their religion and what is expected, so men in general ... young men ... are expected to have sex with females even before they marriage. ... It depended on their religion, of course, but it's very common that it is accepted almost. That is what is going to happen from a very early age. (Ms. Emily Bustamante)

And, you know, a lot of the Latino community is fairly conservative. They're often Catholic or even Evangelical. Your parents are often very traditional and fairly religious. And for that reason, you know, many of

them are not “out” in terms of their sexual or gender identity. And that creates, you know, huge issues, you know, when it comes to dealing with HIV; that makes it hard or impossible for them to access familial support.

(Dr. Barry Michaels)

Providers did not all view cultural values as challenges. Some providers saw religion as an important tool for youth to begin to address their diagnosis and their care and treatment. One provider noted, “I think we need groups that explore religion, because it’s pretty engrained in our culture.” Youths’ religious faith helps them view their diagnosis as a blessing in disguise, as they were not in a good place prior to their diagnosis. The diagnosis, then, renewed their sense of faith and facilitated their engagement because they felt that God, in some way, was giving them a second chance. In addition, providers acknowledged that more socially liberal religious communities are more vocal about accepting diverse sexual orientations. As one provider noted “I am so thankful that this new pope has stepped out and has had much more open view towards homosexuality in general.”

I think another big thing, especially in the Latino cultural that a lot of people don’t talk about, is the incorporation of spirituality and religion. It’s something that gets ignored, it’s something that as of, I think most people, but Latinos bring this up to their health professionals because it hasn’t been really accepted in the community. (Dr. Henry Garcia)

Acculturation. Acculturation is the process of adaptation in which immigrants alter their attitudes, beliefs, and behaviors to resemble those of the

host society in which they reside. Providers highlighted some challenges and opportunities related to acculturation factors that impact engagement in care across the continuum of care. Providers discussed issues of acculturation mainly related to uptake of mainstream popular culture, longer length of time in the United States, predominant English speaking, and greater identification with U.S. culture. Providers presented notable differences between more acculturated youth, in contrast to less acculturated or foreign-born LYLWH.

Um, maybe some cultural competence, not necessarily language because most of the youth that I see speak English, but cultural competence, in that an understanding of immigration. Families, you know, are that immigrants, understanding the youths' oftentimes bicultural kind of existence. So the parents still operate like the old country, but the child wants to be modern American since they're living here now. And it's usually some kind of a compromise between the two in the household. (Dr. Lawrence French)

Guess I'd just say generally that many of our clients, the vast majority of our clients, are immigrants. Probably 70% of them. And they, they come here and they take the lead from the population ahead of them. Whether that's the lead in sexual behavioral norms or access to care norms. (Mr. Sam Frank)

Policy-level factors. Policy-level factors reflect those factors that make up part of the macrolevel in the socioecological framework. For LYLWH, providers discussed three major themes. First, providers discussed the role of U.S.

immigration policy. Second, providers discussed the role of U.S. healthcare access. Finally, providers discussed the role of the healthcare system as a challenge or facilitator for engagement across the continuum of care.

U.S. immigration policy. The current immigration policy in the United States complicates services for many undocumented LYLWH. First, U.S. immigration policy has not addressed issues related to mixed-status families, where families consists of members who are U.S. residents or citizens and members who are undocumented. This immigration issue affects the degree to which LYLWH obtain services because it raises the family's fear of being caught. As one social worker noted, "if you are going to healthcare ... they are going to ask you questions about me (undocumented parents) and that can lead back to me and have a fear of being caught."

U.S. immigration also has not produced policy addressing children who arrived in the United States without documentation but have been living in the United States unaware of lacking proper documentation. The lack of U.S. policy to address these issues has contributed to an anti-immigrant sentiment across the United States. One participant noted regional differences in accessing care based on the local restrictions to accessing care for immigrants or undocumented individuals. Mr. Torres contributed, "Yeah, I mean immigration status issues are still alive yes: they may be citizens but they are wondering about their families and fears about their families. You know those concerns are definitely raised." In contrast, Ms. Woods said, "We have very few people who have immigration issues, but the one who did have some immigration issues, it was a big barrier.

New York is pretty good, way better than Illinois and Chicago where I used to work.”

They feel like they can't go back to their native country for fear that they will not be able to come back. They feel like that culturally they might be different because they have accepted not only their own culture but also somewhat acculturated into this culture. So, going back would, is not really an option. Yet, they can't move ahead and make a better life for themselves. So, oftentimes there is a sense of hopelessness. So that's a group that's really. ... I'm not sure what solutions are unless we change immigration laws. So immigration plays a big role—immigration laws, immigration policies ... so unless we address immigration laws, issues of health—health access, the undocumented won't be able to access the Affordable Care Act, so they're going to be stuck in limbo also. (Dr. Julio Medrano)

Second, documentation status is another important factor that affects engagement in care for LYLWH. For LYLWH who are undocumented, that is, are living in the United States without a U.S. birth certificate, valid U.S. permanent resident status, or a valid U.S. visa, accessing services is particularly burdensome. Although providers acknowledged that documentation status was a barrier to accessing services, they recognized that undocumented LYLWH were rarely denied services. Providers recognized other ways of providing healthcare services to this marginalized group, such as through the AIDS Drug Assistance Program or private donations. They recognized, however, that they had greater

difficulty testing for HIV or reaching out to services. Although some of this challenge reflects individual-level factors, such as fear of being caught or jeopardizing a family's life in the United States, policies restrict the availability of healthcare services for undocumented individuals. For example, with the implementation of the ACA, explicit language allows no federal coverage to access these services. In addition, although U.S. citizens, lawfully present individuals, or children of undocumented parents are eligible for such services, LYLWH often felt quite wary of providing such information to government entities (i.e., public health departments, hospitals or other community-based organizations).

And they are many that pay, however, for the undocumented person, I see they really feel that stigma and are very afraid to come forward to engage in care, because they think, they're afraid that there is a link between immigration and whatever the service is ... immigration is it INS? (Dr. Alicia Fernandez)

In some cases fear, if they are undocumented and I tested someone and they turned out to be positive and of course he was freaked out because he had HIV but the fact that he was undocumented added a whole new level of anxiety to him. (Mr. Fabian Bruno)

Health access. Health insurance status is an important indicator for continued engagement in care. Providers highlighted challenges in maintaining engagement when participants did not have access to healthcare insurance. This

lack was a challenge primarily for engagement in care because, oftentimes, LYLWH could not access services during the linkage-to-care process if there were delays in getting youth insurance coverage. In addition, having to maintain paperwork for ongoing healthcare insurance can be a challenge to long-term engagement, as youth can perceive the paperwork necessary to document their insurance eligibility as a challenge. When considering medication adherence, providers worried that limited funds for alcohol and drug-abuse programs caused interruptions in medication treatment. Although Part B of the Ryan White HIV/AIDS Treatment Extension Act of 2009 is a national grant program, alcohol and drug-abuse programs use locally established criteria. This means that YLWH can be eligible for services in one jurisdiction but ineligible in another jurisdiction. Despite the availability of such services, providers asserted that LYLWH still express concerns about their ability to access these services. The services for these youth are often very limited to nonprofit agencies or public services.

For both the undocumented and those that are citizens there's the issue of insurance, health insurance for seeking healthcare. About 60–75% of those that are undocumented have no access to healthcare for at least 2 years prior to coming in to see me. When they come in, they are referred by other sources because they have nowhere else to go. ... For those that are documented, many of their parents are working parents that don't have health insurance. As the Affordable Care Act kicks in, maybe things will change. So, those are structural issues. (Dr. Julio Medrano)

Um ... you know, I don't think that in general people really think, or clinicians or providers, clinics, really discriminate, "Oh you are undocumented, uh, we cannot see you." But kind of, in the back end, yes, that's a stigma against those, if they don't have insurance. If they have insurance it doesn't really matter. (Dr. Alicia Fernandez)

Healthcare system. Providers found that the U.S. medical model was a policy-level barrier that posed challenges for working with YLWH in general. Primarily, the U.S. medical system was too fragmented and second, many administrative challenges exist to successfully deliver care.

Fragmented services. Providers believed the medical model was too fragmented to address the complex issues LYLWH faced. Providers cited that LYLWH often needed, not only HIV services, but also ancillary supportive services such as case management, mental health, substance-abuse treatment/counseling, food, housing, emergency shelter, and transportation. The process to gain access to these services under the current U.S. medical system made this burdensome for YLWH, and more so for LYLWH. Furthermore, the current system limits providers' ability to address these challenges in a holistic manner. For the most part, providers believed that the current social work model was inappropriate for youth. Providers described the social work model as one that relied on individuals coming to the clinic and expressing their needs to the healthcare professional; then having the provider refer out the services. Providers opined that this process, compared to the one-stop process, created additional stress, as youth needed to make the linkages for these services on their own.

The [current model] is more social work model. ... “Tell me what you need. I give you resources, and you go and seek it out.” For these youth, just getting a referral does not necessarily mean that they will get that service. You have to be able to help them get to that referral. Oftentimes we accompany them. It can be really difficult. (Dr. Julio Medrano)

I think there's kind of interesting ... the whole support system for youth, ah, in general, for people with HIV, has become very regimented that the grants that cover case managers, mental health, have become very proscriptive over the years. And there's such focus on, on getting the right data and the paperwork—and this is your job and somebody else has to do that job, that it's made it less personal and less kind of—what is it that the individual actually needs. ... So it's an ongoing challenge that it's actually harder to meet the needs of an individual, even though I wouldn't say there's less resources. They're just so much more proscriptive now, whether it's [Health Resources and Services Administration] funded or Ryan White funded through the county, you know, it's very interesting to me how much more difficult it is to, you know, be able to “Oh I can't provide you with housing services, that's somebody else's job. I can only work with you on your medical side of HIV.” I mean it's not quite that bad but, it just ... you know, it just, has that flavor of, you know, what people's roles are and what their, you know, the grants that pay their

salary, has made it less ... I think, ah, you know, youth friendly, less patient friendly. (Dr. Barry Michaels)

Administrative barriers. One of the biggest drawbacks to having a fragmented service-delivery system is that it creates a tremendous administrative barrier for providers, as well as for YLWH. Providers discussed at length the burden completing paperwork placed on youth, particularly on those who are newly diagnosed. One doctor noted, youth were “spending a lot of time, spending half an hour or an hour, just dealing with paperwork.” This is particularly frustrating for providers because, as one provider noted, “Cause it’s all about the paperwork rather than about the interpersonal relationship with the provider. So it’s intimidating them.” In addition to completing the paperwork initially, youth have to routinely complete paperwork to get their medications regularly. LYLWH with limited English- or Spanish-reading fluency can feel intimidated and frustrated because completing this paperwork may take even longer. Furthermore, paperwork is not streamlined for services outside of the originating agency. Thus, youth may need to fill out similar paperwork for various ancillary services outside of the originating agency, which can add to the frustration and time commitment needed to come in for their appointments. In addition to completing the paperwork, young people also need to maintain all proper documentation that is required to successfully complete the paperwork. In addition to the burdensome requirement and its associated paperwork, the verification process, oftentimes, can lead to actual delays in receipt of care. Providers stated that youth may not get their medication or get an appointment if their paperwork is delayed. The

verification process also seems to constantly change, making it complex to access services. One health educator noted, “youth kinda get lost in mazes of paperwork, you know aspects that sometimes adults have to deal with. I’ve also had to hear a lot about youth transitioning services.”

I know one of the things, for example, that I don’t do specifically is, I know a lot of people get really frustrated when they are applying for housing assistance, is they need this paper work and they need this ID and that ID and they have to need get it faxed and they don’t know how to fill out the paper work and the fax is lost. There is a lot of breakdown in the actual process. So, I think more streamlined services between all of the agencies that providing the services to the youth are really important. (Ms. Janet Brady)

Once they see their doctor, they’re coming every 3 months on a routine basis, but the other problem is getting their medication every month. They have to, now they can’t give away 3 months worth, it’s 1 month. So they to, ship to the house, it’s a hassle to renew their medication every month. A lot of the paperwork too. They’re dealing with eligibility paperwork for 6 months rather than every year. And different programs have different eligibility criteria, and all the paperwork that comes with it. They spend an hour just filling out paperwork they’re first coming here. I mean it’s just finding everything and all the documents. (Mr. Gabriel Gusto)

CHAPTER IV

DISCUSSION

The purpose of this study was to explore the factors that contribute to engagement in care across the HIV continuum of care for LYLWH. Comprised of in-depth interviews with adolescent-specific providers working with LYLWH, the study explored barriers and facilitators affecting engagement in care including HIV testing, HIV linkage-to-care, receiving some HIV medical care, entered but lost to follow-up, and fully engaged in HIV care. Understanding these factors from the providers' perspective is critical, given the growing recognition that HIV is a chronic disease that requires lifelong involvement in care and treatment to maintain health and well-being, while reducing the likelihood of transmitting HIV to others. Furthermore, by using a socioecological framework, emphasis is on understanding those factors that impact engagement in care beyond the individual level of analysis and the unique challenges and facilitators for groups experiencing a disproportionate burden of HIV.

I ascertained themes for this study by analyzing the responses from the semistructured interviews of 26 clinical, mental health, social work, or direct-service providers with at least 1-year of experience serving LYLWH at one of four geographic locations (Chicago, Los Angeles, Miami, and New York City). These interviews examined specific challenges and facilitators from a socioecological framework. I analyzed interviews using a psychological phenomenological approach, which included a deductive and inductive analytic approach.

The following themes emerged as important factors impacting engagement in care for LYLWH. Individual-level themes specific to LYLWH included mental health issues, substance use, adjustment to HIV diagnosis, and HIV education. Intrapersonal-level themes specific to LYLWH included the systematic impacts of family, providers, and one-on-one relationships with peers and romantic or sexual partners. Pertaining to community-level factors impacting engagement in care for LYLWH, providers discussed the role of compounded stigma surrounding HIV and LGBT issues, along with HIV-related stigma, poverty/unstable housing, and social-community norms. Sociocultural and policy-level factors include traditional Latino cultural beliefs, religious beliefs, acculturation, U.S. immigration policy, U.S. healthcare access and the healthcare system. In sum, study results reveal that individual (intrapersonal), interpersonal (microsystem), community (exosystem), and sociocultural/policy-level (macrosystem) factors are critical considerations for engagement in HIV care. Despite the challenges at multiple socioecological levels, access to HIV testing and engagement across the continuum of care is possible for LYLWH with special attention and recognition of these factors.

In light of the increasing number of LYLWH in the United States, and the multiple issues they confront, maintaining engagement in care across the continuum of HIV can be difficult. Moving beyond individual-level influences, stakeholders can view the additional contributing factors for continual engagement across the continuum of HIV care. One model that incorporates the multiple levels of influence is the syndemic model, which can enhance

understanding of the factors that influence engagement in care for LYLWH. The term was first used to describe inextricable and mutually reinforcing connections among health disparities, such as substance abuse, violence, and HIV/AIDS among urban people living in poverty (Singer, 1994). Given the complexity surrounding socioecological factors derived from this study, it is useful to explore engagement in care among LYLWH in the framework of syndemic theory. Syndemic is the synergistic interaction of two or more diseases and its subsequent burden on disease states and outcomes (Singer et al., 2003; Wawryniak et al., 2015).

In the HIV literature, having multiple negative psychosocial and socioeconomic-status issues has aligned with increased odds of being HIV-infected or falling out of care. Researchers more recently have applied a syndemic framework to the additive nature of psychosocial and socioeconomic health problems and their impact on health outcomes; psychosocial factors treated as a syndemic have served as predictors for detrimental outcomes along the HIV care continuum (Stall, Mills, Williamson, et al., 2003). Based on the degree of overlap in the results section among several key issues, I grouped three syndemic research domains that emerged that would be helpful for understanding these issues. Thus, using a syndemic framework can explain the mutually reinforcing interaction of the resulting factors from this study and their impact on engagement in care for LYLWH. In this section, I provide an overview of the prominent findings in three emergent syndemic research domains. A discussion of the strengths and limitations of the current study follows exploration of the implications of the

current findings; the chapter ends with recommendations for future research and practice.

Syndemic Research Domain 1: Psychological Distress, Substance Use and HIV-Risk Factors

The first syndemic research domain highlights the role of psychological distress, substance use, and HIV-risk factors as intersecting conditions among many Latino youth-at-risk for HIV or for LYLWH. Providers acknowledged that Latino youth face a myriad of issues that often complicate youths' lives and place them at risk for interruptions in their HIV care. Providers perceived youths' levels of psychological distress, aligned with depressive symptomology, to be higher among Latino youth, compared to other youth they serve and that many of these youth have not received or accessed such treatment. Multiple studies supported this outlook, describing Latino adolescents as expressing higher levels of depression compared to youth from other ethnic backgrounds, suggesting that some mental health issues preexist LYLWH's HIV diagnosis, and were perhaps unrecognized (Blazer, Kessler, McGonagle, & Swartz, 1994; Roberts, Roberts, & Chen, 1997; Roberts & Sobhan, 1992; Twenge & Neolen-Hoeksema, 2002).

Researchers documented within-group differences in the prevalence of psychosocial distress among Latino youth that warrant further attention. Latino YMSM and Latinas are two subpopulations at heightened risk for experiencing psychological distress, which was also evidenced by providers in this study.

First, providers in this study described Latino YMSM as experiencing greater levels of psychological distress associated with acceptance of their gay or

bisexual identity than other YMSM of other races or ethnicities in their clinic population. In general, researchers indicated that LGBT-individuals are heightened risk for mental health issues including depression and suicidal ideation, resulting from the daily homophobia they experience in their lives, compared to their heterosexual counterparts (Garofalo & Katz, 2001; Harper & Schneider, 2003). The extant literature described mixed results that Latino YMSM experience higher levels of psychological distress than other YMSM. For example, in a nationally representative sample of adolescents in the United States, researchers found that Latino youth with same-gender attractions are at heightened risk for reporting such distress (Consolacion et al., 2004). However, another study focused solely on YMSM found no support for the notion that Latino YMSM experience greater psychological distress compared to YMSM of other racial or ethnic groups (Storholm, Siconolfi, Halkitis, et al., 2013). Specific to YLWH, researchers indicated that rates of psychological distress are high among this group in general (Brown, Whiteley, Harper, et al., 2015; Fernandez, Huszti, Wilson, et al., 2015; Martinez, Hosek & Carlton, 2009). Therefore, underlying factors such as lower socioeconomic status, unstable housing, and school nonenrollment may contribute to the onset of the psychological distress among YMSM, in general, and may exist prior to their HIV diagnosis.

Second, providers highlighted pronounced psychological distress among Latina youth living with HIV. This finding supports research that suggested Latina girls in particular exhibit high rates of depressive and suicidal ideation, compared to other racial/ethnic groups; thus, these high levels of psychological

distress may preexist their HIV diagnosis (Schoen, Davis, Collins, et al., 1997). Among young women, Latina girls report greater symptoms of depression compared to other groups (Saluja, Iachan, Scheidt et al., 2004; Schoen et al., 1997), requiring that special attention should be given to the mental health problems of young Latina women. Data on young Latina women living with HIV is scarce, but Martinez and colleagues (2012) reported experiences of psychological distress among Latina young women living with HIV. Substance abuse and high rates of psychiatric disorders are barriers to engagement in care for women living with HIV (Cook, Cohen, Grey et al., 2002; Shapiro et al., 1999). Thus, this study supports the perspective that study should continue on the mental health status of Latina adolescents, particularly those living with HIV.

Providers specifically discussed important transition periods among LYLWH that can exacerbate psychological distress, thereby negatively affecting their engagement in care. One key transition period is during their initial adjustment to their HIV diagnosis period, which can last up to a year, when youth may struggle with integrating HIV into their evolving adolescent identity. This finding supports the finding by Martinez and colleagues (2012) and Hosek, Harper, Lemos et al. (2007) that the first year after receiving an HIV diagnosis was a particularly difficult period of psychosocial adjustment for LYLWH. In summary, findings from this dissertation study support research that suggests Latino youth in general experience greater burden of psychological distress and that special attention is needed to address psychological distress during key transition periods.

Providers in this study indicated a strong relationship between psychological distress and substance use, especially among youth who were not receiving mental health services. Providers were concerned that untreated psychological distress could result in youth using or abusing illicit substances as a means of self-medicating. Providers were primarily concerned with the use of club drugs among Latino YMSM living with HIV. Club drugs in particular contributed to engaging in high-risk sexual behaviors such as sex with multiple partners or sex without condoms. This concern was supported by researchers who demonstrated a strong link between mental health problems and substance abuse, and their relationship to increased HIV risk (Rosario, Schrimshaw, & Hunter, 2006). Illicit drug use, such as the use of party drugs, can heighten sexual exposure, including unprotected anal intercourse, which can result in increased transmission of HIV (Garofalo, Mustanski, Johnson et al., 2010; Mutchler, McKay, Candelario et al., 2011). Furthermore, multiple studies have supported that illicit drug use, in particular methamphetamine and “poppers” are related to increased HIV-risk behaviors among YMSM, particularly among Caucasian and Latino YMSM (Diaz , Heckert, & Sanchez, 2005; Garofalo et al., 2010; Mutchler et al., 2011; Ramirez-Valles et al., 2008).

Providers in this study often discussed that periods of illicit drug use resulted in falling out of care for LYLWH, which also meant that some youth stopped taking their medications, which can increase viral load. For those living with HIV, increased use of these drugs can lead to onward sexual transmission of HIV, specifically if viral load if the insertive partner remains high. Limited

research findings focused on MSM living with HIV support this finding that illicit drug use, specifically club-drug use, affects HIV medication adherence, through planned nonadherence or unplanned nonadherence while using club drugs (Mayer, Colfax & Guzman, 2006; Reback, Larkin, & Shoptaw, 2004).

Although providers in this study acknowledged the potentially detrimental effects of other substances common among adolescents on engagement in care, such as alcohol and marijuana, they did not deem it as detrimental among LYLWH as club drugs. Although, club drugs play an important role in affecting engagement in care, in general, the proportion of Latino youth that use club drugs is generally lower than the proportion of Latino youth that endorse alcohol or marijuana use. Alcohol and marijuana abuse can affect medication adherence in the same manner that club-drug use affects medication adherence, but researchers showed mixed results in how they affect medication adherence. Hosek, Harper and Domanico (2005) and Murphy et al. (2001) reported that among HIV-infected adolescents/young adults, depressive symptoms and prolonged marijuana use or substance use predicted nonadherence. However, MacDonell, Naar-King, Murphy, et al. (2010) found that substance use did not vary among those adherent, compared to a nonadherent group, but a large proportion were not adherent in the previous month, suggesting that substance use alone does not determine medication adherence. It is possible that the cumulative effects of mental health problems along with substance use could cumulatively impact medication adherence (MacDonell et al., 2010). Finally, drug and substance use affects medical-appointment adherence among adolescents living with HIV. Dietz, Clum,

Chung et al. (2010) found that among young women living with HIV, frequent marijuana use was the only variable associated with missed medical visits, whereas depressive symptoms were high among this population but did not contribute significantly to missed appointments. Thus, addressing substance abuse for marijuana and alcohol use may be warranted for LYLWH, in light of the research findings, to enhance engagement in care at all levels.

Providers discussed multiple ways that substance use can directly or indirectly affect engagement in care, supported by research findings. Although researchers have not established a direct cause-and-effect relationship among substance use and engagement across the HIV continuum of care, the context-hypothesis posits that social activities may be the main factor that distracts from maintaining engagement in HIV care, rather than the disinhibition hypothesis that posits that individuals use drugs, then decide not to go to their appointments or take their medications (Dietz et al., 2010; Servin, Muñoz, & Zuñiga, 2014). For example, social and sexual networks can promote or inhibit engagement in care depending on the social norms that are part of these networks. Identifying particularly risky networks was of importance for providers to better address challenges with HIV drug adherence. As previously discussed, providers expressed concerns about particular social and sexual networks that promoted high-risk behaviors, including illicit drug use and high-risk sexual behaviors. These sexual networks were not prevalent among all LYLWH, but concerns arose, especially for those who were homeless. Homeless youth could fall into dangerous social networks that primarily focus on “getting high.” High-risk

behaviors occur in a close-knit network that facilitates the transmission of HIV, especially, if youth are not adhering to their medications, thereby increasing their viral load. This is particularly concerning because LGBT youth are more likely to be homeless (Keuroghlian, Shtasel, & Bassuk, 2014; Van Leeuwen, Boyle, Salomensen-Sautel et al., 2006). The potential to fall into these risky social and sexual networks is particularly high among homeless youth, and LGBT homeless youth are more likely to depend on street relationships than family that is instrumentally or emotionally supportive (Johnson, Whitbeck, & Hoyt, 2005).

Overall, psychological distress, substance use, and HIV-risk behaviors each uniquely contribute to the ongoing HIV epidemic to some degree. Although HIV-risk behaviors most directly relate to HIV infection and transmission, this study made clear that psychological distress and substance use impact HIV risk behaviors through direct and indirect mechanisms. Furthermore, mental health problems and substance-use problems extend beyond individual-level factors, and must be approached from a community-level or cultural-level lens to better understand how these factors impact HIV transmission and engagement in care (Servin, Munoz, & Zuniga, 2014). In a syndemic framework, this interrelated set of factors, as they relate to HIV infection and transmission, serves as a way to understand how these factors interrelate with engagement in care.

Syndemic Research Domain 2: LGBT Stigma, Gender-Specific Cultural Norms,
and HIV Stigma

The second set of interrelated themes that emerged from this study pertain to LGBT stigma, HIV stigma, and the interplay of gender-specific cultural norms.

As previously discussed, existent or perceived social norms that stigmatize same-sex behaviors, HIV, or gender-based expectations result in significant barriers to engagement across the continuum of care in multiple forms. LGBT stigma, HIV stigma, and gender-specific cultural values are not independent of each other and likely contribute interdependently to affect engagement in care across the continuum of care, thereby supporting the syndemic framework in discussing these issues (Halkitis, Wolitski, & Millett, 2013; Mustanski, Garofalo, & Herrick et al., 2007).

Although LGBT stigma is a general concern in society, in the context of this study, providers focused on LGBT stigma in healthcare settings as an important area of concern for engagement in care of LYLWH. According to providers, LGBT stigma limits receipt of HIV-related services by limiting the provision and uptake of HIV services across the continuum of care. This viewpoint aligns with researchers who suggested LGBT stigma affects healthcare experiences of LGBT across diverse healthcare settings (Wilson & Yoshikawa, 2007). Although a significant proportion of YMSM receive HIV testing in LGBT-community centers or venues, LGBT centers are not universally accessible or available to all LGBT. LGBT centers may only be accessible in LGBT-designated communities or LGBT-friendly community centers (Brooks, Etzel, Hinojos et al., 2005). LGBT youth may not have the option to access services at these centers if they do not have the adequate resources or time. Furthermore, they may have to access healthcare services at family health centers or primary-care centers where their parents also seek care. Therefore, it is important to understand how LGBT

stigma manifests in these settings, which may inhibit disclosure of LGBT orientation or same-sex activities, thereby limiting full-provision relevant risk-reduction counseling regarding social and behavioral health issues, including mental health, substance use, and sexual health (Makadon, Mayer, Potter & Goldhammer, 2008). This study lends support to the notion that healthcare professionals need to better understand the healthcare use patterns of LGBT youth.

Providers recognized the importance of ensuring access to equal treatment and quality of care for LGBT patients in primary-care settings. One way to improve such care is to educate, improve, and provide proper LGBT training for healthcare staff to better understand LGBT health issues. Of the few studies performed on providers' attitudes toward LGBT patients, approximately 25 to 28% of physicians or medical students felt somewhat uncomfortable or uncomfortable addressing LGBT needs (Dahan, Feldman, Hermoni, 2008; Wimberly, Hogben, Moore-Ruffin et al., 2006). Providers in this dissertation did not discuss LGBT stigma as coming directly from healthcare providers, per se, but did indicate concerns with LGBT-stigma directed toward LGBT youth at the clinic-level, mostly through insensitive front-line staff or heterosexist questionnaires that did not always account for sexual-orientation diversity among clients. Furthermore, providers in this study felt that stigma contributed to high rates of undiagnosed HIV among LYLWH seeking services in community-based health centers. Providers recognized addressing stigma as a challenge because LGBT Latino youth may not express or be asked about MSM behaviors by their providers, and thus, not receive appropriate routine screening for HIV or STI

services. For example, limited studies on discussion of sexual orientation found limited discussion of sexual orientation while obtaining sexual histories (Klitzmen & Gleenberg, 2002) and limited comfort of pediatrician, adolescent-medicine, or general practitioners in addressing the issue with patients (East & El Rayess, 1998). However, with the widespread implementation of electronic-health-record collection to gather sensitive information (Cahill, Singal, Grassal, et al., 2014) and enhanced educational initiatives discussing LGBT-related topics (Obedin-Maliver, Goldsmith, Stewart et al., 2011), this practice may be changing (Cahill et al., 2014). These clinic-level barriers have also been observed by providers in this study when they discussed gender-related differences in accessing HIV/STI testing services.

Providers expressed concerns with Latino youth accessing preventive services, such as HIV testing, in LGBT settings because of LGBT stigma, but also due to a sense of alienation from the larger LGBT community. Latino YMSM may also feel a lower connection to the gay community that can provide beneficial social support and health-promoting behaviors and services, supporting these findings (Harper, Fernandez, Bruce et al., 2013; Rosario, Hunter, Maguen et al., 2001; Waldo, Hesson-McInnis & D'Augelli, 1998). Furthermore O'Donnell and colleagues (2002) examined the role of gay-community attachment among 456 Latino YMSM in New York City and found that gay-community attachment was low among this group and related to unprotected anal intercourse; thus, it is not surprising that Latino YMSM would not seek services at LGBT-health centers.

Providers discussed the specific cultural norms prevalent in the Latino community and their impact on engagement in care. As previously stated, cultural norms related to traditional gender roles such as *machismo* and *marianismo*, which emphasize traditional husband and wife roles, promote HIV-risk behaviors due to the ability to discourage open discussion regarding sex before marriage, homosexuality, and equality in sexual relationships (Amaro & Raj, 2000; Maldonado, 1999; Mason, Marks, Simoni, Ruiz, & Richardson, 1995). For example, members of traditional Latino cultures tend to stigmatize and reject homosexual thoughts, fantasies, and behaviors, which can result in discrimination, rejection, and isolation from family and friends through the upholding of *machismo* or *marianismo* ideals (Diaz, 1998; Zea, Reisen, Poppen et al., 2003). This study supports researchers' findings that pressures from specific cultural expectations affect family, sex, and gender, and how nonconformity to those pressures can negatively impact YMSM from different racial and ethnic-minority backgrounds (Diaz, 1998; Peterson & Carbello-Dieiguez, 2000; Warren, Fernandez, Harper et al., 2008). This study further expands on extant literature by exploring how Latino cultural norms focus on gender-specific roles that uniquely serve as barriers or facilitators that can affect uptake of HIV services.

In the current study, providers discussed the gender-specific daily-life stressors and their effect on engagement in care for young women living with HIV. Providers described many of the young women as young mothers or having been diagnosed at time of pregnancy, which results in the expectation that they are to uphold family responsibilities such as being the primary caregiver for

partner, children, and family members. Primary-caregiver expectations relate to the cultural norm specific to *familismo*, which suggests family should come above an individual's needs. This cultural demand can affect adherence with medication and appointments because young women living with HIV may forego their own care when looking after family members. This cultural value of *familismo* may also be a source of support for engagement, as providers and researchers have also acknowledged that during specific circumstances such as during pregnancy, young women adhere to their medication to primarily prevent mother-to-child transmission (Nachega, Uthman, Anderson et al., 2012).

Familismo cultural emphasis requires Latino young men to contribute to the household financially, which may require these young men to take jobs that do not offer flexibility or paid time off to attend medical appointments, especially when they are not feeling sick. This finding is supported by studies suggesting companies hire Latino immigrants disproportionately for minimum-wage, service-industry positions and agricultural work that afford no benefits and limited job security (Larsen, 2004; Pew Centers for Research, 2007). Thus, when youth feel pressured to abide by these culturally specific gender demands stemming from *marianismo/machismo* or *familismo*, LYLWH may forego care to help the household with financial or family caregiving contributions.

A strong sense that HIV is highly stigmatized in the Latino community because of LGBT stigma and prevalent Latino cultural norms regarding gender and sexuality. HIV stigma, consisting of unfavorable attitudes, beliefs, and policies directed toward people perceived to have HIV/AIDS and their significant

others, peers, and communities (Chenard, 2007; Herek, 1999; Herek, Capitano, & Widaman, 2002; Lee, Kochman, & Sikkema, 2002; Parker & Aggleton, 2003) continues to contribute to fears of disclosure of HIV/AIDS status to significant others and healthcare providers (Harper et al., 2013; Swendeman, Rotheram-Borus, Comulada et al., 2006; Tobias et al., 2007; Wolitski, Pals, Kidder et al., 2009). HIV stigma was a primary deterrent to HIV disclosure, due to fear of potential prejudice, discrimination, and rejection. YMSM are affected by HIV stigma because they have acquired HIV through a socially unacceptable mode of transmission, in this case through MSM behavior (Herek & Capitano, 1999; Nepal & Ross, 2010). HIV stigma is a significant barrier to HIV disclosure, which directly affects obtaining social support with adjustment to HIV diagnosis.

HIV stigma affects where and how youth access services across the continuum of care. This aligns with significant research highlighting the relationship between HIV stigma and access to HIV services (Harper et al., 2013; Tobias et al., 2007; Wolitski et al., 2009). For example, when clinics provide HIV services, youth may avoid them, even for HIV testing, so as not to bear the HIV stigma (Harper et al., 2013; Tobias et al., 2007; Wolitski et al., 2009). Studies examining perceived HIV stigma from providers reported significant associations with lower access to care (Kinsler, Wong, Sayles, Davis, & Cunningham, 2007) and greater likelihood of missing doctors' appointments (Bird, Bogart, & Delhanty, 2004). PLWH who perceive stigma from healthcare providers may avoid healthcare contexts because they anticipate stigma from providers. PLWH must openly discuss the emotional distress associated with having to disclose their

HIV status to multiple providers without knowing how they will react. Oftentimes, providers discussed LYLWH experiencing difficulty with disclosing to others out of fear of rejection or discrimination. Furthermore, PLWH who perceive stigma from others in general are also more likely to miss clinic appointments for HIV care (Hosek, Harper, & Domanico, 2005; Murphy et al., 2001; Rao, Kekwaletswe, Hosek et al., 2007; Vanable, Carey, Blair, & Littlewood, 2006).

Although each of these factors contribute significantly to engagement in care for LYLWH, many have difficulty documenting these factors independently, thereby warranting a syndemic framework. Each of these factors strongly overlaps in how they affect LYLWH. Silent HIV stigma is pronounced among certain groups including among African American and Latino communities and among religious groups (Berg & Ross, 2014). A primary reason for HIV stigma in the Latino community is its association with strong cultural norms surrounding *machismo*, as HIV signifies a lack of masculinity (Berg & Ross, 2014). LGBT youth living with HIV may feel further alienated in these settings because of the lack of culturally sensitive and appropriate education to address each of these compounding issues. One relevant contribution of the syndemic framework is that the concept of deviance and cultural norms underlays stigma, and one stigma of HIV stems from male homosexuality and deviation from scripted cultural norms, thereby contributing to an increased sense of social marginalization.

Syndemic Research Domain 3: Poverty, Acculturation, and U.S. Documentation

Status

The final set of interrelated themes that emerged from this study pertain to poverty, acculturation, and U.S. documentation. Researchers documented that a large proportion of Latinos live in poverty, experience some degree of acculturation during their adolescent development, and a significant number of LYLWH have experiences with undocumented status, either individually or among family members. These themes tend to cluster as community-level and policy-level factors.

A significant barrier for engagement in HIV care among LYLWH is living in poverty. A large portion of Latino youth experience poverty. According to the U.S. Census Bureau, in 2013, Latinos were overrepresented among the poor, making up approximately 28% of poor Americans and 37% of children in poverty. The disproportionate rates of poverty among Latinos, specifically among children and adolescents, have important implications for engagement in care, as families experiencing poverty may experience significant financial barriers to accessing regular care. One of the difficulties in establishing engagement in care often relates to the lack of access to health insurance, which makes it difficult for providers to promote regular care, in comparison to acute care. This finding is supported by multiple researchers who asserted that lower socioeconomic status is not only a risk factor for HIV infection, but is also a leading cause in the progression to full AIDS: a likelihood much greater for financially impoverished individuals (Amaro, 1995; Borrayo & Jenkins, 2003; Giordano et al., 2005; Marin, 1993; van Servellen, Chang, & Lombardi, 2002) due to poverty-related outcomes, such as lack

of access to health care. In addition, and for reasons still unknown, individuals with lower socioeconomic status are not always given more advanced or aggressive available treatments (Lopez, 2007). Thus, poverty is an independent and significant contributor that poses barriers for continued engagement in care among LYLWH.

Acculturation, which focuses on the process of integrating one's identity to that of the dominant culture, is a relevant factor for maintaining engagement in care among LYLWH. More recent, less acculturated youth take part in more health-promoting behaviors, compared to more acculturated and "Americanized" LYLWH. This outcome supports researchers' documentation of significant relationships between immigration, acculturation, and health status among Latinos living in the United States (Denner et al., 2005; Ehrlich et al., 2007; Marin et al., 1993; Organista, Carrillo, & Ayala, 2004; Rodriguez, Bustamante, & Ang, 2009; Sanchez et al., 2012; Villaruel et al., 2004). Earlier findings, termed the immigrant health paradox, suggested that acculturation has important implications for accessing healthcare services and engaging in health-promoting behaviors (Rodriguez, Bustamante, & Ang, 2009). Initially, the immigrant health paradox demonstrated better health outcomes among more recent immigrants than among U.S.-born Latinos, despite having poorer access to healthcare preventive services, perhaps due to lower participation in HIV risk behaviors (Denner et al., 2005; Ehrlich et al., 2007; Rodriguez, Bustamante, & Ang, 2009). Providers in this study supported the notion that less acculturated and more recent immigrants engaged in less HIV risk behaviors.

However, for HIV, the immigrant paradox reveals more complicated relationships regarding the outcomes of U.S.-born and foreign-born Latinos living

with HIV (Espinoza et al., 2012; Levy et al., 2006). Findings largely supported this complicated relationship. Providers recognized differences in prognosis related to HIV/AIDS among immigrant and U.S.-born Latino YLWH. More recent immigrant youth were more likely to receive a diagnosis at a later stage, usually exhibiting AIDS or very rapidly declining health, suggesting they may have been infected for a long time. For the most part, providers attributed this late-stage diagnosis to lack of access to preventive services, along with stigma surrounding HIV testing. However, once diagnosed, recent-immigrant youth more likely adhered to care and medications: immigrant LYLWH had better engagement across the continuum of care after diagnosis. However, immigrant youth living in the United States since childhood were more similar to that of U.S.-born LYLWH. Some providers expressed stark differences in treatment adherence and engagement between recent immigrants and U.S.-born LYLWH. Recent immigrants engaged in fewer risk behaviors such as binge drinking or frequent illicit drug use, which have been linked to reduced interruptions in adherence to medication or medical appointments. In contrast, U.S.-born LYLWH struggled more with medication and appointment adherence for HIV-related care due to increased participation in risk behaviors such as binge drinking and illicit drug use. These findings support research highlighting the role of acculturation in acquiring HIV among Latino immigrants. Specifically, acculturation may increase vulnerability among immigrants by fostering the selection of risky behaviors (e.g., drug use, unsafe sex practices; CDC, 2009).

The final thematic finding in this study relates to the role of documentation status for LYLWH or family members and its importance in understanding disruptions in engagement in care. Although not all Latinos or Latino immigrants are undocumented, a sizeable proportion of Latino youth who are undocumented currently live in the United States. Furthermore, some U.S.-born Latino youth have at least one parent who is undocumented. According to the Pew Center (2010), it is estimated that 8% of youth in the U.S. have at least one undocumented parent. Given the relatively recent enactment of ACA, a dearth of research describes how ACA will impact these youth in engagement across the continuum of HIV care. ACA mandates apply only to legal U.S. residents or citizens, thereby leaving the undocumented population without ACA provisions for health insurance. Providers acknowledged that documentation status does not inherently present challenges for treatment and care, as many safety-net services are available through the Ryan White Care Act and last-resort state or local funding. Researchers estimated that, after implementation of the Deferred Action for Childhood Arrivals in 2012, 2 million undocumented youth received a 2-year amnesty; however, they continue to face the same restrictions regarding health coverage as other undocumented individuals (Castaneda & Melo, 2014; Gonzales-Guarda, McCabe, Florom-Smith et al., 2014; Martinez, 2014). As to medication adherence, providers did not discuss wait lists or inability to enroll undocumented youth into care or treatment; thus, researchers should further examine the context under which these services are extended for these youth, as

documentation status serves as a barrier to healthcare insurance access and use in general (Gonzales et al., 2014).

The underlying issue surrounding documentation status relates to perceptions of confidentiality and privacy that often serve as barriers to accessing services, such as HIV testing and linkage to care for Latino youth, particularly more recent immigrant youth. Many providers acknowledged this sense of distrust from LYLWH, stemming from fears that their or their family's undocumented status would be shared with government officials. Providers, who have limited contact with youth, have difficulty overcoming this perception, for example, at public venues or venue-based testing events. These findings align with previous research with undocumented Latinos living with HIV: fear of deportation deterred them from seeking medical care (Cunningham et al., 2000; Dang, Giordano, & Kim, 2012). Fear of deportation has important implications for delaying or foregoing HIV treatment among undocumented individuals, when deportation can result in complete loss of HIV care. Furthermore, those youth who arrive in the United States without parental supervision have higher risk of transiency, making it difficult to maintain regular engagement at a particular site or to be consistent in keeping appointments.

Providers acknowledged acculturation as significantly interacting with being primarily monolingual Spanish-speaking. This was particularly relevant for late testing (i.e., receipt of an AIDS diagnosis within a year after testing) among LYLWH. For example, in a study of 45 U.S. border communities, people who were foreign-born were most likely to be late testers (Espinoza, Hall, Helick, &

Hu, 2008). For Latino immigrants, especially those who are Spanish-language dominant, these barriers to care may carry important significance due to great differences in the healthcare systems and requisites between the United States and their home countries (Gonzales et al., 2009). Learning to navigate these systems can be an emotional and time-intensive challenge that may hinder access to important healthcare services. Spanish-language dominance marks a particularly vulnerable subpopulation of U.S. Latinos for whom access to care and use of preventive care are more difficult than for English-speaking Latinos.

In summary, these community-level and societal-level factors contribute to a syndemic host of barriers and opportunities for engagement that can affect uptake and continued engagement across the continuum of HIV care, which affect individual-level outcomes of LYLWH. The intersection of poverty, acculturation, and immigration status may widen disparities related to engagement in care, including access to services, quality of life, and continuity of care. Socioeconomic disadvantages in income, documentation status, level of acculturation, and primarily Spanish-language dominance place LYLWH at stark risk for falling out of care.

Specific Findings From the Current Socioecological Framework

This section explores how the current findings extend the current literature on specific socioecological factors that contribute to engagement in care for LYLWH. Mugavero et al. (2011) and Poundstone (2004) highlighted the importance of understanding the biological, social, political, and historical factors that influence HIV acquisition and disease progression to improve engagement in

care for PLWH. Thus, in the following section, I highlight relevant findings from this study, by socioecological level, and discuss how they affect engagement in care for LYLWH. I also discuss how each of these findings fit with extant literature and describe gaps in the current research.

Individual-Level Factors

In this study, providers described several individual-level factors that affect engagement in care across the continuum of care for LYLWH. Predisposing factors such as age, gender, mental health, substance use, and survival needs can facilitate or challenge engagement in care. Of these, providers described challenges with mental health, substance use, and survival needs as most challenging for engagement in care. Researchers documented how these factors affect medication adherence; specifically those psychosocial barriers related to depression, concerns about stigma, and fear of disclosing their HIV status through medications and other substance use, particularly marijuana (Hosek, Harper, & Domanico, 2005; Murphy et al., 2001; Rao, Kekwaletswe, Hosek et al., 2007). The current study extends the research by expanding how these findings affect different aspects of the continuum of HIV care for Latino youth living with HIV, including prevention, linkage to care, engagement, and retention in care.

Primarily, this study supports a wealth of research that suggests mental health demands special attention among subgroups of Latinos including Latinas, adolescents, and MSM. LYLWH struggle with untreated preexisting mental health issues such as childhood sexual trauma or depression and anxiety, which could be exacerbated by the HIV diagnosis. Depressive symptoms are prevalent in

the Latino community, with rates as high as 50% among Latina women and 20% among Latino men (Familiar et al., 2011; Minsky, Vega, Miskimen et al., 2003; Rhodes et al., 2013; Todorova, Falcon, Lincoln et al., 2010; Vasquez, Gonzalez-Guarda & Santis, 2011). A respondent-driven study of Latino GBT men suggested that the rates are much higher among this population, ranging from 69.2% to 74.8% (Rhodes et al., 2013). As a response mechanism, youth may withdraw from care, including medication, as they try to address their emotional health, usually without professional help. One common way to address untreated mental health traumas or illnesses is through the use of alcohol or other drugs. Thus, LYLWH coping with mental health issues and substance use/abuse may be more difficult to engage over time, as their substance use takes greater precedence over their health. Providers highlighted substance abuse as one of the challenges for continued engagement in care.

Researchers documented that substance use, not just substance abuse, affects engagement in care among PLWH. Various drugs have different effects on whether people engage in care or adhere to their medications, with more illicit drugs affecting medical engagement and more common drugs more directly affecting medication adherence. For example, Ramirez-Valles and colleagues (2008) reported that among Latino GBT populations, drug and alcohol use were a significant public health problem; however, drug use more closely linked to HIV sexual-risk behaviors such as unprotected anal intercourse, which can result in HIV transmission or reinfection. Drug use ties to cyclical interruptions in care as well as medication adherence. Providers expressed critical points, such as when

youth undergo active substance-abuse binges, as when they are more likely to drop out of care and not take their medications.

Attention is growing about the role of protective factors among YLWH in positive contextual, social, and individual forces that disrupt or interfere with disruptions for engagement in care (Fergus & Zimmerman, 2005; Harper et al., 2014; Zimmerman, 2013). Providers observed that LYLWH who had healthy sexual-orientation self-assessment and self-esteem were more likely to remain engaged in care, despite experiencing similar barriers about potential exposure of their GBT or HIV status at a particular clinic. Youth with a healthy sense of who they are will not be as affected emotionally, cognitively, and interpersonally if their sexual orientation or HIV status is revealed because the health-promoting cognitive processes promote healthy behavioral practices that, in turn, encourage youth to enlist supportive others and empower others. These findings extend the Harper et al. (2014) research that young gay and bisexual males living with HIV who are able to reveal their HIV diagnosis and maintain a positive self-image desire to obtain supportive and educative roles. These roles reinforce their desire to serve as healthy role models for others who are at risk for HIV or who are living with HIV. To serve as healthy role models, they live a healthy life style, supporting active engagement across the continuum of care, reinforced by taking responsibility for their health care and health outcomes.

Providers felt youth did not perceive or acknowledge their risky sexual behaviors; thus, they did not see a need for routine HIV-prevention testing or for using condoms. Among those living with HIV, perceptions of being healthy

affected whether they felt the need to continually engage in care. Youths' definition of healthy also complicated their ability to remain engaged in care, as many tied their asymptomatic state to being healthy, and perhaps not needing to be involved in care. Other reasons stem from cultural conceptions of health that I will describe further at the cultural level.

This study found support for the psychosocial impact of disclosure and its impact on engagement across the continuum of care. Providers described specific challenges with medication adherence for those youth who are keeping HIV a secret from others. For example, providers described how psychologically stressing it can be to keep HIV a secret, as youth must plan out every detail about their medication including storage, uptake, and pharmacy refills or deliveries. These findings fit with the descriptions of the psychosocial stressors associated with disclosure among PLWH and YLWH, particularly the vulnerabilities surrounding disclosing to family members and significant others (Hosek, Harper, & Domanico, 2005; Martinez et al., 2012; Murphy et al., 2001; Rao, Kekwaletswe, Hosek et al., 2007). This study extended findings by describing the contextual vulnerabilities experienced by these youth. Youth may become overwhelmed when their privacy is limited by environmental constraints (i.e., sharing a room or living at home); they may seek to forego medications, especially if they do not feel sick. These dynamics have important implications for providers who wish to assist in improving medication adherence.

Interpersonal-Level Factors

Interpersonal-level factors were extremely important in promoting engagement in care for LYLWH. Providers described key relationship dynamics with family, providers, friends, and sexual partners that affected engagement in care. The following section highlights relevant contributions, describing how interpersonal-level factors relate to extant literature on engagement in care.

Research on the HIV epidemic among Latinos generally focus on parents and sexual or romantic partners (Harper et al., 2012; Miller, McCoy, Olson & Wallace, 1986). This study confirmed findings that family-level relationships across mesosystemic connections were crucial to generate protective effects against HIV risk behaviors (Garbarino & Abramowitz, 1992). This study extends these findings by highlighting the importance of mesosystemic connections between parents or family members and medical providers. In this study, providers found that relationships between parents and clinics was important to maintain engagement of care for LYLWH. Providers overwhelmingly described the importance of having family members involved in LYLWH's care. Interestingly, providers noted tension between HIV and acceptance of sexual-orientation status for YMSM and their families, but oftentimes, families would prioritize their health status over their sexual orientation. Providers deemed this conditional acceptance to mean that the family would still be emotionally and instrumentally supportive in youths' HIV care, but would still not approve of their sexual orientation. Providers highlighted that even conditional support was a facilitator to maximize engagement.

Provider dynamics serve as crucial facilitators for maintaining engagement in care. Mallinson, Rajabiun, and Coleman (2007) conducted in-depth interviews with PLWH and reported that provider behaviors characterized as engaging, validating, and partnering facilitated engagement and retention in care; behaviors described as paternalistic served as barriers to care. Thus, providers should emphasize positive characteristics as clinic-level variables that affect engagement in care for PLWH. Participants in the Mallinson et al. study indicated they desired a care partnership with an empathetic provider who had effective communication skills. Specifically, the interplay of cultural values and relationship dynamics among LYLWH are important considerations for engagement in care.

This study confirmed results that providers serve as an important source of support for LYLWH. Providers recognized that these relationships gained relevance, particularly when youth had not disclosed their status to anyone else. Providers who could connect socially, emotionally, or culturally were specifically relevant. Socially, these providers were able to put the youth at ease. Emotionally, providers could express genuine emotion that translated to a youth feeling they mattered and the provider recognized them. At times, providers could also demonstrate interest in the youths' culture or indicate if they were from a similar cultural background. Cultural background could extend to providers reflecting the youth across diverse domains such as similar sexual orientation, race/ethnicity, or language skills. Providers recognized that staff also needed to possess these skills to work with such youth. However, these skills were practiced intermittently by providers or clinical staff, oftentimes reflecting the culture of the clinic providing

such services. If clinic administrators do not value these skills or hire personnel that reflected the diversity of those being served, youth may feel unwelcomed.

Providers acknowledged several clinic-level factors that affected engagement in care for LYLWH. Despite limited data on healthcare delivery and medical care of YLWH, useful tools should be implemented when developing adolescent-specific models of care for YLWH. The World Health Organization (WHO, 2005) called for the development of youth-friendly services worldwide. Issues related to accessibility, appropriateness, availability, and effectiveness were relevant to promoting or inhibiting engagement across the continuum of care.

The present study highlights the importance of these clinic-level services for LYLWH. Accessibility was an important consideration for LYLWH: providers recognized that any insurance or monetary requirements could translate into barriers to accessing care. In general, clinics provided free- or reduced-fee services for the clinic population because, for many youth, particularly those who are undocumented, these clinics were often last-resort services.

Providers acknowledged that cultural sensitivity is important for working with Latino youth. Along with cultural appropriateness, sexual-orientation diversity and competency are important. Youth seek services that are accepting and nonjudgmental toward their GBT identity. The importance of cultural appropriateness can affect whether youth receive continued services at the clinic. Cultural and GBT appropriateness ensures providers can build long-term relationships with youth and helps promote communication about any healthcare needs or services.

Interestingly, although adolescence is a time when friend and romantic relationships are forming and becoming increasingly important for youth, providers felt these relationships were not as crucial for maintaining engagement in care for LYLWH. Perhaps, due to the rapidly changing and, at times, tumultuous dynamics in these relationships, providers assessed they are not stable enough to help promote engagement for these youth. In contrast, providers recognized that breaks in these relationships affected engagement in care because ending a relationship or friendship could result in increased substance use or depressed or anxious mood. Breaks in relationships were periods of concern for providers who did not want youth to fall out of care during these times. Providers believed that youth had unhealthy coping skills to navigate such relationships. Especially if relationship dynamics were unhealthy from the onset, such break ups tended to be much more tumultuous and impactful on youths' engagement in care. For example, they were more likely to miss a medical visit because they were feeling depressed or perhaps, stopped taking their medications if they have been intoxicated or under the influence of drugs or alcohol.

One study with young women living with HIV found that romantic partners or expartners served as sources of stress after diagnosis. Generally, the men rejected the women after hearing of their HIV status or subjected or augmented the emotional abuse of the women in the relationships (Hosek, Brothers, Lemos & ATN, 2012). Although rejection and emotional abuse occur in relationships, these relationships can also be supportive. For example, Harper and colleagues (2014) reported that young gay and bisexual men living with HIV

described romantic partners or expartners as an important source of positive support, emphasizing a strong affective component that suggested these relationships provide an important opportunity for psychosocial well-being.

Community-Level Factors

Community-level factors stemmed from compounded stigma in communities. Many LYLWH were exposed to compounded stigma against LGBT and HIV in their communities or surrounding communities. The community-level stigma toward HIV may compound or interact with the individual-level acceptance of their HIV status. Youth who accept their HIV status can experience discrimination or heightened risk for bullying or violence in their neighborhoods or communities (Earnshaw, Bogart, Dovidio & Williams, 2013). Furthermore, living in communities in which LGBT stigma is high or perceived to be high may affect whether youth are able or willing to receive ongoing HIV-related services in their community. Youth are keenly aware of the cues in their communities and can be reluctant to access services in their community if agencies providing services are particularly tied to a stigmatized group. For example, if a community clinic is known to provide services to people living with HIV, youth may be unlikely to want to access such services. If the community clinic is known to provide services to LGBTQ-identified individuals, youth who are not open about their status will avoid these clinics to prevent exposing their identity. Furthermore, Latino youth who are undocumented may forego services they believe may expose their residency status to local or state authorities (Earnshaw, Bogart, Dovidio, & Williams, 2013).

Sociocultural/Policy Level Factors

Providers described many sociocultural factors tied to the Latino culture that can affect engagement across the continuum of care for LYLWH. Although not all LYLWH share these cultural values, a significant subset of these youth have been exposed to these values, either through their upbringing or through their community's shared values. Such values can facilitate or inhibit engagement in care. Specifically, *machismo*, *familialismo*, *respeto*, *fatalismo*, and *personalismo/simpatia* all have important implications for engagement in care. Furthermore, the role of cultural religiosity, distrust of government and healthcare systems, and uptake and use of folkloric or homeopathic medicine also affect engagement in care. Studies confirmed that cultural values affect uptake of such services for chronic illnesses such as diabetes, breast screening, and other health concerns (Borrayo & Jenkins, 2001; Keesee, Ahmad, Nelson et al., 2004).

Strong identification or exposure to these values has the potential to positively or negatively influence engagement in care in unique ways. For example, Keesee (2004) applied a cultural health model with LYLWH along the U.S.–Mexico border and found that experiencing a lack of symptoms led to questions about validity of the diagnosis and the potential for nonadherence to medical-treatment regimens. The current study supports these findings as providers acknowledged that cultural factors may not necessarily inhibit engagement in care such that youth would not forego healthcare services, but these values affect uptake and decision making related to medication adherence and clinic-appointment adherence.

These cultural factors are particularly relevant to communication dynamics among providers, family members, and LYLWH. In addition, providers acknowledged that awareness and attention to these cultural values has the potential to promote long-term relationships with LYLWH, as they can allow youth to openly express their concerns. *Fatalismo*, or the belief that HIV/AIDS is a fatal illness, can have an impact on regular testing and early service access, as the fear of being diagnosed can keep youth from being tested initially or obtaining their test results. Keesee et al. (2004) found support for this perception among patients living with HIV. Furthermore, Martinez et al. (2012) found that LYLWH experienced such denial when obtaining test results, perhaps as a protective mechanism against the pending “death sentence.” Many providers focused on the role of *marianismo/machismo*, due to the contextual vulnerabilities of sexuality and gender due to the behavioral transmission of HIV; however, understanding cultural values that extend beyond these are also important to improve engagement in care among LYLWH.

At the policy level, several findings supported current research documenting that medical insurance, U.S. documentation status, and the current U.S. medical model can pose challenges for continuity of HIV care for YLWH. Although medical insurance is widely available for PLWH, challenges and barriers continue to emerge that put LYLWH at risk of falling out of care. Providers discussed challenges with LYLWH falling through the linkage-to-care process, and therefore not receiving access to medical insurance in a timely manner. Providers described the process of gaining healthcare insurance and

maintaining it as cumbersome for youth, particularly in filling out paperwork and other tedious requirements to maintain insurance.

U.S.-documentation status severely affects engagement in care because it creates distrust for accessing medical services out of fear of being deported or having family members deported. Initially, this serves as a deterrent, particularly for HIV testing and linkage-to-care. Providers acknowledged that as they built trust with clients, they were able to calm the fears of these youth, which improved engagement in care.

Providers acknowledged that barriers would arise as undocumented individuals would not qualify for ACA medical coverage. Researchers documented that severe restrictions imposed on immigrants' eligibility for Medicaid-funded services followed the passage in 1996 of the federal Personal Responsibility and Work Opportunity Reform Act and the Illegal Immigration Reform and Immigrant Responsibility Act (Nandi, Galea, Lopez et al., 2008). Furthermore, the recent passage of ACA further excluded undocumented immigrants from obtaining healthcare insurance. Therefore, undocumented immigrants represent a vulnerable population at higher risk for disease and injury than either documented immigrants or native-born U.S. citizens (Kullgren, 2003; Marshall, Urritia-Rojas, Mas et al. 2005).

More than two thirds of undocumented immigrants are uninsured, less than 60% have a regular medical provider, and the majority rely on federally qualified health centers and emergency departments for last-resort care (Sommers, 2013). Thus, policy measures should consider how to ensure privacy and

confidentiality across medical settings, particularly when immigration law enforcement produces a “chilling effect” on Medicaid participation by eligible citizens who live with noncitizen family members (Sommers, 2013; Sommers, Roberts Tomasi, & Swartz, 2012). A disproportionate number of Latinos living with HIV rely on Ryan White HIV/AIDS program services; although Latinos represent 17% of the U.S. population, they account for a quarter of participants in Ryan White HIV/AIDS programs.

Providers discussed the challenges associated with maintaining engagement because of the ongoing paperwork necessary to obtain such paperwork. In a study conducted by the Health Resources and Services Administration regarding the needs of Latinos and HIV services, participants reported barriers to completing intake forms more than 40-pages long and often completing them more than once. Thus, it is important to understand how these processes can be streamlined to reduce patient burden, particularly among those who already experience limited English-language facility or limited experience navigating the U.S. healthcare system (Health Resources and Services Administration, 2011).

Implications for Practice and Intervention Development

In this section, I present an overview of the results and how they can be used in preventive, clinical, and community settings to promote engagement in care across the continuum of care for LYLWH. Findings from this study have various implications for research, practice, and policy. By exploring providers’ perspectives and experiences working with LYLWH, I generated

recommendations that guide the development of tailored approaches for multilevel interventions on engagement in care for Latino youth living with HIV or for Latino youth at high-risk of acquiring HIV.

Providers described strong linkages between substance use and abuse, mental health issues, and HIV-related risk factors as important contributors to continued engagement in HIV care. These intersecting conditions can detrimentally affect continued engagement at any stage along the continuum of HIV. Therefore, it is important to target these health or behavioral conditions among Latinos. Although these conditions have high rates of co-occurrence with mental health disorders and substance use, relatively few programs support youth with these conditions or circumstances. Few programs provide support for Latino youth in addressing substance abuse (De Arellano et al., 2005; Jaycox et al., 2002; Rossello & Bernal, 1999). Programs fail to address the critical issues highlighted in this study: the need to examine Latino youth's lives in entirety from a socioecological framework, to understand and recognize the many influences that shape how and where they are able to receive HIV services across the continuum of care. A review of the literature did not uncover any study that focused exclusively on the barriers or facilitators for engagement to care among LYLWH, much less one that examined the contextual factors and issues affecting this particular population. This qualitative study, in exploring the perceptions of providers working with this population, provides a richer understanding than existed in the current literature to date.

In addition to the theoretical implications alluded to earlier, this study has important implications for the field of community psychology, particularly in the areas of practice and intervention development. In addition, many implications are relevant for professionals in allied disciplines (public health, health care, etc.), given the emphasis in this study on the nature of HIV/AIDS, the psychosocial needs of LYLWH, and the continuum of HIV care.

First, this study may benefit those who work with Latino youth who are at risk for HIV infection, LYLWH, or all Latino youth. Understanding youths' situations from a socioecological framework requires detailed information about the barriers and challenges for engagement in care of Latino youth not found elsewhere. Although provider perspectives cannot duplicate perspectives of Latino youth or LYLWH, the data nevertheless suggest the kinds of issues clients, patients, or service recipients may present in medical, research, and mental health settings.

Second, effective community psychologists working with LYLWH require an understanding of and appreciation for the context of their lives. This dissertation illuminates for practitioners how poverty, culturally prescribed values and beliefs, and political forces, individually and in combination, influence not only how others see Latino youth, but more importantly how Latino youth make meaning of their own lives. Although disease and illness in society have a primarily biological underpinning, in general, they do not occur in a vacuum isolated from other social forces, and the effects of these social forces are more pronounced among stigmatized diseases such as HIV. Therefore, it is important to

examine how these social forces affect how Latino youth hear and respond to prevention and treatment approaches. This dissertation adds to the knowledge base that will help practitioners identify the barriers and facilitators of engaging more Latino youth across the continuum of care, in particular to improve the uptake of prevention approaches to help curb the HIV epidemic among this population of concern.

Third, practitioners must learn about the relationship dynamics that impact Latino youth, if they are to respond effectively with interventions or programs. Practitioners should be able to identify barriers that impede empowerment and to equip Latino youth with the tools necessary to allow youth to advocate for themselves the types of treatment and prevention approaches that best meet their needs. Special attention is demanded to understanding the cultural requirements and influences on Latino youths' ability to obtain education, prevention, and treatment access. Thus, practitioners should be mindful of finding culturally appropriate ways to educate Latino youth.

The results from this study highlight important considerations for practitioners working with LYLWH. In considering practice recommendations, I integrated the relevant themes from this study with extant literature regarding effective interventions that assist in engagement in care. I intend these recommendations to impact change across socioecological levels to enhance engagement in care by specifically targeting the challenges and integrating the facilitators to engagement in care discussed by providers. I offer the following recommendations for practitioners to consider when designing programs or

interventions using a socioecological approach to improve engagement in care for Latino youth across the continuum of care:

Individual-Level

1. Promote culturally appropriate and sensitive HIV education, health literacy, and life-skills training that especially attend to age, gender, language, immigration status, and level of acculturation.
2. Provide referrals or provide assistance with basic needs that compete with HIV care such as those related to poverty, unstable housing, or lack of insurance.
3. Facilitate entry to care for special populations such as recent immigrants, youth aging up to adult services, and youth who are homeless.
4. Implement routine assessment and linkage for prevalent conditions among Latino youth such as mental illness, substance abuse, or addiction.
5. Develop and implement culturally tailored and language-appropriate HIV-prevention programs to address HIV risk factors related to falling out of care or late entry, such as lack of HIV knowledge, HIV course of disease, and factors related to engagement in HIV care such as provider–client communication skills (assertiveness skills).
6. Attend to gender-specific needs of young people living with HIV that consider psychosocial barriers to engagement in care, such as

disclosure concerns surrounding HIV or sexual orientation to family members.

Interpersonal Factors

7. Provide psychosocial support using a family-centered model to attend to concerns of Latino families of LYLWH.
8. Attend to family-centered model of HIV care and treatment for LYLWH to build on the strengths of Latino families of LYLWH.
9. Use peers in the clinic settings that reflect the diversity of clients: for LYLWH include young women and Latino YMSM, and GBT-identified youth for outreach, education, navigation, and psychosocial support.
10. Improve provider communication regarding sensitive issues relevant to healthcare beliefs, cultural beliefs, traditional medicine, and so on.
11. Include bilingual English- and Spanish-speaking bicultural staff members who can communicate with LYLWH and their family members.
12. Provide education materials in English and Spanish at the facility.

Clinic-Level Factors

13. Train providers and front-line staff to provide culturally sensitive, adolescent-friendly, and LGBT-sensitive services and communication with clients.

14. Provide rapid or same-day intake and initial clinical assessments to minimize burden on clients, especially those with limited control over their schedules.
15. Implement scheduling and reminders to reduce missed appointments among LYLWH.
16. Ensure access to medical case management to improve adherence to appointments and to link LYLWH to other needed services.
17. Provide accessible HIV care through one-stop centers, family-centered care, child-care services and youth-friendly services to minimize travel demands on clients. Youth friendly services should include youth input in the decoration and design of waiting rooms or clinic spaces.
18. Provide incentives for treatment such as bus fare and meals or snacks to minimize burden of long clinic visits.
19. Implement a universal HIV-testing protocol to reduce participant burden to disclose potentially stigmatizing HIV risk behaviors.
20. Implement a universal substance-abuse and mental health-screening protocol to improve linkage to care for youth experiencing these issues.
21. Train staff on holistic medicines and practices used by Latino patients to treat disease and promote well-being.

Community-Level and Sociocultural-Level Factors

22. Develop partnerships with community-based organizations to address HIV, LGBT, and mental health stigma.

23. Promote culturally relevant, gender-specific HIV education through local media venues.
24. Promote HIV testing initiatives that integrate other general-health initiatives such as cervical cancer screening and diabetes screenings.

Sociocultural/Policy-Level Factors

25. Design and implement social-marketing campaigns to change social and cultural norms such as the negative effects of *machismo/marianismo*, cultural sexual silence, or *fatalismo* attitudes.
26. Advocate for income equality to address issues surrounding poverty.
27. Advocate for immigration reform that provides a pathway to citizenship for undocumented parents of mixed-status households as a basic step to improving the well-being of children and adolescents.
28. Advocate fair labor practices for immigrant workers to allow flexibility and requested time off to ensure continuity of care.
29. Incorporate into universal and selective prevention programs understanding of the societal-level influences of heterosexism and masculinity ideology and the individual-level influences of sexual-identity and ethnic-identity development.

Strengths and Limitations

This study has several strengths and limitations. An important strength of this study is the examination of multiple ecological factors that may impact engagement across the continuum of care for LYLWH. Although engagement in care can be viewed strictly as individual-level behavior by focusing on the act of

attending medical appointments continually, engagement in care does not occur in a vacuum independent of other factors; this study attempted to explore the impact of socioecological factors—including culture, religion, and policy—that effect engagement in care for LYLWH.

Another strength of this study was its qualitative design. Using qualitative data allowed for a fuller description of providers' insights pertaining to engagement in care. Providers explained their ideas and understandings of contributing factors and challenges in their own words. Spontaneous outcomes arose that may not have emerged if the study was quantitative. For example, discussions about specific cultural attributes (*fatalismo*, *personalismo*) that affect engagement in care may not have emerged if providers did not describe their experiences of the challenges to engagement for LYLWH.

A third major strength of the study was the focus on the population of interest, LYLWH, specifically by focusing on the age and diversity of the demographic groups explored for this study. For example, providers shared insights gained from working with various Latino ethnic groups (e.g., Puerto Rican, Mexican, and Dominican), which allowed for exploration of a diversity of experiences. As a result, this study examined the needs and challenges of Latino youth, at risk or living with HIV; a relatively understudied adolescent sample in the academic literature and practice. Last, this study incorporated a diversity of provider types from large city, clinical, and community settings across four cities in the United States. This strength lends credence to the idea that the experiences reported by participants are not geographically unique.

Despite multiple strengths to this study, limitations also exist. The biggest limitation is that the data were not collected with the primary population of interest, LYLWH; instead data accrued using providers' perspectives. This prevented the in-depth analysis of narratives on specific aspects of engagement in care originally conceptualized or obtaining first-hand narratives of the challenges these youth face, which may differ from the challenges providers perceive. Furthermore, narratives of providers' may be biased based on their own demographic and professional background and through their own unique experiences with Latino youth. Unfortunately a one-time interview may not be able to fully capture and account for this in the analysis.

Second, I recruited participants from large cities: one in the Midwest, one in the East, one in the Southeast, and one on the West Coast. The experience of adolescents and providers from small cities, rural areas, or different parts of the country may be different from the experiences from adolescents and providers in the present sample. Furthermore, these data are not generalizable to Hispanics/Latinos in the other U.S. regions, although this is not the intent of qualitative studies. For example, border regions along the U.S./Mexico border may exhibit different healthcare use practices, given their binational proximity. Last, factors such as country of origin, geographic location, documentation status, and level of acculturation may play unique and independent roles in the context of facilitators and barriers to health care; these factors should be considered in future studies.

Finally, this study would have benefitted from incorporation of an ethnographic component (Emerson, 1985) that would have included some vignettes specific to the clinics and community-based organizations to help frame the context from which these providers discussed their experiences working with LYLWH. Ethnographic methods such as participant observation in these diverse settings would provide additional insight on additional layers and dimensions of nuance and tension (Larsen, 2004, 2007; O'Reilly, 2012).

Directions for Future Research

This exploratory study serves as a starting point toward understanding factors that contribute to continued and sustained engagement in HIV prevention and care among Latino youth. Specifically, I examined individual, interpersonal, community, policy, and cultural barriers and facilitators that affect engagement in care for LYLWH. Results revealed that many forces overlap and intersect, such that many preexist an HIV diagnosis. Also, many are primarily structurally situated, such as those related to cultural norms regarding health, gender, and sexuality, as well as immigration policies, and poverty. I identified important facilitators of engagement in HIV at multiple levels, including those that promote engagement for LYLWH. For example, emphasis on cultural sensitivity surrounding race/ethnicity, spirituality, gender, sexual orientation, and family values were facilitators that promoted individual engagement for LYLWH. Furthermore, access to mental health and substance-use treatment is culturally sensitive, and can improve engagement in HIV care when properly diagnosed and linked to care.

The next step to understanding the phenomena of interest would be to conduct exploratory studies with LYLWH to explore their socioecological perceptions of the challenges and facilitators for engagement to HIV care. Furthermore, future studies should consider extending the member checking process to incorporate the population of interest, such as LYLWH, to extend the discussion and context surrounding the themes identified by the providers. Obtaining insight from the population of interest on the perspectives of these providers would enrich and perhaps, extend, the topics identified by these providers.

Additional research is needed to understand whether mental health treatment and substance-use treatment are feasible, acceptable, and effective for Latino youth. Limited research has focused on the effectiveness of traditional psychosocial therapy among Latino youth (De Arellano et al., 2005; Jaycox et al., 2002; Rossello & Bernal, 1999). Additional research is needed on the types of mental health treatments that are most effective among Latino youth and the degree of involvement needed from family members for effective mental health treatment.

Romantic and sexual relationships of LYLWH did not emerge as a significant barrier or facilitator for engagement in care, as conceptualized by providers. However, discussions with YLWH may produce different results, as they are better able to describe the impact of these relationships on their daily lives. LYLWH may describe potentially helpful or harmful factors, specific to romantic and sexual relationships that may impact HIV prevention or engagement

in HIV care. Providers may not have had time to discuss the in-depth complexities of such relationships or discern that the culture of sexual silence extends to maintaining these relationships secret from healthcare professionals in response to feelings of guilt and shame about the nature of these relationships. Future research should focus on the nature of these sexual relationships, particularly whether they change pre- and postdiagnosis and over time, to identify particular stressors and facilitators for engagement in HIV care.

Last, substantial indirect evidence supports the utility of the socioecological framework for understanding how multilevel factors, broadly defined, may predict engagement in care, and ultimately health outcomes, through interrelated psychosocial and multilevel ecological risk and resiliency factors (Hosek et al., 2008; Mugavero et al., 2011). Additional research is needed to determine the utility of the socioecological model as a guiding framework. Furthermore, research is needed to better understand clinic-level and policy-dictated resources and their direct role in the relationship between social status and health outcomes. Ultimately, this study highlights the impact of policy and social forces on engagement in care for LYLWH which call for increased attention for community-level, policy-level and socialcultural-level interventions to effectively address the HIV epidemic among this group.

CHAPTER V

CONCLUSION

The current study bridges the literature of community psychology and public health in a qualitative analysis of the socioecological factors impacting engagement in care for LYLWH. The purpose of this exploration was to understand the socioecological factors relevant to LYLWH's ability to maintain engagement across the continuum of HIV care, including HIV testing, HIV linkage to care, engagement in HIV care, medication adherence, and retention in care. Previous research did not investigate these factors for this population. Also, previous researchers did not use a socioecological framework. This study used a psychological phenomenological approach, through inductive and deductive analysis, to explore the socioecological factors that specifically affect engagement in care for LYLWH from providers' perspective.

Although most of the focus was on individual or intrapersonal factors, the qualitative-study results illustrated the significant roles of community and sociocultural/policy-level factors in impacting engagement in care for these youth. It is clear from the current study that LYLWH engage across the continuum of care in distinctive ways, resulting from community-level factors and the sociocultural and policy-level factors that directly and indirectly affect their ability to maintain optimal engagement in their HIV care. Additionally, these macro-systemic factors relate to other syndemic experiences such as mental health disorders and substance abuse, poverty, and HIV and LGBT stigma affecting

Latino youth in general in our current society. By addressing these factors, society can positively affect the health of youth, inclusive of LYLWH.

The greatest strength of this study, however, is that, through the voices of the providers, LYLWH, an understudied group in research literature, have an emerging voice to help frame understanding of their challenges and facilitators for engagement in HIV. This study provides insight into how to best meet their needs. In the words of Isabel Allende, “Write what should not be forgotten.”

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APPENDIX A
GLOSSARY OF ACRONYMS

ACA Affordable Care Act

ACCEPT Adolescents Coping, Connecting, Empowering and Protecting Together

AIDS acquired immunodeficiency syndrome

ART antiretroviral therapy

ATN Adolescent Trails Network

CBO community-based organization

CBPR Community-Based Participatory Research

CD4 cluster of differentiation 4

CDC Centers for Disease Control and Prevention

CLEAR Choosing Life: Empowerment, Actions, Results

CLICK an individual, web-based application designed to enhance sexual-risk
reduction skills among perinatally infected youth

GBT gay, bisexual, or transgender

HIV human immunodeficiency virus

HSHPH Health-Serving Professional Institutions Network

IRB Institutional Review Board

LGBTQ lesbian, gay, bisexual, transgender, and queer people

LPR Lawful Permanent Resident

LYLWH Latinos YLWH

MSM men who have sex with men

PLWH people living with HIV

SAMH Society for Adolescent Health & Medicine

STI sexually transmitted infections

STYLE Strength Through Youth Livin' Empowered

TLC Together Learning Choices

YLWH young people living with HIV

YMSM young men who have sex with men

APPENDIX B
PROVIDER INFORMATION SHEET

I would like to share with you why I am conducting this interview with you today. We are asking you to participate in this interview because you are a member of the professional staff at site and you have at least 1 year of experience working with Latino HIV-positive youth. We hope to interview three providers from each medical site from different geographic areas across the United States (for up to 30 interviews with healthcare providers). The purpose of the study is to elicit information about the challenges, strengths, and needed areas of support associated with receiving an HIV diagnosis among Latino youth living with HIV (YLWH). Findings from the study will be used to inform culturally sensitive and developmentally appropriate intervention (or set of interventions) for Latino YLWH.

I will be asking you a series of questions about the general critical areas of stress and about general critical areas for engagement in care for Latino YLWH based on your clinical experience in providing care and services.

I will not be asking you any for any personal information other than basic demographic and professional experience data. I will only be asking you to share your experiences about your work with Latino YLWH. In sharing your perspectives, you'll be reflecting on your work with Latino YLWH to date and providing insight that will guide the development of socioecological interventions aimed at improving engagement across the continuum of HIV care among Latino YLWH.

This interview should take about 1 hour. Everything you say will be completely confidential. I'll take some notes as we talk and audiotape the interview, but I will not ask for your name or any other personal identifiers. The audio-tape and interview notes will be stored in a locked and limited access area. As the Principal Investigator, I will use the audio digital recordings to validate the content of the notes taken during the interview. Once the interview notes are validated, the audio digital recordings will be destroyed. In addition, any information that is inadvertently collected in the interview notes that could reveal your personal identity will be completely removed and each interview will be assigned a provider ID number. Furthermore, when reporting information from the interview notes, no identifying information will be included.

As I've stated, some of the questions will ask about your personal perspective on the range of facilitators and challenges that Latino YLWH face, thus it is possible that you may experience some degree of discomfort related to revealing your own views on this topic. You may choose not to answer any questions you wish or you may decide to terminate the interview at any time without any negative consequences. You may also choose to participate without having the interview audio-taped. Remember, being in this interview is entirely up to you and you do not have to participate.

Although there are no direct benefits associated with your participation in this interview, we hope that the information we obtain will assist us in creating an outline and development plan for a culturally sensitive and developmentally appropriate interventions for Latino YLWH.

The researcher in charge of this study is Diana Lemos, M.P.H., a graduate student at DePaul University as a requirement to obtain her Doctorate degree She is under the supervision of her faculty advisor, Gary Harper, PhD, MPH at DePaul University. If you have any questions about this study before or after taking part in the interview, she may be contacted via e-mail at dlemos@depaul.edu or via phone at 312-864-8012. If you have questions about your rights as a research subject, you may contact Susan Loess-Perez, DePaul University's Director of Research Protections at 312-362-7593 or by email at sloesspe@depaul.edu.

Do you have any questions about what I've just explained to you? If at any time during this interview you have any questions or if something I say is not clear, please let me know and I will clarify. Remember that you are free to refuse to answer any questions or to end the interview at any time. Also remember that after it has been transcribed, the audiotape will be erased.

Do I have permission to conduct the interview with you? Yes No

Do I have your permission to audiotape this interview? Yes No

Interviewer's Signature: _____ Date _____

APPENDIX C
INTERVIEWER ASSESSMENT

1. Was the interview completed? If not, why not?
2. Where did the interview occur?
3. Under what conditions?
4. How did the interviewee react to the questions?
5. How well did you establish rapport with the interviewee?
6. Did you feel the interviewee was reliable (i.e., trying to give honest, accurate answers, able to think and remember clearly)?
7. Were there particular questions or portions of the interview that you felt the interviewee did not respond to honestly? If so, which ones?
8. Were there particular questions that the interviewee did not want to respond to? If so which ones?
9. Were there noticeable inconsistencies in responses? If so, please describe?
10. Describe the interviewee's emotional and mental state (if s/he seemed high, got agitated, got upset, etc.)

APPENDIX D

PROVIDER SEMISTRUCTURED IN-DEPTH INTERVIEW GUIDE

I. Introduction and Care Utilization History

Thank you for agreeing to be part of this study. The purpose of this study is to understand your experience as a healthcare provider working with young Latino/a living with HIV. We will discuss many aspects of HIV including those related to engagement in care including HIV medical care, specifically attending doctor appointments and obtaining clinical labs and/or procedures. Remember, all your responses are confidential. We are equally interested in understanding what works to help youth maintain engagement in medical care, and what can make it more challenging. We hope that from your perspective, we may be able to help Latino YLWH maintain engagement in care.

I may also take some notes as we are talking, this is just to help me remember main themes in your answers, and to be sure your experiences are fully understood and represented, we will also be audio taping the interview. Remember all of your responses are confidential and individual responses will not be shared with any outside authorities or with the clinic where you provide your services. If a question makes you feel uncomfortable, you do not have to answer the question. Do you have any questions before we begin? I'd like to ask you questions about your experience with YLWH. First, what is your health-care role as a provider for Latino YLWH? YLWH?

Type	What type of healthcare provider are you? <input type="checkbox"/> Medical provider <input type="checkbox"/> Case manager <input type="checkbox"/> Mental health provider <input type="checkbox"/> Other _____
Size	Approximately how many Latino living with HIV population do you serve? Of those, approximately, how many are Spanish speaking? How many of these are adolescents?
Location	What is location of where services are provided?
Years Working with YLWH?	How many years have you worked with Latino YLWH?
Position/Job Title	What is your position/job title within the healthcare setting?

Now, we are going to talk about the HIV and healthcare history of Latino YLWH. Please answer these questions to be best of your knowledge thinking about these youth as a whole. Some questions may or may not apply to your experiences in general, and that is ok, as well.

1. What are the **individual-level factors or characteristics** (coping strategies, competencies, etc.) that impact the continuum of care for Latino YLWH?
 - a. How do these individual-level factors impact HIV testing?

- i. What are the barriers that impact HIV testing?
 - ii. What are the facilitators that impact HIV testing?
 - b. How do these individual-level factors impact linkage to care?
 - i. What are the barriers that impact linkage to care?
 - ii. What are the facilitators that impact linkage to?
 - c. How do these individual-level factors impact receipt of HIV care?
 - i. What are the barriers that impact receipt of HIV care?
 - ii. What are the facilitators that impact receipt of HIV care?
 - d. How do these individual-level factors impact retention in care?
 - i. What are the barriers that impact retention in care?
 - ii. What are the facilitators that impact retention in care?
 - e. How do these individual-level factors impact sufficient use of ART?
 - i. What are the barriers that impact sufficient use of ART?
 - ii. What are the facilitators that impact sufficient use of ART?
2. What are the **interpersonal-level factors** (relationships with parents, friends, providers) that impact the continuum of care for Latino YLWH?
 - a. How do these interpersonal-level factors impact HIV testing?
 - i. What are the barriers that impact HIV testing?
 - ii. What are the facilitators that impact HIV testing?
 - b. How do these interpersonal-level factors impact linkage to care?
 - i. What are the barriers that impact linkage to care?
 - ii. What are the facilitators that impact linkage to?
 - c. How do these interpersonal-level factors impact receipt of HIV care?
 - i. What are the barriers that impact receipt of HIV care?
 - ii. What are the facilitators that impact receipt of HIV care?
 - d. How do these interpersonal-level factors impact retention in care?
 - i. What are the barriers that impact retention in care?
 - ii. What are the facilitators that impact retention in care?
 - e. How do these interpersonal-level factors impact sufficient use of ART?
 - i. What are the barriers that impact sufficient use of ART?
 - ii. What are the facilitators that impact sufficient use of ART?
3. What are the **clinic-level factors** (setting-related factors) that impact the continuum of care for Latino YLWH?
 - a. How do these clinic-level factors impact HIV testing?
 - i. What are the barriers that impact HIV testing?
 - ii. What are the facilitators that impact HIV testing?
 - b. How do these clinic-level factors impact linkage to care?
 - i. What are the barriers that impact linkage to care?
 - ii. What are the facilitators that impact linkage to?
 - c. How do these clinic-level factors impact receipt of HIV care?
 - i. What are the barriers that impact receipt of HIV care?
 - ii. What are the facilitators that impact receipt of HIV care?

- d. How do these clinic-level factors impact retention in care?
 - i. What are the barriers that impact retention in care?
 - ii. What are the facilitators that impact retention in care?
- e. How do these clinic-level factors impact sufficient use of ART?
 - i. What are the barriers that impact sufficient use of ART?
 - ii. What are the facilitators that impact sufficient use of ART?
- 4. What are the **sociocultural factors** (the cultural context, attitudes, and practices within a cultural or community) impact the continuum of care for Latino YLWH?
 - a. How do these sociocultural factors impact HIV testing?
 - i. What are the barriers that impact HIV testing?
 - ii. What are the facilitators that impact HIV testing?
 - b. How do these sociocultural factors impact linkage to care?
 - i. What are the barriers that impact linkage to care?
 - ii. What are the facilitators that impact linkage to?
 - c. How do these sociocultural factors impact receipt of HIV care?
 - i. What are the barriers that impact receipt of HIV care?
 - ii. What are the facilitators that impact receipt of HIV care?
 - d. How do these sociocultural factors impact retention in care?
 - i. What are the barriers that impact retention in care?
 - ii. What are the facilitators that impact retention in care?
 - e. How do these sociocultural factors impact sufficient use of ART?
 - i. What are the barriers that impact sufficient use of ART?
 - ii. What are the facilitators that impact sufficient use of ART?

Doctors, Clinics and service providers

- 1) Do Latino YLWH have a regular doctor?
- 2) What kind of things makes someone a good doctor for d Latino YLWH? Do you think it's difficult to find someone?
- 3) Where do these youth go to receive healthcare services?
- 4) What kind of things makes someplace a good clinic for Latino YLWH? Do you think it's difficult to find a clinic like that?
- 5) What other service providers do these youth typically see (i.e., a case manager, a therapist, etc.) What kind of things makes someone a good service provider for Latino YLWH? Do you think it's difficult to find someone?

HIV Treatment Barriers

- 1) Typically, after a Latino YLWH is first diagnosed as HIV-positive, how long is it before they are able to see a doctor about HIV?

Because having HIV is only one part of who you are as a person, many people have different life experiences that may take precedence or need more attention than getting into see your doctor or get lab work done for their HIV.

- 2) What types of situations make it really hard for these youth to get in to see their doctor?

Now I'd like to ask you some questions that may relate to your beliefs or feelings about getting HIV care. I want you to consider your own personal beliefs and feelings as well as the types of beliefs and feelings people who are close to you (such as your family or friends) or may share the same culture as you.

- 3) What are the challenges or sacrifices they typically make to make to get in to see their HIV care provider or get labs done at least once every 3–4 months?
- 4) What encourages these youth to come in to their doctor or get labs done regularly, say at least once every 3–4 months?
- 5) What does it mean for these youth to see a doctor or receive medical care in general on a regular basis?
- 6) What does it mean for these youth to receive HIV medical care on an ongoing basis?
- 7) Please describe anytime(s) you ever felt that these youth were disrespected or discriminated against or did not receive the same level of HIV care because of their:
- Race/ethnicity
 - Gender
 - Sexual orientation
 - a. Please describe these experiences.
 - b. How do these experiences make them feel about coming to their HIV-related appointments? (e.g., anxious, nervous, worried, not want to come back?)

Sociocultural Experiences

- 1) Now, we are going to talk about the areas where these youth typically live. In your experience, where do these youth live? How long have they lived there? Are these typically permanent places of residence?
- 2) Who do they typically live with? Are these people typically aware of that the youth positive?
- 3) Who are the important people in their lives? Who do they count on for support?
- 4) Are they typically out about their HIV status? Do they comfortable talking with other people about being HIV positive?

- 5) What are some challenges within their communities that may impact how they receive HIV-related services on a regular basis?
- 6) What are the facilitators within their communities that may impact how they receive HIV-related services on a regular basis?

Suggestions for Improving Engagement in Care

Now I'd like to ask you some questions about different skills or strategies that may help Latino YLWH to see their HIV doctors or get their labs done more regularly.

- 1) What kinds of things do these young people need to be able to do to keep coming in for regular HIV care visits?
- 2) What is the most common reasons why they are unable to make it to our medical care appointments?
- 3) Are there certain skills or strategies they've developed that help them to make it to their care visits?
- 4) What nonmedical services do these youth use to help you meet your regular medical care appointments? (e.g., financial assistance, transportation services, substance abuse support or harm reduction services, mental health services)
- 5) Are there any particular services you think would be helpful for either yourself or others?
- 6) How does clinic staff influence youth attending their medical care appointments?
—Courteous helpful staff
—Difficult staff
- 7) Given everything else going on in their life, what kinds of other priorities make getting to a HIV care appointment difficult sometimes? (e.g., child care, housing status, recent history of incarceration)
- 8) Is there anything else related to HIV medical care that I didn't ask you that you feel is important for either the doctors, staff, or other people living with HIV to know?
- 9) Can you tell me how you felt about the interview questions? What are some recommendations regarding flow, content, or language?

Those are all of my questions. I'd like to thank you for taking the time to talk with me. Your responses will be important in helping us better understand the unique challenges of Latino dominant YLWH. Before we end, do you have any questions for me?