A 3-CITY STUDY on HIV care engagement and treatment adherence among Latino gay and bisexual men and men who have sex with men living with HIV and AIDS.
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Suggested citation

Disclaimer: The photographs of persons in this report are used for illustrative purposes only.
We Want to Thank...

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We owe immense gratitude to all of the study participants who shared their life experiences and opinions through focus groups and surveys. While they remain anonymous, their stories will support us and other organizations in providing culturally and linguistically appropriate services throughout the United States to improve the health and lives of many other Latino gay and bisexual men and men who have sex with men (GBM/MSM) living with HIV.

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Executive Summary

HIV incidence (new HIV infections) declined rapidly throughout the 90s and the first decade of the 21st century due to prevention and treatment efforts, including biomedical interventions. Nonetheless, HIV incidence has plateaued or remained stable over the past years due to lack of effective HIV prevention services and HIV treatment not adequately reaching those who could benefit the most, particularly men of color who have sex with men.

Of the 37,515 new HIV diagnoses in the United States (U.S.) and dependent areas in 2018, Latinos represented about 26% (9,820) and Hispanic/Latino men 22.5% (8,442). The new infections among Hispanic/Latino men were overwhelmingly through male-to-male sexual contact (87.6%).

Not only are Latino gay and bisexual men and men who have sex with men (GBM/MSM) overrepresented in new infections among Hispanics, the number of new infections among Hispanics has also increased in the last few years driven by new infections among Latino GBM/MSM. New diagnoses of HIV infection attributed to male-to-male sexual contact among Hispanic/Latino men increased from 7,114 in 2014 to 7,400 in 2018.

Thanks to End the Epidemic (ETE) efforts, outcomes along the treatment cascade are being gradually achieved, including increased engagement and retention in HIV treatment and undetectable viral loads. With some exceptions, progress along the continuum of care is somewhat similar across racial/ethnic groups.

However, there is a lack of information on barriers and facilitators to ensure that the continuum of care indicators continue improving to achieve the 2030 End of the HIV Epidemic goals, particularly among subgroups of Latino GBM/MSM.

For instance, foreign-born Hispanics/Latinos and those born in Puerto Rico present better HIV clinical outcomes than their peers born in mainland U.S., including linkage to care and viral suppression. At the same time, foreign-born GBM/MSM experienced barriers to culturally
and linguistically appropriate services, lack comprehensive access to health services beyond those related to HIV, and endure xenophobia in addition to racism and homophobia.

These differences in HIV outcomes point to critical differences in service needs among Hispanic/Latino subgroups in the U.S. A better understanding of the diversity within and across subgroups will help us: (1) design more culturally and linguistically appropriate strategies, and (2) adapt and tailor effective strategies for different subgroups.

However, the small amount of research exploring care and treatment needs among Latino GBM/MSM has overlooked or disregarded important differences in terms of racial/ethnic identities, cultural norms, beliefs, language, acculturation, and immigration experiences.

Better understanding of these particular characteristics, and the needs of mainland-U.S.-born, Puerto Rico-born, and foreign-born Latino GBM/MSM can be used to engage these high-risk and vulnerable groups in treatment efforts in a culturally and linguistically responsive manner.

This study examined engagement in care and treatment adherence among Latino GBM/MSM living in three major metropolitan areas, Miami, Los Angeles, and New York City. The information gathered from this study seeks to help health care engagement and treatment efforts for subgroups of HIV positive Latino GBM/MSM most at-risk for dropping out of care, discontinuing treatment, and not achieving viral suppression.

**Study description:**

This study explored engagement in HIV care and treatment adherence among Latino gay and bisexual men and men who have sex with men (GBM/MSM), living with HIV, ages 18 to 49, and residing in Los Angeles, Miami, and New York City metropolitan areas. Therefore, this study examined a variety of issues that could impact their ability to engage and remain in HIV care and adhere to HIV treatment, including quality of life, satisfaction with treatment, quality of care, patient-provider relationship, substance use, immigration, age, and country of birth.

This mixed-method cross-sectional study employed semi-structured focus groups and anonymous surveys to collect qualitative and quantitative data from a convenience sample of Latino GBM/MSM. Facilitated by two staff members of the Latino Commission on AIDS and conducted in both Spanish and English, the focus groups included the following discussion areas:

(a) experiences accessing and utilizing HIV care;

(b) experiences accessing and utilizing health care services, including those related to comorbidities, sexual health, and mental health;

(c) HIV treatment initiation and adherence experiences, barriers, and facilitators;

(d) immigration experiences and the intersection with HIV issues; and

(e) views on improving services.

The anonymous survey was conducted both in English and Spanish to ensure cultural and linguistic appropriateness. The survey included the following domains: (a) demographics; (b) health status and health care seeking behaviors; (c) HIV, AIDS history; (d) experiences with engagement in HIV health care; (e) quality of life; (f) HIV medication adherence; (g) treatment satisfaction; and (h) substance use and sexual behaviors.

The survey also included the following validated instruments, with minor adaptations to ensure cultural appropriateness: HIV/AIDS-targeted of life quality of life (HAT-QoL) instrument, Simplified Medication Adherence Questionnaire (SMAQ), and HIV Treatment Satisfaction Questionnaire (HIVTSQ).

From January to October 2018, quantitative data from 559 Latino GB/MSM living with HIV/AIDS were collected through an online survey and data collection system (SurveyMonkey) as well as paper-based surveys in Spanish and English. Qualitative data from 106 Latino GBM/MSM living with HIV/AIDS were collected through 13 semi-structured, facilitated focus groups.
Limitations:

This study has several limitations. First, we used a convenience sampling strategy to recruit participants for the survey and the focus groups, many of whom were connected to service organizations. The demographics of survey respondents were not representative of the Latino GBM/MSM in New York City, Miami, or Los Angeles. Similarly, focus group participants were overwhelmingly Spanish speaking, as nine of the thirteen focus groups were held in Spanish, and no focus groups in English were held in New York City. Over three quarters of the participants had been born outside mainland U.S., and the mean age was 40.5 years of age.

Second, the findings are based on self-reported data, increasing the risk of socially desirable responses. Particularly, participants in the focus groups might have felt compelled to minimize stigmatizing behaviors such as substance use or exaggerate socially approved ones such as treatment adherence. Because many focus group participants were connected to service organizations, they might have been embarrassed or hesitant to report negative information that they thought could impact their access to services.

Thus, these findings, while pointing toward critical issues, should not be taken as representative of the entire population of Latino GBM/MSM living in the U.S. At the same time, some of the study features support the internal validity of our findings for these particular sub-samples. First, the surveys were voluntary, and the questions did not ask for any identifiable information.

Second, focus group transcriptions showed the willingness of participants to agree and disagree with each other and disclose sensitive and stigmatizing information. Transcripts also showed a similarity of themes emerging across the 13 focus groups as well as differences based on the demographics of the group participants.

Finally, these features combined with similar findings in other studies increase the possibility that similar findings may apply to other Latino GBM/MSM in large urban areas.
Discussion of findings:

The vast majority of participants had a regular health provider (93.6%), had seen a health care provider for HIV treatment in the previous 12 months (94.3%), were in treatment (93.9%), had taken their HIV medication in the previous 4 weeks (93.7%), and had been told by their Primary Care Provider (PCP) that their viral load was undetectable (88.5%). Perhaps as a result of the connection of participants to HIV organizations, the overall sample of survey participants reported outcomes along the continuum of care slightly higher than some epidemiological reports.17

However, outcomes along the continuum of care were not the same across Latino subgroups by age and place of birth. Older and foreign-born participants tended to present better outcomes along the continuum of care than younger Latino GBM/MSM and those born in mainland U.S. and Puerto Rico. In addition, older participants were experiencing health and social needs that went beyond HIV-related services, including multimorbidities and polypharmacy.

Younger Latino GBM/MSM

The younger participants in this study were more likely to experience delay or lack of HIV care than their older counterparts. They were less likely to have a regular health provider, have visited a PCP in the previous 12 months, report being in HIV treatment, and to have taken their medication in the previous 4 weeks than their older counterparts. Younger participants reported more difficulty adhering to treatment than their older counterparts. Not surprisingly, younger participants were less likely to report having been told that they have undetectable viral load.

The younger participants also reported some differences from their older counterparts related to HIV in general. Younger men were more likely to live with their families and have worries about disclosure (HAT-QOL domain). Older participants had lived with HIV for a much longer time (mean 11.78 years vs. 4.85 years) which might have shaped their relationship to HIV treatment. For instance, older participants were less likely to report medication worries and disclosure worries, and more likely to report HIV mastery (HAT-QOL domains) than their younger counterparts. In 2017 NYC, almost 1 in 5 (18%) of Latino GBM/MSM born in mainland U.S. and living with HIV were under 30 years of age. In contrast, among foreign-born Latino GBM/MSM living with HIV, 1 in 10 (11%) were under 30 years of age.45

Latino GBM/MSM born in mainland U.S. and Puerto Rico

Some differences related to engagement in care and treatment adherence were also found based on place of birth. Participants born in Puerto Rico were less likely to have a regular provider and less likely to report undetectable viral load than those born in mainland U.S. and foreign-born participants. Those born in mainland U.S. were less likely to be in treatment and have taken medication in the previous 4 weeks than the other two groups. Participants born in Puerto Rico and mainland U.S. were more likely to forget their medication than other groups and no take the medication as prescribed. Similar findings can be found elsewhere. For instance, in 2017 in NYC, viral suppression among foreign-born Latino GBM/MSM was 82% but 75% for those born in Puerto Rico.45

Immigrant Latino GBM/MSM

Foreign born and Puerto Rico born Latino GBM/MSM share with the other subgroups a variety of factors hindering their ability to achieve undetectable viral load. However, they also reported specific challenges to remain in care and adhere to treatment, including lack of Spanish-speaking PCPs, health coverage limitations, and concerns over their immigration status.

Specifically, participants reported feeling frustrated with the medical appointment as they were not able to effectively communicate their health needs and understand the information about their medical conditions or treatment.

As foreign-born participants age, their health and social needs increase and require a broader range of services besides those directly related to HIV. Those who depended on ADAP and Ryan
White Services also reported on the challenges of accessing comprehensive and long-term health services to effectively address multi-morbidity and polypharmacy issues.

Foreign-born participants reported on their fears and concerns about utilizing programs and services that could have a later detrimental impact in their ability to obtain permanent residency or citizenship. In fact, participants reported on stress, anxiety and depression symptoms over their current immigration status and their ability to feel safe accessing services.

**Aging population**

While older participants presented better HIV outcomes, they were more likely to experience multi-morbidities than their younger counterparts. Despite the presence of multi-morbidities, focus group participants reported their HIV primary care providers were not attending to their multiple needs, particularly because of the emphasis on HIV clinical markers with the HIV care.

For some Latino GBM/MSM who have already stabilized their HIV care and become undetectable, HIV has become less pressing than other health and social needs. Despite ART advances, life expectancy in well-treated OPLWH is still lower than in the general population. The probability of multimorbidity and polypharmacy increases by age and number of years living with HIV. Furthermore, non-HIV morbidities are more common in PLWH, even after adjusting for age, ART, and other risk factors.

**Substance use**

In addition to the aforementioned barriers, participants reported individual behaviors that might have hindered their ability to fully engage in care and adhere to treatment. While over half of the sample engaged in alcohol and drug use, younger and mainland-born participants were more likely to report drug use than foreign born.

In fact, current substance use was inversely correlated with having been told to have undetectable viral load. While substance use may impact treatment adherence, the connection between substance use and treatment adherence is nuanced as reported by the focus group participants. Active users of drugs and alcohol reported on recurring instances in which they had skipped their medications because of heavy use.

On the other hand, some participants spoke of negotiating their substance use and the adherence to treatment, including developing strategies for taking their HIV medication while using drugs or stopping treatment temporarily. There were also some who had opted for sobriety and abstinence as their only effective strategy.

**Stigmatization of HIV and sexual orientation**

Stigma was a central theme of the focus groups. Fear of stigmatization and rejection prevented many of the participants from disclosing sexual orientation and HIV status to people in their social networks who may provide emotional, instrumental and social support.

Within a cultural context that blamed their sexual orientation as the reason for acquiring HIV, many participants withheld information about both their sexuality and HIV status for fear of their family’s reactions. These concerns about the negative consequences of disclosure were not unfounded. For some participants, disclosure of their HIV status resulted in housing instability, loss of social support, and financial and emotional stress. As reported in the focus groups, multiple sources and experiences of stigmatization increased isolation and
recommendations

Greater attention to the needs of Latino GBM/MSM born in mainland U.S. & Puerto Rico

There is a lack of intervention research based on place of birth, immigration experience, or cultural attachment relating to issues such as sexual risk, substance use, family and social support, racial/ethnic intersectional identities, and stigmatization of HIV and sexual orientation. HIV interventions need to include services that are culturally and linguistically responsive to the needs of English-speaking Latino GBM/MSM, including young immigrants, as well as those born in Puerto Rico.

Greater attention to the specific needs of Latino young GBM/MSM, particularly those born in mainland U.S.

There is a need to develop new tailored and nuanced programs for young Latino GBM/MSM, particularly those born in mainland U.S., that consider their particular lived experiences, including the challenges of disclosure of HIV status and sexual orientation, denial of HIV diagnosis, and substance use.

While the lapse between diagnosis and treatment initiation has reduced, there is a need to increase HIV treatment education for newly diagnosed youth in order to increase their ability to manage side effects and treatment regimens (HIV mastery). Furthermore, programs must capitalize on social media strategies and expand the use of technology-based interventions as a means to reduce disparities in clinical outcomes among young individuals.

Greater attention to the specific needs of immigrant Latino GBM/MSM

There is a need to develop and provide services within a language justice framework and with particular attention to cultural and linguistic differences and commonalities across Latinx subgroups. There is also a need to increase the capacity of service providers to develop and provide culturally and linguistically appropriate services by increasing the presence of minorities in the medical workforce, as well as policies to enhance the capacity of health organizations serving immigrant and monolingual communities.
While many foreign-born Latino GBM/MSM have achieved undetectable viral load, there is a need to extend primary and preventative health coverage to Latino GBM/MSM irrespective of immigration status. Preventative health is particularly important in light on their growing aging health-related needs. Similarly, immigrant Latino GBM/MSM are in great need of long-term and low-cost behavioral health services to address the overlapping stigmatization and discrimination related to social and structural racism, homophobia and xenophobia.

**Greater attention to the non-HIV health and social needs of aging Latino GBM/MSM**

The emerging health and social needs of older Latino GBM/MSM require changes to the standard HIV care approach, including the need for additional aging-related screenings, polypharmacy reconciliation, specialty care, and geriatric care. There is also a need to provide greater attention to their social integration needs, particularly as their social networks become smaller and their isolation is exacerbated by issues of mobility. This must include an examination of key social and cultural views on aging and geriatric care among Latino communities.

**Continue efforts to address stigmatization of sexual orientation and HIV**

We must continue our efforts to address the impact of stigma among Latino GBM/MSM living with HIV. For instance, there is a need to increase the cultural and linguistic capacity of service providers to identify and address concerns about disclosing stigmatizing information in the consultation room as well as to support patients’ assessment of the benefits and risks of disclosure to social networks and family members.

Moreover, there is a need for partnering with non-traditional organizations such as Latino-led churches, immigrant worker organizations, and businesses to enhance the community knowledge of HIV and dispel rooted misconceptions about HIV and homosexuality. We must also develop and implement community-level and structural interventions to address multiple sources of stigma, including xenophobia, ageism, and racism.

**Obtain better information on those not achieving viral suppression**

There is a need for a deeper understanding of the reasons for differences in engagement in care and treatment based on place of birth and immigration experience, particularly for younger Latino GBM/MSM. Given the over-representation of Latino GBM/MSM among those living with HIV, the Centers for Disease Control and Prevention, the National Institutes of Health, the U.S. Department of Health and Human Services, local and state departments of health, and research institutions must disaggregate data collection to fully understand and address the long existing health disparities across racial/ethnic groups and within Latino sub-populations.

If we are to achieve the Ending the Epidemic goals for 2030, there is a need to improve and integrate data collection at the local, state, and federal level to understand the heterogeneity in the Latino experience, particularly among those subgroups who have limited access to quality care, are not engaged in quality care, or struggle adhering to treatment.
Decline of HIV diagnoses & HIV-related deaths

HIV incidence (new HIV infections) declined rapidly throughout the 90s and the first decade of the 21st century and then started to stabilize in 2013.²,³ Prevention and treatment efforts, including biomedical interventions, have contributed to this decline.⁴-⁶ In fact, HIV-related mortality has also continuously decreased in the U.S. since the introduction of Highly Active Antiretroviral Therapy (HAART) in 1996. For instance, Figure 1 below shows major markers and trends in the history of the HIV epidemic in NYC (1981-2018).¹

Nonetheless, HIV incidence has plateaued or remained stable over the past years due to lack of effective HIV prevention services and HIV treatment not adequately reaching those who could benefit the most.⁵ Furthermore, progress in reducing HIV infections and HIV-related mortality has not been equitable across certain demographic groups, particularly men of color who have sex with men.³ Of the 37,515 new HIV diagnoses in the United States (U.S.) and dependent areas in 2018, Latinos represented about 26% (9,820) and Hispanic/Latino men 22.5% (8,442).⁷ The new infections among Hispanic/Latino men were overwhelmingly through male-to-male sexual contact (87.6%).⁷

Not only are Latino gay and bisexual men and men who have sex with men (GBM/MSM) overrepresented in new infections, the number of new infections among Hispanics in the U.S. has also increased in the last few years driven by new infections among Latino GBM/MSM.³,⁷-⁹ New diagnoses of HIV infection attributed to male-to-male sexual contact among Hispanic/Latino men increased from 7,114 in 2014 to 7,400 in 2018.⁷

While mortality rates among Hispanics living with HIV has slowly decreased,³,⁵ the total number of Hispanics/Latinos living with HIV has continuously increased. The overrepresentation of Latino GBM/MSM living with HIV means that most deaths are among this group. Access to and retention in HIV care and treatment adherence are key aspects of reducing new infections.

**FIGURE 1.** NYCDOH - History of the HIV epidemic, NYC 1981-2018¹
HIV care & treatment among Latino GBM/MSM

Thanks to End the Epidemic (ETE) efforts, outcomes along the treatment cascade are being gradually achieved, including increased engagement and retention in HIV treatment and undetectable viral loads. With some exceptions, progress along the continuum of care is very similar across groups. For every 100 people living with HIV in 2017, 86 of them were diagnosed, 64 received care, 49 were retained in care, and 53 were virally suppressed. For every 100 Hispanics/Latinos living with HIV in 2016, 60 received some HIV care, 49 were retained in care, and 51 were virally suppressed.

For every 100 Hispanic/Latino gay and bisexual men living with HIV in 2016, 76 received some HIV care, 62 were retained in care, and 61 were virally suppressed. However, there is a lack of information on barriers and facilitators to ensure that the continuum of care indicators continue improving to achieve the 2030 End of the HIV Epidemic goals, particularly among Latino GBM/MSM.

For instance, there is evidence of differences in HIV clinical outcomes among Hispanics/Latinos based on place of birth. Specifically, foreign-born Hispanics/Latinos and those born in Puerto Rico present better HIV clinical outcomes than their peers born in mainland U.S., including linkage to care and viral suppression.

The Medical Monitoring Project examined data from 2,564 Hispanic/Latino adults living with a HIV and found that foreign-born Hispanics/Latinos were more likely to be prescribed ART (91% vs. 79%), retained in care (87% vs. 77%), and have sustained viral suppression (74% vs. 57%) than Hispanics/Latinos born in mainland U.S. Similarly, Puerto Rico-born Hispanics/Latinos were more likely to have sustained viral suppression (75%) than Hispanics/Latinos born in mainland U.S. (57%).

These differences in HIV outcomes point to critical differences in service needs among Hispanic/Latino subgroups in the U.S. A better understanding of the diversity within and across

In 2018, 88% of the new HIV infections among Latino men were through male-to-male sexual contact.

For every 100 Latino gay and bisexual men living with HIV in 2016, 76 received some HIV care, 62 were retained in care, and 61 were virally suppressed.

It is important to outline the specific risk factors that lead to HIV health disparities among Latino GBM/MSM.
subgroups will help us (1) design more culturally and linguistically appropriate strategies, and (2) adapt and tailor effective strategies for specific subgroups.

However, the small amount of research exploring care and treatment needs among Latino GBM/MSM has overlooked or disregarded important differences in terms of racial/ethnic identities, cultural norms, beliefs, language, acculturation, and immigration experiences. A better understanding of these particular characteristics, and the needs of U.S.-born, Puerto Rico-born, and foreign-born Latino GBM/MSM is needed.

The particular lived experiences of Latino GBM/MSM

Although GBM/MSM tend to do better with regard to linkage to care and retention in care, little is known about the specific service needs and utilization among Latino GBM/MSM. However, little research has been conducted on how social determinants of health operate across foreign-born Latino GBM/MSM as compared to their Puerto Rico-born and U.S.-born counterparts. Furthermore, there is a need to better understand how geographic differences among Latino GBM/MSM might have an impact on their ability to access quality care.

Past research has shown that language barriers, socio-economic status, poverty levels, and educational attainment levels are associated with inadequate knowledge about HIV and HIV testing rates. Furthermore, poor mental health outcomes, intimate partner violence, and substance use issues among Hispanics/Latinos greatly impact their HIV prevention and treatment needs, as well as health care service access.

Latinos experience less access to care and treatment for substance use compared to non-Hispanic whites. Moreover, a recent study within a sample of Latino sexual minorities in the Southern U.S. identified depressive symptoms, sexual compulsivity, and internalized homophobia as stressors related to discrimination.

Latino GBM/MSM who report experiences of both homophobia and racism are more likely to report condom-less receptive anal intercourse in comparison to those who experience neither. Notably, violence, specifically intimate partner violence, was first theorized to be part of the syndemics fueling HIV, but has recently been found to be independently associated with HIV.

Contributing factors leading to these disturbing inequities are linked to social determinants of health, including lack of culturally responsive quality services, housing instability, language barriers, limited educational and employment opportunities, and unsolved immigration status.

This study examined Latino GBM/MSM living in three major metropolitan areas, Miami, Los Angeles, and New York City. Latinos GBM/MSM made up a substantial proportion (33%) of all GBM/MSM living with HIV in NYC in 2017; 55% of the cumulative adult AIDS cases in 2017 in Miami-Dade County; and 88% of those living with HIV in Los Angeles County.

The information gathered from this study seeks to help health care engagement and treatment efforts for HIV positive Latino GBM/MSM most at-risk for dropping out of care, discontinuing treatment, and not achieving viral suppression, in a culturally and linguistically responsive manner.
Study Design

This study explored engagement in HIV care and treatment adherence among Latino gay and bisexual men and men who have sex with men (GBM/MSM) in Los Angeles, Miami, and New York City metropolitan areas. Participants were foreign-born, Puerto Rico-born, and U.S.-born Latino GBM/MSM living with HIV, ages 18 to 49, and whose primarily language was Spanish, English, or a combination of both.

The study examined a variety of issues that could impact their ability to engage and remain in HIV care and adhere to HIV treatment, including quality of life, satisfaction with treatment, quality of care, patient-provider relationship, substance use, immigration, age, and country of birth.

Human Protection

This study was reviewed and approved by Solutions IRB (https://www.solutionsirb.com) on January 19, 2018. All individuals participating in the study, both in the survey and focus groups, gave informed consent to participate, either in paper or electronically online, and received a gift certificate of $40 for their participation. Focus group participants additionally agreed to the recording of the session and received an additional $40 dollars for their participation.

Methodology

This mixed-method cross sectional study employed semi-structured focus groups and anonymous surveys to collect qualitative and quantitative data from a convenience sample of Latino GBM/MSM. Qualitative and quantitative data were collected concurrently.

Focus groups: The focus-group discussions aimed to understand barriers and facilitators to engagement in HIV care and treatment adherence among U.S.-born, Puerto Rico-born, and foreign-born Hispanic/Latino GBM/MSM living HIV. The discussions were facilitated by two staff members of the Latino Commission on AIDS and conducted in both Spanish and English. All focus groups were recorded and transcribed.

For the focus groups, the study utilized a semi-structured guide that included the following discussion areas: (a) experiences accessing and utilizing HIV care; (b) experiences accessing and utilizing health care services, including those related to comorbidities, sexual health, and mental health; (c) HIV treatment initiation and adherence experiences, barriers, and facilitators; (d) immigration experiences and the intersection with HIV issues; and (e) views on improving services.

Survey: The survey was conducted both in English and Spanish to accommodate the language needs of the different Hispanic subgroups. The study team reviewed and piloted the instruments to ensure cultural and linguistic appropriateness.

The survey included the following domains:

a) demographics;
b) health status and health care seeking behaviors;
c) HIV, AIDS history;
d) experiences with engagement in HIV health care;
e) quality of life;
f) HIV medication adherence;
g) treatment satisfaction; and
h) substance use and sexual behaviors.

The survey also included the following validated instruments, with minor adaptations to ensure cultural appropriateness: HIV/AIDS-targeted of life quality of life (HAT-QoL) instrument, Simplified Medication Adherence Questionnaire (SMAQ), and HIV Treatment Satisfaction Questionnaire (HIVTSQ).

Sampling and recruitment: The study utilized a convenience sample of diverse Latino GBM/MSM in three major U.S. metropolitan areas with high rates of HIV prevalence and high concentrations of Latinos: New York City, Miami, and Los Angeles. For the survey, the study sought to collect data on 600 Latino GBM/MSM, ages 18 to 49, living with HIV, and residing in any of the aforementioned metropolitan areas.

Sampling strategies sought to have diversity with regards to place of birth, language preference, level of acculturation (years in the U.S.), and level of engagement in care. Similarly, the study sought to recruit a diverse sample of focus group participants at each city.
Participants were recruited via fieldwork outreach, referrals from local community-based organizations (CBOs), social networking applications (e.g. Facebook, Instagram), and word of mouth. Advertisements were placed in a gay dating application used for social networking with a link to the survey hosted on SurveyMonkey.

Participants in the survey component were also asked if they were interested in participating in the focus groups. If they agreed, their contact information was collected through a separate link.

Data collection: From January to October 2018, quantitative data from 559 Latino GB/MSM living with HIV/AIDS were collected through an online data collection system (SurveyMonkey) as well as paper-based surveys in both Spanish and English. Qualitative data from 106 Latino GBM/MSM living with HIV/AIDS were collected through 13 semi-structured, facilitated focus groups.

The focus groups were convened in the selected cities with the support of community partners, who helped advertise and recruit participants: AltaMed and APLA in Los Angeles; Borinquen Health Care Center, Pridelines and Latinos Salud in Miami; OASIS Latino LGBTTS Wellness Center and Casa Betsaida of Catholic Charities in New York City. Nine focus groups were held in Spanish, 4 in NYC, 1 in Miami, and 4 in Los Angeles. Four focus groups were held in English, 1 in Miami and 3 in Los Angeles.

Data analysis

Quantitative analysis: Surveys were analyzed with SPSS 26. Means, standard deviations, frequencies, and percentages were used to describe demographics and the main areas of inquiry. We used Chi-squared tests of independence in the sample main characteristics of analysis based on age (i.e., 19 to 29 and 30 to 49 years of age) or place of birth (i.e., mainland U.S., Puerto Rico, and foreign born).

We also used analysis of variance (ANOVA) with multiple comparison analysis using LSD for further exploring specific differences based on place of birth for selected variables.

Among other domains, we analyzed statistical differences for length of HIV diagnosis, physical health indicators, multi-morbidity, access to health insurance, engagement in care, progress along the continuum of care, patient – Primary Care Provider (PCP) relationship, quality of life scores, substance use, and sexual behaviors.

Qualitative analysis: Focus groups were recorded, transcribed, and translated to English, when necessary. Transcripts were then analyzed in NVivo 12 using a focused content analysis strategy.

First, we developed content categories based on the focus group discussion guides. Secondly, the coding used sentences as the level of analysis, and allowed for flexibility to add categories and subcategories throughout the coding process.

The initial identification of themes was conducted by a study team member and the final coding was conducted by a different study team member. Quotations were then analyzed per category, and general trends and patterns were identified in each category.
Survey Findings

Sample characteristics

A total of 559 Latino GBM/MSM living with HIV, AIDS responded the survey. After reviewing the participant data for completeness and eligibility (i.e., Hispanic/Latino identification, having sex with men, age between 18 to 49, HIV positive status, and resident of NYC, Miami or Los Angeles metropolitan areas), 506 valid surveys were kept for the analysis presented in this report.

Findings are reported for all 506 surveys unless stated otherwise. This report examined the findings as a group as well as differences and similarities based on age (18-29 and 30-49), birth of place (mainland U.S., Puerto Rico, and foreign born), and, when appropriate, residency city.

Demographics

Over half of the sample resided in NYC (276, 54.5%), close to a third in Los Angeles (160, 31.6%), and the rest in Miami (70, 13.8%). Roughly half of respondents (51.2%, 259) were foreign born, 7.7% (39) were born in Puerto Rico, and the rest were born in mainland U.S. (40.7%, 206).1 Over a quarter of those foreign born were from Mexico (27.8%, n=72), followed by Colombia (13.9%, 36) and Venezuela (11.6%, n=30). In total participants came from 20 different countries.2

There was a significant relation between place of birth and city of residence (p=.000). Foreign born accounted for 58.2% (n=160) of respondents in NYC, 58% (n=40) in Miami, and over one third (36.9%, n=59) in Los Angeles. Those born in Puerto Rico resided mostly in NYC (74.4%, n=29) or Miami (20.5%, n=8). While those born in Puerto Rico had migrated to mainland U.S. at different times, out of the 259 foreign born participants, 43.7% (n=112) had arrived in the previous 10 years, between 2008 and 2018 (year of the survey).

Over half of the sample answered the survey in English (56.7%, n=287). Most participants born in mainland U.S. answered the survey in English (93.7%, n=193), half of those born in Puerto Rico (51.3%, n=20) and 28.6% of foreign born. The majority, 72.3% (n=366), chose English, 72.7% Spanish, and 3% Portuguese as their spoken language of preference (multiple choice question).

Age ranged between 19 and 49 (M=35.9, SD=8.0), with a greater percentage between 30 and 49 years of age (71.7%, n=363). There were significant differences in age based on place of birth. Close to 40% of U.S.-born respondents were between 19 and 29 compared to 17.9% among those born in Puerto Rico and 21.2% foreign born (p=.000).

Most participants identified as gay (n=458, 90.5%), followed by homosexual (n=66, 13%) or bisexual (n=41, 8.1%) -multiple choice. A smaller percentage identified as Queer (n=31, 6.1%) or same gender loving (n=20, 4.0%). Some participants identified as both gay and bisexual (n=15, 3%), queer and gay (n=23, 4.5%), and gay and homosexual (n=61, 12%). Only 3 participants identified as questioning; 4 participants identified as straight, with 3 of them also identifying as bisexual.

Over a quarter of the sample (28.3%, n=141) had a high school degree or less, a third (33.5%, n=167) had some college, and 38.2% (n=190) had a college degree or postsecondary education.3 Over 1 in 10 (11.2%) did not have a high school degree, and 1 in 10 (12.6%) had postsecondary education. Two thirds of the sample (62.1%, n=314) had some type of employment, either part-time (20.6%) or full-time (41.5%). A quarter were unemployed (25.9%, n=131) and 5.3% (n=27) were on disability.

Close to 1 in 5 (18.4%, n=93) reported living with relatives, 4.7% (n=24) were in assisted living facilities, 14.6% (n=74) with partners, 29.6% (n=150) alone, and 19.2% (n=97) with roommates. Almost 1 in 9 were homeless or living in shelters (43, 8.5%). There were no significant differences in homelessness rates based on age category, place of birth, or residence. The mean annual income of the sample was $38,135.

Table 1 below presents demographic information by place of residence, Table 2 by place of birth, and Table 3 by age category.

---

1 Two participants did not provide place of birth.
ii One participant did not provide country of birth.
iii Six participants did not provide education information.
### Table 1. Selected demographics by place of residence

<table>
<thead>
<tr>
<th>Variable</th>
<th>NYC (n=276)</th>
<th>LA (n=160)</th>
<th>Miami (n=70)</th>
<th>Total (n=506)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Language Preferences (multiple choice)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>64.5% (178)</td>
<td>85.0% (136)</td>
<td>74.3% (52)</td>
<td>72.3% (366)</td>
<td>.000***</td>
</tr>
<tr>
<td>Spanish</td>
<td>77.5% (214)</td>
<td>58.1% (93)</td>
<td>87.1% (61)</td>
<td>72.6% (366)</td>
<td>.000***</td>
</tr>
<tr>
<td>Portuguese</td>
<td>3.3% (9)</td>
<td>0.6% (1)</td>
<td>7.1% (5)</td>
<td>3.0% (15)</td>
<td>.025**</td>
</tr>
<tr>
<td><strong>Sexual Orientation (multiple choice)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gay/homosexual</td>
<td>90.6% (250)</td>
<td>90.6% (145)</td>
<td>97.1% (68)</td>
<td>91.5% (463)</td>
<td>.190</td>
</tr>
<tr>
<td>Bisexual</td>
<td>7.2% (20)</td>
<td>11.9% (19)</td>
<td>2.9% (2)</td>
<td>1.1% (41)</td>
<td>.052</td>
</tr>
<tr>
<td>Queer</td>
<td>5.8% (16)</td>
<td>8.8% (14)</td>
<td>1.4% (1)</td>
<td>6.1% (31)</td>
<td>.098</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HS or less</td>
<td>29.9% (81)</td>
<td>31.3% (50)</td>
<td>14.5% (10)</td>
<td>28.2% (141)</td>
<td></td>
</tr>
<tr>
<td>Some college</td>
<td>30.3% (82)</td>
<td>39.4% (63)</td>
<td>33.3% (23)</td>
<td>33.6% (168)</td>
<td></td>
</tr>
<tr>
<td>College degree or above</td>
<td>39.9% (108)</td>
<td>29.4% (47)</td>
<td>52.2% (36)</td>
<td>38.2% (191)</td>
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<tr>
<td><strong>Employment</strong></td>
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<td></td>
<td></td>
<td></td>
<td>.287</td>
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<tr>
<td>Employed (part and full time)</td>
<td>59.4% (164)</td>
<td>62.5% (100)</td>
<td>71.4% (50)</td>
<td>62.1% (314)</td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>26.4% (73)</td>
<td>26.3% (42)</td>
<td>22.9% (16)</td>
<td>25.9% (131)</td>
<td></td>
</tr>
<tr>
<td><strong>Living situation (multiple choice)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Homeless or in shelter</td>
<td>10.1% (28)</td>
<td>7.5% (12)</td>
<td>4.3% (3)</td>
<td>8.5% (43)</td>
<td>.251</td>
</tr>
<tr>
<td>Living with family</td>
<td>12.0% (33)</td>
<td>28.1% (45)</td>
<td>21.4% (15)</td>
<td>18.4% (93)</td>
<td>.000***</td>
</tr>
<tr>
<td>Living with partner</td>
<td>11.9% (33)</td>
<td>15.0% (24)</td>
<td>31.4% (22)</td>
<td>25.0% (74)</td>
<td>.000***</td>
</tr>
<tr>
<td>Living alone</td>
<td>33.7% (93)</td>
<td>24.4% (39)</td>
<td>25.7% (18)</td>
<td>29.6% (150)</td>
<td>.090</td>
</tr>
<tr>
<td><strong>Relationship</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>67.4% (186)</td>
<td>75.0% (120)</td>
<td>58.6% (41)</td>
<td>68.6% (347)</td>
<td>.039*</td>
</tr>
<tr>
<td>Married</td>
<td>6.5% (18)</td>
<td>12.5% (20)</td>
<td>21.4% (15)</td>
<td>10.5% (53)</td>
<td>.001***</td>
</tr>
</tbody>
</table>

Table 2. Selected demographics by place of birth

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mainland Born (n=206)</th>
<th>Puerto Rican Born (n=39)</th>
<th>Foreign born (n=259)</th>
<th>Total (n=506)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Language Preferences (multiple choice)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>64.1% (202)</td>
<td>84.1% (25)</td>
<td>53.3% (138)</td>
<td>72.4% (365)</td>
<td>.000**</td>
</tr>
<tr>
<td>Spanish</td>
<td>48.1% (99)</td>
<td>87.2% (34)</td>
<td>90.0% (233)</td>
<td>72.6% (366)</td>
<td>.000***</td>
</tr>
<tr>
<td>Portuguese</td>
<td>2.4% (4)</td>
<td>5.1% (2)</td>
<td>3.1% (8)</td>
<td>3.0% (15)</td>
<td>.653</td>
</tr>
<tr>
<td><strong>Sexual Orientation (multiple choice)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gay/homosexual</td>
<td>91.3% (188)</td>
<td>94.9% (37)</td>
<td>91.1% (236)</td>
<td>91.5% (461)</td>
<td>.730</td>
</tr>
<tr>
<td>Bisexual</td>
<td>10.2% (21)</td>
<td>2.6% (1)</td>
<td>7.3% (19)</td>
<td>8.1% (41)</td>
<td>.222</td>
</tr>
<tr>
<td>Queer</td>
<td>10.2% (21)</td>
<td>0% (0)</td>
<td>3.9% (10)</td>
<td>6.2% (31)</td>
<td>.005**</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HS or less</td>
<td>19.7% (40)</td>
<td>39.5% (15)</td>
<td>33.5% (86)</td>
<td>28.3% (141)</td>
<td></td>
</tr>
<tr>
<td>Some college</td>
<td>38.4% (78)</td>
<td>28.9% (11)</td>
<td>30.4% (78)</td>
<td>33.5% (167)</td>
<td></td>
</tr>
<tr>
<td>College degree or above</td>
<td>41.9% (85)</td>
<td>31.6% (12)</td>
<td>36.2% (93)</td>
<td>38.2% (190)</td>
<td></td>
</tr>
<tr>
<td><strong>Employment</strong></td>
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<td></td>
<td></td>
<td></td>
<td>.936</td>
</tr>
<tr>
<td>Employed (part and full time)</td>
<td>61.7% (127)</td>
<td>56.4% (22)</td>
<td>62.9% (163)</td>
<td>61.9% (312)</td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>26.7% (55)</td>
<td>28.2% (11)</td>
<td>25.1% (65)</td>
<td>26.0% (131)</td>
<td></td>
</tr>
<tr>
<td><strong>Living situation (multiple choice)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Homeless or in shelter</td>
<td>7.3% (15)</td>
<td>5.1% (2)</td>
<td>10.0% (26)</td>
<td>8.5% (43)</td>
<td>.418</td>
</tr>
<tr>
<td>Living with family</td>
<td>10.5% (15)</td>
<td>0.0% (0)</td>
<td>17.8% (46)</td>
<td>18.5% (93)</td>
<td>.003**</td>
</tr>
<tr>
<td>Living with partner</td>
<td>12.1% (25)</td>
<td>25.6% (10)</td>
<td>14.7% (38)</td>
<td>14.5% (73)</td>
<td>.089</td>
</tr>
<tr>
<td>Living alone</td>
<td>28.2% (58)</td>
<td>46.2% (18)</td>
<td>28.2% (73)</td>
<td>29.6% (149)</td>
<td>.061</td>
</tr>
<tr>
<td><strong>Relationship</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>73.8% (152)</td>
<td>59.0% (16)</td>
<td>10.0% (171)</td>
<td>66.0% (346)</td>
<td>.080</td>
</tr>
<tr>
<td>Married</td>
<td>7.8% (16)</td>
<td>12.6% (5)</td>
<td>12.0% (31)</td>
<td>10.3% (52)</td>
<td>.290</td>
</tr>
</tbody>
</table>

Table 2. Selected demographics by place of birth
<table>
<thead>
<tr>
<th>Variable</th>
<th>18-29yrs (n=143)</th>
<th>30-49yrs (n=362)</th>
<th>Total % (n=506)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Language choice (multiple choice)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>98.1% (202)</td>
<td>64.1% (25)</td>
<td>72.4% (365)</td>
<td>.000***</td>
</tr>
<tr>
<td>Spanish</td>
<td>48.1% (99)</td>
<td>87.2% (34)</td>
<td>72.6% (366)</td>
<td>.000***</td>
</tr>
<tr>
<td>Portuguese</td>
<td>2.1% (3)</td>
<td>3.3% (12)</td>
<td>3.0% (15)</td>
<td>.047*</td>
</tr>
<tr>
<td><strong>Sexual orientation (multiple choice)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gay/homosexual</td>
<td>90.2% (129)</td>
<td>92.0% (334)</td>
<td>91.5% (463)</td>
<td>.513</td>
</tr>
<tr>
<td>Bisexual</td>
<td>7.7% (11)</td>
<td>8.3% (30)</td>
<td>8.1% (41)</td>
<td>.332</td>
</tr>
<tr>
<td>Queer</td>
<td>15.4% (22)</td>
<td>2.5% (9)</td>
<td>6.1% (31)</td>
<td>.000***</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
<td>.291</td>
</tr>
<tr>
<td>HS or less</td>
<td>24.1% (334)</td>
<td>29.8% (107)</td>
<td>28.2% (141)</td>
<td></td>
</tr>
<tr>
<td>Some college</td>
<td>38.3% (54)</td>
<td>31.8% (114)</td>
<td>33.6% (168)</td>
<td></td>
</tr>
<tr>
<td>College degree or above</td>
<td>37.6% (53)</td>
<td>38.4% (138)</td>
<td>38.2% (191)</td>
<td></td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
<td></td>
<td></td>
<td>.083</td>
</tr>
<tr>
<td>Employed (part and full time)</td>
<td>61.5% (88)</td>
<td>62.3% (226)</td>
<td>62.1% (314)</td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>30.8% (44)</td>
<td>24.0% (87)</td>
<td>25.9% (131)</td>
<td></td>
</tr>
<tr>
<td><strong>Living situation (multiple choice)</strong></td>
<td></td>
<td></td>
<td></td>
<td>.957</td>
</tr>
<tr>
<td>Homeless or in shelter</td>
<td>8.4% (12)</td>
<td>8.5% (31)</td>
<td>8.5% (43)</td>
<td>.957</td>
</tr>
<tr>
<td>Living with family</td>
<td>30.1% (43)</td>
<td>13.8% (50)</td>
<td>18.4% (93)</td>
<td>.000***</td>
</tr>
<tr>
<td>Living with partner</td>
<td>10.5% (15)</td>
<td>16.3% (59)</td>
<td>14.6% (74)</td>
<td>.098</td>
</tr>
<tr>
<td>Living alone</td>
<td>18.9% (27)</td>
<td>33.9% (123)</td>
<td>29.6% (150)</td>
<td>.001***</td>
</tr>
<tr>
<td><strong>Relationship</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>8.4% (109)</td>
<td>8.5% (238)</td>
<td>8.5% (347)</td>
<td>.020*</td>
</tr>
<tr>
<td>Married</td>
<td>4.2% (6)</td>
<td>12.9% (47)</td>
<td>10.5% (53)</td>
<td>.004**</td>
</tr>
</tbody>
</table>

Table 3. Selected demographics by age category
Health status, health care seeking behavior, and health access

HIV diagnosis

Most participants (84.2%, n=426) had been diagnosed with HIV in the U.S. or Puerto Rico. The mean number of years of living with an HIV diagnosis was 9.83 (n=476, SD=6.95, Mdn=8.0). Close to 1 in 10 (9.4%) had been diagnosed with HIV for 20 or more years before the survey in 2018, close to a third (31.4%) between 10 and 19 years earlier, and 57.2% in the previous 10 years.

The mean number of years living with HIV for mainland U.S. born participants was lower (8.9 years) than those foreign born (10.55 years, p=.014). There were also significant differences in the number of years living with HIV by age category, with the mean number of years living with HIV lower for younger participants (4.85 years) than their older counterparts (11.78 years, p=.000).

A third of the sample had an AIDS diagnosis (33.2%, n=168). There were not differences on having an AIDS diagnosis by place of birth or residence. However, older participants (30-49) were more likely to have an AIDS diagnosis (38.0%) than their younger counterparts (21.0%, p=.000).

Physical health

Close to two thirds of participants (64.8%, 328) reported good or very good physical health; 29.2% (n=148) reported average physical health; and only 5.9% (n=30) reported poor or very poor physical health. There were not significant differences based on place of birth or age. However, Miami participants were more likely to report good or very good physical health (80.0%) than their counterparts in LA (57.5%, p=.000) and in NYC (64.8%, p=.003).

Multi-morbidity

The following multi-morbidities were examined for this report: diabetes, hypertension, high cholesterol, CVD, asthma, arthritis, depression, anxiety, decreased mobility, dementia, substance abuse, cancer, and HCV. Table 4 shows the prevalence of the selected multi-morbidities.

The number of existing multi-morbidities per participant was calculated for the sample. The mean number of multi-morbidities was 1.507 (SD=1.52). Sixty nine percent (69%, 349) of participants reported one more health conditions besides HIV, and 1 in 5 (21.1%) reported 3 or more. There were no differences based on place of residence or birth. Older participants, however, were more likely to experience diabetes (p=.011), hypertension (p=.001), high cholesterol (p=.000), arthritis (p=.023), cancer (p=.029), AIDS (p=.000), and HCV (p=.034) than their younger counterparts.

<table>
<thead>
<tr>
<th>Diagnosed Condition</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes</td>
<td>28</td>
<td>5.5%</td>
</tr>
<tr>
<td>Hypertension</td>
<td>66</td>
<td>13.0%</td>
</tr>
<tr>
<td>High cholesterol</td>
<td>89</td>
<td>17.6%</td>
</tr>
<tr>
<td>CVD</td>
<td>15</td>
<td>3.0%</td>
</tr>
<tr>
<td>Asthma</td>
<td>64</td>
<td>12.6%</td>
</tr>
<tr>
<td>Arthritis</td>
<td>19</td>
<td>3.8%</td>
</tr>
<tr>
<td>Depression</td>
<td>190</td>
<td>37.5%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>179</td>
<td>35.4%</td>
</tr>
<tr>
<td>Decreased mobility</td>
<td>7</td>
<td>1.4%</td>
</tr>
<tr>
<td>Dementia</td>
<td>2</td>
<td>0.4%</td>
</tr>
<tr>
<td>Substance abuse</td>
<td>58</td>
<td>11.5%</td>
</tr>
<tr>
<td>Cancer</td>
<td>16</td>
<td>3.2%</td>
</tr>
<tr>
<td>HCV</td>
<td>28</td>
<td>5.5%</td>
</tr>
</tbody>
</table>

Table 4. Reported multi-morbidities

Health insurance

Most participants (91.5%, n=463) had health insurance (8.1%, n=41 did not). There were no significant differences based on age categories or place of birth. However, respondents in Miami were more likely to report not having insurance (21.4%, n=15) than in Los Angeles (8.8%, n=14, LSD p=.019) or New York City (4.3%, n=12, LSD p=.000).

Upon further examination of health insurance by age and city or residence, younger participants in Miami were much more likely to report not having insurance than their older counterparts, 42.9% and 16.1% respectively (p=.029). As shown in Table 5, mainland U.S. and Puerto Rico born participants were more likely to rely on private insurance than their foreign-born counterparts. On the other hand, foreign born participants were more likely to rely on ADAP/Ryan White programs for insurance.
Engagement in care

Having and visiting a regular primary care provider (PCP)

Chart 1 shows the results for having insurance and having a regular PCP by age, place of birth, and place of residence. Most participants had a regular health provider (93.6%, n=473). There were no differences based on place of residence. However, older participants (30-49) were more likely to have a regular health provider than their younger counterparts (96.1% vs 86.7%, p=.000). Participants born in Puerto Rico were less likely to have a regular provider than those born in mainland U.S. and foreign-born participants (LSD p=.006 in both cases).

The vast majority had seen a health care provider for HIV treatment in the previous 12 months (94.3%, n=477). There were no differences by age (p=.577) or place of birth (p=.570). Among the 453 participants that responded to the question on number of visits to an HIV PCP in the previous 12 months (M=3.89, SD=2.57), almost three quarters (74.2%) had visited the HIV PCP three times or more. There were not differences in number of visits by age category (p=.650) or place of birth (p=.960).

Delay in care or go without health care

Almost a quarter (24.7%, n=125) had to delay or go without HIV care in the previous 12 months. Table 6 shows the reasons stated for the delay or lack of access to health care for those who delayed care. Two fifths of those with delayed care (40.8%, n=51) reported 2 or more reasons.

There were no differences in delay of care based on place of birth. However, younger participants were more likely to experience delay or lack of HIV care (35.7%, n=51) than their older counterparts (20.4%, n=74), p=.000.
Alternative health practices

Over a quarter of participants (26.3%, n=133) had used alternative healing practices; 1 in 5 (18.8%, n=95) had previously used botanicas; over half (59.9%, n=303) had used home remedies (“remedios caseros”); and 40.3% (n=204) had used prescriptions bought in another country.

There were significant differences in the use of alternative health practices by place of birth (ANOVA analysis). Foreign born participants were more likely to use alternative healing than other groups (LSD p=.037), botanicas (LSD p=.031), home remedies (LSD p=.045), and foreign-bought prescription medicine (LSD p=.000).

Engagement in treatment

The vast majority of participants (n=475, 93.9%) were in treatment. A small percentage of participants (4.6%, n=23) were not in treatment, declined (n=1), or did not know (n=7). A higher percentage of participants born in mainland U.S. were not in HIV treatment compared to those foreign-born (9.0% vs. 1.6%, p=.000) and those born in Puerto Rico (9.0% vs. 2.6%, p=.037). Similarly, a higher percentage of younger participants were not in HIV treatment compared to older participants (9.0% vs. 2.8%, p=.001).

We calculated the lapse between the year of diagnosis and the year of initiation in HIV treatment for those with information about both events (n=446). The mean number of lapse years was 1.14 years (SD=2.83). Two thirds of the sample started treatment within one year (66.1%, n=295), 90.4% (n=403) started HIV treatment within the first three years. All of the cases with 4 or more lapse years (n=43) had been diagnosed prior to 2010.

Among those not in treatment (n=23), the main reasons were cost of treatment (n=6), not knowing where to go for care (n=6), not having a medical provider (n=5), not having health insurance (n=4), not feeling sick (n=4), not liking side effects (n=4), and no one knowing HIV status (n=4). Twelve of the 23 participants not in treatment had 2 or more reasons for not engaging in treatment.

Most participants had taken their HIV medication in the previous 4 weeks (93.7%, n=474/506). Younger participants were less likely to have taken their medication in the previous 4 weeks than their older counterparts (11.2% vs 4.4%, p=.005). Similarly, those participants born in mainland U.S. were less likely to have taken their medication (11.7%) than foreign born participants (1.9%), p=.000.

Side effects

Most participants in treatment (n=334/475, 70.3%) reported not experiencing treatment side effects. There were no differences based on place of birth (p=.123) or age category (p=.226). However, one in 10 (10.5%, n=50) found it difficult or very difficult to adhere to treatment. We compared the means of difficulty (1 very easy, 5 very difficult). Younger participants reported more difficulty adherent to treatment than their older counterparts (M=2.22 vs M=1.86, p=.002). There were no differences based on place of birth.

Blood work and prescription refills

Among those in treatment (n=475), most participants (85.9%, n=408) had blood work conducted the same year than the survey (2018), and almost all had a prescription filled in the previous 12 months (98.3%, n=467). There were no differences by age or place of birth.

HIV Treatment Satisfaction Questionnaire (HIVTSQs)

As mentioned earlier, the study used a modified version of the HIV Treatment Satisfaction Questionnaire. Surveys of those in HIV treatment with complete answers within each domain were selected, i.e., if one or more items were not answered, the case was not selected for analysis. Items were reversed when necessary
to provide a positive direction to the score. Then, mean scores of items within each domain were used to calculate the combined score for each domain. The combined score was then transformed to a linear 0 to 100 scale, with 0 the worst score and 100 the best.

For the 477 surveys analyzed, the mean treatment satisfaction was 76.28 (SD=19.01, Min=22.22, Max=100). There were no significant differences based on place of birth (LSD p=.806) or age category (p=.069). Table 7 shows the mean and standard deviations for the questionnaire domains.

<table>
<thead>
<tr>
<th>Item (6 the best score possible)</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>How satisfied are you with</td>
<td></td>
<td></td>
</tr>
<tr>
<td>your current treatment?</td>
<td>4.6625</td>
<td>1.62611</td>
</tr>
<tr>
<td>the side effects of your current treatment?</td>
<td>4.0943</td>
<td>1.84297</td>
</tr>
<tr>
<td>the demands of your current treatment?</td>
<td>4.4046</td>
<td>1.45936</td>
</tr>
<tr>
<td>your understanding of your HIV?</td>
<td>4.7962</td>
<td>1.53132</td>
</tr>
<tr>
<td>to which your current treatment fits in with your lifestyle?</td>
<td>4.5514</td>
<td>1.59041</td>
</tr>
<tr>
<td>continuing with your current treatment?</td>
<td>4.7673</td>
<td>1.50989</td>
</tr>
<tr>
<td>the amount of discomfort or pain you experience with your current treatment?</td>
<td>4.1153</td>
<td>1.82228</td>
</tr>
<tr>
<td>well controlled is your HIV?</td>
<td>5.0503</td>
<td>1.38023</td>
</tr>
<tr>
<td>convenient is your HIV treatment?</td>
<td>4.9669</td>
<td>1.40162</td>
</tr>
<tr>
<td>flexible is your HIV treatment?</td>
<td>4.5101</td>
<td>1.60191</td>
</tr>
<tr>
<td>recommend</td>
<td>4.9036</td>
<td>1.43161</td>
</tr>
<tr>
<td>difficulty (reversed score 0 best score)</td>
<td>1.9266</td>
<td>1.35669</td>
</tr>
</tbody>
</table>

Table 7. Treatment satisfaction (n=477)

**Simplified Medication Adherence Questionnaire (SMAQ)**

As mentioned earlier, the study also used a modified version of the SMAQ. Out of those currently taking HIV medication (n=480), over half (51.9%, n=249) had sometimes forgotten to take the medication. A larger percentage had forgotten to take the medication as prescribed (60.8%, n=292). Only a small percentage had stopped taking HIV medication because of side effects (8.3%, n=40). Foreign born participants were less likely to forget their medication than other groups (p=.003) and less likely to forget to take the medication as prescribed (p=.004). There were no significant differences by age category. Over a quarter (25.6%, n=123) had stopped taking medication for more than 2 days in the previous 3 months. In the week previous to the survey, over half had never stopped taking the medication (51%, n=245), and 32.1% (n=154) had rarely stopped. In the previous weekend, 80.4% (n=386) had not stopped.

**Undetectable HIV viral load**

Over half of the sample (53.6%, n=271) reported undetectable viral load, 7.7% (n=39) reported detectable viral load, and 38.7% (n=196) did not know or answer the question. Among those who reported on their viral load, there were not significant differences by age category (p=.399) or place of birth (p=.311). On the other hand, most participants reported having been told by their providers that their viral load was undetectable (88.5%, n=448). Younger participants and those born in Puerto Rico were less likely to have been told their viral load was undetectable (LSD ANOVA). See Tables 8 and 9.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mainland Born</th>
<th>Puerto Rican Born</th>
<th>Foreign born</th>
<th>Total</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Undetectable? (n=308)</td>
<td>84.0% (100)</td>
<td>93.1% (27)</td>
<td>88.8% (142)</td>
<td>87.3% (269)</td>
<td>.311</td>
</tr>
<tr>
<td>Been told undetectable? (n=504)</td>
<td>85.0% (175)</td>
<td>84.6% (33)</td>
<td>91.9% (238)</td>
<td>88.5% (446)</td>
<td>.049*</td>
</tr>
</tbody>
</table>

Table 8. Undetectable viral load by place of birth
Continuum of care

We defined “linked to HIV care” as having seen a healthcare provider for HIV treatment in the past 12 months and “engaged in HIV care” as having had 2 or more visits. Treatment adherence was defined as “yes” to taking medications and having had at least one prescription filled in the previous 12 months. For viral suppression, we used the variable “been told by HIV PCP that viral load is undetectable.” See Chart 2 for breakdown of the continuum of care for different groups.

<table>
<thead>
<tr>
<th>Variable</th>
<th>18-29yrs</th>
<th>30-49yrs</th>
<th>Total</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Undetectable? (n=310)</td>
<td>84.5% (60)</td>
<td>88.3% (211)</td>
<td>87.4% (n=271)</td>
<td>.399</td>
</tr>
<tr>
<td>Been told undetectable? (n=506)</td>
<td>82.5% (118)</td>
<td>90.9% (330)</td>
<td>88.5% (448)</td>
<td>.008**</td>
</tr>
</tbody>
</table>

Table 9. Undetectable viral load by age category

CHART 2. HIV Continuum of Care (% of viral suppression shown)

Patient – PCP relationship

Satisfaction with provider

For those with a healthcare provider, patient satisfaction was measured through 3 variables. Close to two thirds of participants (62.5%) were satisfied or very satisfied with their provider in regards to scheduling an appointment and 80.3% with the provider’s knowledge of HIV health issues. Many participants (79.7%) felt respected by their provider. These variables were combined to create an overall satisfaction score, with 1 not at all satisfied and 5 very satisfied (M=4.05, ST=0.899). There were no differences based on age. Satisfaction score for foreign born was significantly lower than for those born in mainland U.S. (3.95 vs 4.17, LSD p=.013).

Patient – PCP relationship

Eleven questions measured the patient – PCP relationship, with 1 poor and 5 excellent. Variables were combined into an overall Patient-PCP relationship score. The mean of the combined score was 3.546, (SD=0.62). There were no significant differences based on place of birth or age category. See Tables 10 and 11.
Topics of discussion with PCP

The survey included questions about whether the PCP had discussed twelve non-HIV topics (see survey). Of particular importance was the lack of discussion on some issues such as eating disorders (13.4%), intimate partner violence (9.7%), nicotine use (25.5%), and safety (28.7%).

Quality of life (HAT-QOL) and behavioral health

To measure quality of life, we use the HAT-QOL questionnaire. Surveys with complete answers within each domain were selected. If one or more items were not answered the case was not selected. Items were reversed when necessary to provide a positive direction to the score. Mean scores of items within each domain were then used to calculate the combined score for each domain. Finally, the combined score was transformed to a linear 0 to 100 scale, with 0 the worst score and 100 the best. See Table 12. Overall, there were no major significant differences based on place of birth. Multiple comparison analysis using LSD found differences in two domains: life satisfaction between those born in mainland U.S. and foreign born (M=61.80 and 67.64, p=.021), and in disclosure (M=64.13 and 57.69, p=.029). As seen in Table 13, there were significant differences in mean scores for several domains of quality of life by age category.
Substance use

Alcohol and drug use behavior was prevalent in our study sample. A little more than 1 in 2 (54.3%) of the sample engaged in alcohol use and, a similar proportion, 52.6% (n=266) used drugs. Younger participants were more likely to report alcohol use (p=.013) and drugs to “get high” (p=.000). There were no differences for alcohol use by place of birth (p=.071) but foreign-born participants were less likely to use drugs than their counterparts born in mainland U.S. (42.1% vs 64.1%, p=.000). About 1 in 10 (12.1%, n=61) were currently in recovery, with 8.5% (n=43) from alcohol use, 11.9% (n=60) from Meth, and 1.0% (n=5) from heroin. There were no differences on current recovery by place of birth (p=.548) or age category (p=.684). About half of the sample (50.2%) reported mixing drugs and sex 20% of times or less; 1 in10 (10.3%) reported having sex and drugs 90% of the time or more. Current substance use was inversely correlated with having been told to be undetectable (p=.017).

Sexual behaviors

Most participants (78.9%, n=399) had had sex within the 30 days before the survey. Of those, most (99.2%, n=502) had had sex with males, 5.1% (26) with females, and a small percentage (1.2%, n=6) with transgender women. Over half of participants had had sex recently with a person living with HIV (56.2%, n=285), and over half with someone HIV- (55.5%, n=281). A large percentage of those who reported having sex with HIV-individuals (69%, n=194) also reported their sexual partner was taking PrEP.

Over half of the sample (59.7%, n=302) reported insertive anal sex with their most recent sexual partner; a similar proportion (62.6%, n=317) reported receptive anal sex; and a small percentage (2.6%, n=13) reported insertive vaginal sex. There were no differences based on place of birth or age category. Over half of the sample did not use condoms in their last sexual encounter (52.2%, n=264). Younger participants were more likely not to use condoms than their older counterparts (62.2% vs 48.2%, p=.004). Those born in mainland U.S. and in Puerto Rico were less likely to use condoms (60.2% and 61.5%) than foreign born participants (44.0%, p=.000 and p=.004 respectively).
Correlates of undetectable viral load

Table 14 presents the correlations between different variables and having been told to have undetectable viral load for the full sample. Simple binary regression analysis was conducted to examine the relationship between the dependent variable “have you been told by your healthcare provider for your HIV that your viral load is ‘undetectable’?” with the following potential predictors: age category, place of birth, current drug use, HAT-QOL domains, patient-PCP relationship score, HIV Treatment Satisfaction Questionnaire (HIVTSQ), and forgetting to take medication as prescribed.

In addition, regression analysis was conducted for those born in mainland U.S. and for those 19 to 29 years of age (see Tables 14 and 15). Due to the small number of Puerto Rico born participants, we did not conduct regression analysis for this subgroup.

As seen in Table 15 for mainland-born participants, having better scores in overall functioning, health worries, and sexual life had significant positive regression weights on reporting that they had been told to have undetectable viral load. Note: The binary regression analysis (n=206, missing cases 41) produced Nagelkerke R Square = .395, DF =14. As seen in Table 16 for participants 19 to 29, having better score in health worries and no current substance use had significant positive regression weights on reporting that they had been told to have undetectable viral load. Note: The binary regression analysis (n=143, missing cases 26) produced Nagelkerke R Square = .384, DF =15.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Undetectable viral load</th>
<th>p correlation (Chi-Square)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having medical insurance</td>
<td>.444</td>
<td>0.97</td>
</tr>
<tr>
<td>Satisfaction with PCP</td>
<td>.597</td>
<td>0.263</td>
</tr>
<tr>
<td>HAT-QOL Overall Functioning</td>
<td>.592</td>
<td>0.263</td>
</tr>
<tr>
<td>HAT-QOL Life satisfaction</td>
<td>.038*</td>
<td>0.127</td>
</tr>
<tr>
<td>HAT-QOL Health Worries</td>
<td>.001***</td>
<td>0.127</td>
</tr>
<tr>
<td>HAT-QOL Financial Worries</td>
<td>.025*</td>
<td>0.127</td>
</tr>
<tr>
<td>HAT-QOL Medication Worries</td>
<td>.003**</td>
<td>0.127</td>
</tr>
<tr>
<td>HAT-QOL HIV Mastery</td>
<td>.017*</td>
<td>0.127</td>
</tr>
<tr>
<td>HAT-QOL Disclosure Worries</td>
<td>.001***</td>
<td>0.127</td>
</tr>
<tr>
<td>HAT-QOL Sexual Life</td>
<td>.016*</td>
<td>0.127</td>
</tr>
<tr>
<td>HAT-QOL Trust</td>
<td>.047*</td>
<td>0.127</td>
</tr>
<tr>
<td>HIV Treatment Satisfaction</td>
<td>.001*</td>
<td>0.127</td>
</tr>
<tr>
<td>Substance use</td>
<td>.017*</td>
<td>0.127</td>
</tr>
</tbody>
</table>

Table 14. Selected variables and undetectable viral load

<table>
<thead>
<tr>
<th>Correlates of having been told to have undetectable viral load among mainland-born Latino GBM/MSM</th>
<th>b</th>
<th>Exp(B)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfaction with PCP</td>
<td>.658</td>
<td>1.944</td>
</tr>
<tr>
<td>HAT-QOL Overall Functioning</td>
<td>.597</td>
<td>1.925</td>
</tr>
<tr>
<td>HAT-QOL Life satisfaction</td>
<td>.263</td>
<td>1.021</td>
</tr>
<tr>
<td>HAT-QOL Health Worries</td>
<td>.001</td>
<td>1.001</td>
</tr>
<tr>
<td>HAT-QOL Financial Worries</td>
<td>.127</td>
<td>1.079</td>
</tr>
<tr>
<td>HAT-QOL Medication Worries</td>
<td>.592</td>
<td>1.028</td>
</tr>
<tr>
<td>HAT-QOL HIV Mastery</td>
<td>.592</td>
<td>1.028</td>
</tr>
<tr>
<td>HAT-QOL Disclosure Worries</td>
<td>.592</td>
<td>1.028</td>
</tr>
<tr>
<td>HAT-QOL Sexual Life</td>
<td>.000*</td>
<td>1.040</td>
</tr>
<tr>
<td>HAT-QOL Trust</td>
<td>.000*</td>
<td>1.040</td>
</tr>
<tr>
<td>HIV Treatment Satisfaction (HIVTSQs)</td>
<td>.000*</td>
<td>1.040</td>
</tr>
<tr>
<td>No current substance use</td>
<td>.000*</td>
<td>1.040</td>
</tr>
<tr>
<td>Forgetting to take medication as prescribed</td>
<td>.000*</td>
<td>1.040</td>
</tr>
<tr>
<td>Age category</td>
<td>.480</td>
<td>.617</td>
</tr>
<tr>
<td>Constant = Exp(B)</td>
<td>89.974</td>
<td></td>
</tr>
</tbody>
</table>

Table 15. Undetectable viral load among mainland-born Latino GBM/MSM

<table>
<thead>
<tr>
<th>Correlates of having been told to have undetectable viral load among Latino GBM/MSM ages 19 to 29</th>
<th>b</th>
<th>Exp(B)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfaction with PCP</td>
<td>.759</td>
<td>1.332</td>
</tr>
<tr>
<td>HAT-QOL Overall Functioning</td>
<td>.754</td>
<td>1.332</td>
</tr>
<tr>
<td>HAT-QOL Life satisfaction</td>
<td>.250</td>
<td>1.066</td>
</tr>
<tr>
<td>HAT-QOL Health Worries</td>
<td>.014*</td>
<td>1.066</td>
</tr>
<tr>
<td>HAT-QOL Financial Worries</td>
<td>.972</td>
<td>1.066</td>
</tr>
<tr>
<td>HAT-QOL Medication Worries</td>
<td>.924</td>
<td>1.066</td>
</tr>
<tr>
<td>HAT-QOL HIV Mastery</td>
<td>.924</td>
<td>1.066</td>
</tr>
<tr>
<td>HAT-QOL Disclosure Worries</td>
<td>.924</td>
<td>1.066</td>
</tr>
<tr>
<td>HAT-QOL Sexual Life</td>
<td>.110</td>
<td>1.0234</td>
</tr>
<tr>
<td>HAT-QOL Trust</td>
<td>.173</td>
<td>1.074</td>
</tr>
<tr>
<td>HIV Treatment Satisfaction (HIVTSQs)</td>
<td>.198</td>
<td>1.043</td>
</tr>
<tr>
<td>No current substance use</td>
<td>.021</td>
<td>1.021</td>
</tr>
<tr>
<td>Forgetting to take medication as prescribed</td>
<td>.451</td>
<td>.336</td>
</tr>
<tr>
<td>Place of birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mainland born</td>
<td>.656</td>
<td></td>
</tr>
<tr>
<td>Puerto Rico born</td>
<td>.600</td>
<td>1.509</td>
</tr>
<tr>
<td>Foreign born</td>
<td>.915</td>
<td>1.656</td>
</tr>
<tr>
<td>Constant = Exp(B)</td>
<td>.241</td>
<td></td>
</tr>
</tbody>
</table>

Table 16. Undetectable viral load among Latino GBM/MSM ages 19 to 29
A total of 106 individuals participated in the thirteen focus groups. The mean age of participants was 40.5 years of age (SD=8.140); all of whom identified as male. Close to half (47, 44.3%) resided in Los Angeles metropolitan area, 15 in Miami metropolitan area (14.2%), and 44 in New York City metropolitan area (41.5%). Over three quarters of participants (78.3%, 83) were born outside mainland U.S., 36 of them in Mexico, 9 in Colombia, 7 in Cuba, and 2 in Puerto Rico.

This report focuses on the following overarching themes that were central to the discussions in the focus groups: living with HIV, quality of care, the patient-PCP relationship, and treatment adherence and continuity of care. As expected, these four themes were intricately and unavoidably interconnected with other issues as participants discussed their lived experiences. While focus group participants reported on many challenges, they also reported on strategies to cope with the stress of living with HIV, become more pro-active in their engagement with care and PCPs, and manage the challenges of treatment adherence.

Living with HIV

While focus group participants reported on a variety of issues related to living with HIV, their discussions centered on (a) the emotional toll of receiving an HIV diagnosis and/or living with HIV; (b) the experiences and fear of stigmatization and the connection to their ability or willingness to disclose to others their sexual orientation and/or HIV status; and (c) their concerns about their immigration status in relation to living with HIV.

The toll of living with HIV

Living with HIV took a physical and emotional toll on many participants as they tried to adhere to their HIV treatment, to manage multi-morbidities and polypharmacy, or to find appropriate care. As reported by a participant,

> I think it’s just coping with HIV, and trying to get other services for other health factors that makes you [think], “Do I want to take my HIV meds, or do I want to take this one for this one?” I mean, how do I find a balance? Where do I find a balance to fit my HIV meds, trying to get services for the other stuff that I suffer from, and finding the right doctor or the right specialist to find a balance? (LA Focus Group, English)

Many participants reported on the frustration and uncertainty created by multi-morbidities and polypharmacy. For instance, a participant reported taking six psychiatric medications a day in addition to his HIV meds, and another participant reported taking 9 medications, including those for smoking cessation and multi-vitamins. A participant, who had been diagnosed with HIV, hepatitis B, and a mental disorder, described the physical and emotional challenges of managing his health:

> But you still suffer through a worry stage where you’re like, “There are medications that I can’t take because if I take hepatitis B medication, it won’t work anymore if I take certain mental medications.” So, it’s a very frustrating and demanding situation in a sense where you sleep over it. You’re like, “Am I ever going to get better? Am I ever going to be a hundred percent?” (Miami Focus Group, Spanish)

The emotional and physical toll of living with HIV was often experienced in isolation since social stigmatization of HIV and lack of community understanding of HIV made them wary of disclosing their HIV status to family members. To obtain social support from loved ones, some participants resorted to partial disclosure to selected family members while holding disclosure to other members.
I’m very close with my family and the only one that knows is one of my sisters only because she’s a nurse, and she knows about medicine and all that stuff, so I let her know. In case anything happens to me, at least she knows. (Miami Focus Group, English)

While social support systems may provide emotional support to those living with HIV and prevent further isolation, some respondents saw limitations of relying on friends, including lack of supportive skills and confidentiality issues.

Sometimes you can talk to a friend but you have to be careful because you don’t know if he is going to tell someone someday. You never know. And a therapist knows that it’s his or her job and they can never divulge that information because it’s their profession. (NYC Focus Group, Spanish)

Participants acknowledged the need for professional mental health services to cope with the emotional impact of living with HIV. At the same time, they spoke about key factors precluding them from accessing these very services, including lack of health coverage and cultural views on mental health. Equally important, the cultural stigma associated with accessing mental health services—which equates accessing mental health services with “being crazy”—prevented some of them further from getting needed services.

It’s very much needed because there is – that’s a stigma that I find, and that I think it’s still not something that we’ve been able to overcome. When you tell someone, “You have to go see a psychologist or a psychiatrist” they think you’re telling them they’re crazy. (NYC Focus Group, Spanish)

In addition to the stigmatization of accessing mental health services, cultural views on self-reliance as a masculine trait may prevent Latino men from accessing mental health services. The emphasis on self-reliance often increased their already heightened sense of isolation and being on their own. As a participant stated,

Often times the Latino community stigmatizes the seeking out of mental health, let alone participating in it. [...] There’s also this front that as men, we shouldn’t seek out help and as independent individuals, you should be able to handle your shit on your own. (LA Focus Group, English)

As a response to cultural stigmatization of mental health and the related hesitance to use mental health services, participants provided some recommendations to increase the use of these services. In particular participants spoke of conducting routine mental health screenings and integrating HIV and mental health care as standard of practice to normalize these services.

There should be a mental health specialist, and they should do a general check-up. If he decides that this person should follow this treatment, be it a psychology, or whatever, maybe for the adherence of the medication, if they don’t want to take it now. (NYC Focus Group, Spanish)

I’d think that within the assessment we have every three months, which is to see the nurse, or see the doctor, we should also see the therapist. It should be something part of the process of every three months. (NYC Focus Group, Spanish)

For many participants, having to manage HIV, multi-morbidity, and polypharmacy took a physical and emotional toll. This physical and emotional toll was often experienced in isolation as they felt hesitant to disclose to their social networks or access needed mental health services for fear of stigmatization.
Multiple stigmatization: being gay and HIV positive

Many participants were concerned about the synergistic double impact of stigmatization due to their sexual orientation and HIV status. Those who had already experienced stigmatization due to their sexual orientation were hesitant to add another source of stigmatization by disclosing their HIV status. Within a cultural context that blamed their sexual orientation as the reason for acquiring HIV, many participants withheld information about both their sexuality and HIV status for fear of their family’s reactions.

“I haven’t disclosed to my parents about my sexuality or my HIV status, and I feel like, if, those two things… “it’s because you made the choice or acted on being gay, that is why you have HIV.” That’s not the case, but I definitely feel that would be definitely how they’re going to see it, as like those two things are connected. (LA Focus Group, English)

In many instances, participants had withheld information about their HIV status in isolation or disclosed only to a few loved ones due to their concerns about rejection and stigmatization. In some cases, the anxiety over disclosing sexual orientation and/or HIV had lingered for long periods of time.

“I would love to tell my parents or my sister and let them know, prove to them that I’m fine and it’s just a chronic condition. Initially, I didn’t share it because I felt that they’re such worry-warts and I didn’t want to deal with me going through this diagnosis, maybe not being equipped to answer their questions. I was so new, I didn’t know if I was gonna die like two or three months into it. I told a few friends and they were all unbelievably supportive and really awesome. Then the years progressed and I felt like, “Let me just get five years under my belt. Have you seen me in the last five years? Haven’t I been legit? I’m fine.” Then five years came in went. Then ten years. (LA Focus Group, English)

These concerns about the negative consequences of disclosure were not unfounded. For some participants, disclosure of their HIV status resulted in housing instability, loss of social support, and financial and emotional stress.

“And when I finally told him [his brother], he – I did experience rejection. And then he started to tell me that the best thing would be for me to look for a room and that he would pay for it. In so many words, they asked me not to put them at risk. (NYC Focus Group, Spanish)

Disclosure of sexual orientation and/or HIV status weighted heavy on many participants as they considered disclosing to others outside of their close social networks, including to health care providers and employers.

“Sometimes, we get these workshops about disclosure, and sometimes, I’m not quite sure about telling my employers. But sometimes, I feel like I have to, because what if I need to – what if it’s a job that requires me to be there all the time? And, sometimes, people would give me the advice, or just tell me, "Well, just tell them that you need to go to the doctor, and just bring a doctor’s notification." But then, they start asking, "Why?" (LA Focus Group, English)

As the participants above described, fear of stigmatization and rejection prevented many of them from disclosing sexual orientation and HIV status to people in their social networks who could provide emotional, instrumental and social support.
Immigration and HIV

Immigration in itself was cause of stress for many participants. Many undocumented participants reported heightened stress, uncertainty, depression, and anxiety over their immigration status.

_Not having a migratory status makes me feel really stressed – not knowing what my future holds, not knowing what’s going to happen, not knowing if I will be able to see my mother before she dies._ (NYC Focus Group, Spanish)

In addition to immigration itself, participants described ways in which immigration and HIV had intersected or still intersected to increase their stress about discrimination, their future, or receiving care.

_So, as an undocumented Hispanic person, you have to say, “I have HIV and I am undocumented.” So, you wonder, are they not going to treat me? Or you have to go and say something or you have to stay quiet. You can say – “I am okay.” In this case, if I am going to the hospital and I have an emergency, so I say, “Should I say that I have HIV or not? Or what should I do?”_ (NYC Focus Group, Spanish)

Some participants had delayed their legalizations process for many years out of fear of deportation or denial of citizenship. The uncertainty and fear constituted traumatic experiences for those wanting to legalize their status. Furthermore, the denial of legalization impacted their sense of confidence on who they were as individuals as they felt stigmatized because of their HIV status.

_I got infected here. And the first thing that has made an impact in my life is that they denied my papers back in 2006, they denied my green card just by being HIV positive, and that was under the Bush Administration. So, I was like, "Damn, but I’m not a terrorist; I’m not a freaking – I’m not any of that, I don’t do any of that." As a matter of fact, I had been living in the states for 21 years now, and I don’t have no record, like that. I don’t have no record. And so, I would tell my mum, I feel like a loser because the reason that I moved to the states is to have a better life, and to have help out my family back home._ (LA Focus Group, English)

While immigration laws and regulations have changed, some participants still felt wary about the impact of HIV status in their legalization process, therefore were cautious about utilizing services. In addition to concerns about the legalization process, immigrant participants expressed concern and anxiety about the consequences of having to return to their countries of origin and not being able to access medication due to availability or cost.

_I was diagnosed in 2016 and I started taking a private treatment and I had to pay for my medication but imagine my country where the minimum wage is $350.00 and the medication was $150.00. I had to take Atripla. So, it was very expensive._ (Miami Focus Group, Spanish)

Participants’ concerns went beyond cost or availability. Some of them were concerned about having to stop effective state-of-the-art medication.

_I mean, you have to be here because the medication is available here and it’s not in our countries. We don’t want to die. So, how can we be sure? For example, if I want to go to my country and I have HIV, so how can I be sure that I am going to get the same medication that I am getting here? I mean, how can I be sure? I mean, you can’t._ (Miami Focus Group, Spanish)

Across focus groups immigrant participants felt general anxiety about their immigration status as well as specific anxiety about being able to continue their HIV treatment and care.
Language barriers

While many participants were comfortable discussing their care in either Spanish or English, language barriers constituted a critical barrier to quality care for some participants. Specifically, participants reported not being able to communicate and understand the information about medical conditions or treatment and, therefore, feeling frustrated with the medical appointment.

You can’t communicate your condition – your medical condition, you can’t communicate it because they don’t understand you. They don’t understand you, you don’t understand them, and it ends up being the same or even worse sometimes. You end up frustrated. (LA Focus Group, Spanish)

A few participants felt positive about the use of translators and other bilingual staff during the patient-physician interaction. However, for some the use of translators was not an effective solution to the language barrier because of the availability of translators, the cumbersomeness of the interaction, as well as confidentiality concerns.

Well, sometimes I don’t understand him very well because the doctor speaks English and I speak Spanish. And I am like, “What is this?” And I have to ask for a translator. And sometimes there is nobody available. So, that is a bad thing. All of the doctors that I have seen only speak English. (Miami Focus Group, Spanish)

So, they use a translator but sometimes I don’t want it because I prefer my appointments to be confidential. (NYC Focus Group, Spanish)

As we will see below, participants expected PCPs to provide adequate and easy to understand health and medical information to patients. The discussions on language barriers within the focus groups highlighted both the need for Spanish-speaking PCPs as well as the limitations of the use of translation services.

Comprehensive care beyond undetectable viral load

Many respondents reported having multiple health issues besides HIV, including diabetes, high cholesterol, neuropathy, erectile dysfunction, kidney problems, obesity, and hepatitis. Some participants reported that despite the presence of multi-morbidities, their HIV primary care providers were not attending to their multiple needs besides HIV. Participants saw lack of attention to other health issues as the result of the single-focused approach on HIV treatment at the expense of other health needs. The disregard for morbidities made some participants feel that they were not treated in a holistic manner as a “complete person.”

Well, my doctor in Fort Lauderdale would just see my HIV status, and I am a complete person. Do you understand me? She ignored nutrition and many other things. She just saw a paper and she would say something like, “Oh, your viral load is undetectable.” And they send you somewhere else. And since I didn’t have many symptoms, I was ignored. (Miami Focus Group, English)

Unfortunately, my experience has been really negative, it has been bad because unfortunately they don’t understand that people with HIV, or AIDS, have extra complications that sometimes have nothing to do with HIV. And unfortunately, they refuse to provide us with attention.
In describing what constitutes a “good appointment,” participants expected comprehensive care and regarded the attention to multi-morbidities as a sign of good practice. Participants also highlighted the need for PCPs to go beyond HIV clinical markers and address life circumstances that could impact their health and well-being, including their social support systems.

*My ideal appointment is, which I’ve had with him, when I tell him everything from the lump in my eye, which has not gone away, to my sciatic pain. In just one appointment I could tell him everything – doctor, my surgery scar looks bad. Doctor, I got a lump here. Okay, he refers me to wherever I want right away. (NYC Focus Group, Spanish)*

*They’re [the PCPs in the organization] very open with having a discussion with how our lives are being affected by the medication and how it interworks with our community, our families, to make sure that we are on our road to recovery and that we reach a level of health that can be like anybody else’s one day. (Miami Focus Group, Spanish)*

The focus of PCPs on HIV clinical markers may also result on participants receiving less frequent care. For instance, a participant reported on the downside of being undetectable as it meant visits further apart.

*And I do like the one I am seeing right now, but she told me that I needed to come every six months. And I used to come for a visit every three months. So, I asked her why my appointments were further apart now. And she told me that it was because everything was fine because I am taking my medication and my viral load is undetectable. (NYC Focus Group, Spanish)*

While most participants were overall satisfied with their HIV care, many participants reported insufficient attention being paid to other health and social needs due to lack of attention to multi-morbidities, insurance limitations, or emphasis on HIV clinical markers.

**Quality of care**

In addition to the physical and emotional toll of living with HIV, participants reported a variety of barriers to accessing and remaining in quality care, including lack of Spanish-speaking Primary Care Physicians (PCPs), transportation, short consultation time, or ability to take time off from work. As the participants below reported, there is a variety of interrelated social determinants that makes it harder for some to access quality health care.

*And I myself acknowledging the privilege that I’m bilingual, that I have a college education, a vehicle, and a job, accessing HIV care for me has been easy. I might have to drive far or don’t deal with the administrative hoops about getting care and submitting forms and it’s kind of a hassle for anyone. (LA Focus Group, English)*

For some, the ability to attend appointments may be determined by their ability to take time off from work or by the level of support in their work environments.

*And then a lot of Latinos that do work undocumented and they don’t have that privilege to tell their bosses, oh, you know, I need to take this time off work for a doctor’s appointment, because they’re just like, no, you can’t. And they have really no say so, because then they lose their source of income. (LA Focus Group, English)*

Even those accessing regular care or with health insurance described a variety of challenges to obtaining quality care, including disruptions in health insurance coverage, complex health insurance plans, changes in PCP, and poor coordination of services. A major source of disruption of care was the change of PCPs. On the one hand, some participants took proactive steps to change PCPs when they felt the care was not adequate.
Everything is fine with my provider. But a year ago after having a doctor for ten years I asked for a change, not for anything in particular, I got along well with that doctor, but I wanted to make a change. She dedicates more time to me now. (LA Focus Group, Spanish)

On the other hand, clinic-initiated changes increased the feeling among patients that they lacked control over health care decisions. Participants valued having the same PCP over long periods of time and resented the disruptions of their patient-PCP relationship. In some cases, the disruption negatively impacted the quality of care as their new PCP did not speak their primary language, the service quality declined, or the trust would need to be rebuilt.

It makes me feel uncomfortable because I don’t trust the doctor. If he were to tell me two or three days in advance, then I could be mentally prepared and say, “I am going to see another doctor.” But when I am in the reception and they tell me, “Come early. Be here like 15 minutes earlier.” I am here 15 earlier. And they tell me, “The doctor is not here because he went out or because he had something to do but you can see another doctor.” And this happens very often. (LA Focus Group, Spanish)

Multiple factors impacted the participants’ ability to access quality care, from being unable to take time off from work to disruptions in coverage. An important component of quality care is the quality of the patient-PCP relations as we will see below. Clinic-initiated changes in assigned PCPs disrupts this relationship.

Consultation time

Participants considered adequate consultation time as a key component of quality care as it allows for patients and PCPs to discuss multi-morbidities, identify potential health issues, and general well-being. Participants who had more consultation time expressed greater openness with their health care providers.

I can tell you that, my doctor, she’s incredible. She’s a woman who takes her time. She’s not like – the experience I had before with the doctor I had at another clinic, before her, that was like an appointment like, “Give me a glass of water and leave.” It was like 10 minutes. My doctor takes 30 to 40 minutes. “What do you want? What do you need? How do you feel? Are you taking your medication? Is everything all right?” (NYC Focus Group, Spanish)

Many participants were also cognizant of their PCP’s limitations and acknowledged empathetically the challenges experienced by PCPs to provide sufficient consultation time.

Sometimes the doctors – my doctor, personally – I have been with him for many years, and he is a very good doctor. I am very satisfied with him, but sometimes I notice that he is very stressed due to the number of persons he now attends. (LA Focus Group, Spanish)

However, many participants complained about the lack of sufficient consultation time as an indicator of poor quality of care. Specifically, insufficient consultation time impacted participants’ ability to discuss broader and more comprehensive health issues. Participants also complained that even when consultation time was reduced, there were long waits to be seen by the doctor, increasing their frustration with the quality of care.
There are doctors that are just like, “Sit down. How are you doing?” “Well.” “Okay, you are here for this reason.” Okay, they get up from their chair. “Go to the front desk and you have an appointment for this date.” And that is it. They don’t say anything like, “What can I help you with?” (LA Focus Group, Spanish)

While a team approach care can be an effective time-management strategy, participants felt shuffled from one staff to another. As the participant described below, the final interaction of the consultation became even more depersonalized.

And here you have to see the person that works at the lab, you have to go to see the person that takes your blood pressure, another person takes your temperature and another person weighs you. When you finally arrive to see the doctor, he is looking at the computer and he is not looking at you. They take a look and are like, “Everything is fine.” (LA Focus Group, English)

In the presence of multi-morbidities, language barriers, and challenges understanding complex health information, short consultation time impacted the quality of the care participants received.

The Patient-PCP relationship

A good appointment is when you sit in front of the doctor and you talk to him about your problems and he is paying attention to your problems. And another thing is that he proposes – when he sees that your medication is affecting you or if he sees that there are very strong side-effects – he proposes solutions like changing the treatment or changing the pill. He looks for alternatives. He says, “We are going to try and find what the problem is.” And you see that he is concerned about your health. And he is not just focused on the monitor. But he is telling you things like, “Your triglycerides are this high and your cells are this high. Your CD4 is this high. Your blood pressure is fine. You need to lose some weight.” These details make a good appointment. (LA Focus Group, Spanish)

A recurring theme in the focus groups was the type and quality of relationship between health care providers and patients. The patient-PCP relationship was often evaluated in terms of the quality of the interpersonal communication as reflected in the PCP’s ability to listen to the patient’s concerns, explain complex health information, engage the patient in the decision-making, create a trusting relationship, and demonstrate authentic concern. On the other hand, participants also spoke of the need to take a pro-active stance in the relationship and suggested strategies for engaging more in the care and treatment process.

Listening and explaining

Many participants expressed their satisfaction with care when they felt that their PCPs were not only listening to their concerns but also asking them questions about other health concerns as well as about their emotional, financial, and social lives. Participants across all focus groups mentioned PCP’s listening, paying attention, and explaining as indicators of quality care.

They’re not your friend, but for an instant they become it, they are [your friend]. It’s when they ask you how you feel, how’s it been, and when I’ve said something, “I have problems with my mom. I have problems with my dad –” and in the next appointment, when they ask you, “How did the problem you had turn out?” (NYC Focus Group, Spanish)

I give my doctor a lot of work. Anything that I have – look, I have a lump, and this and that. He is very understanding and he understands me in that sense. He pays attention to my needs. (NYC Focus Group, Spanish)

Nonetheless, many participants felt dissatisfied with the communication with their PCP due to the lack of interpersonal communication, hastiness, and poor bed-side manners.
I practically have no communication with my doctor. She tells her nurse to treat me and the only communication I have is with the nurse and the doctor just writes a few things and that’s it. (LA Focus Group, Spanish)

They take your pulse. They don’t even look at your face. Not even that. And off you go. And people are very satisfied because they came out with their medication. And you have many doubts. You want to know about your lungs and you want them to check them. (NYC Focus Group, Spanish)

The PCP’s ability to provide quality care and address emerging health issues depends on the quality of the communication with their patient. As the participant below described, patients need to feel they are listened to and that they can trust their PCP before they disclose health issues.

The doctor needs to show you that he listens to you. When you talk to him, or when you want to know something, or when you explain something to him. For example, let’s say that you had sex without condom, so, I have the – how should I say this? I had sex with a condom that broke, and I want to know if I’m sick or not. I need to feel that trust with my doctor to be able to tell him what happened. (NYC Focus Group, Spanish)

Participants were appreciative when PCPs took time during the consultation to explain in detail health information that could be complex. They saw explaining health information as a component of quality health care, as a necessary step to address their health concerns, and a factor in patient satisfaction.

I have an appointment with my doctor where he explains how everything is doing and he takes his time. And my biggest concern is to cover all of my worries with my doctor. To know – even when I don’t understand medical or technical terminology, to know that my health is good. (NYC Focus Group, Spanish)

Participants also described ways in which the PCP could enhance the communication, including follow-up questions at the end of the consultation to increase the quality of care. For many, authentic concern was demonstrated not only in the quality of services provided during the clinical encounter but also afterwards through personalized follow-ups.

That he’ll ask you before you leave, "Are you satisfied? Do you need any more information?" Or, "Is the prescription that I gave you sufficient enough that makes you feel like your overall visit was good?" Some of them would take the time and ask you, "Are you okay with the visit that you came in?" (LA Focus Group, English)

And he calls me every time he gets the results. Because, I had a problem with high triglycerides, cholesterol, and anemia. And he calls me and he tells me, “Look, the anemia didn’t come up again. The triglycerides went down to this much. You don’t have cholesterol.” (NYC Focus Group, Spanish)

While participants were overall satisfied with their care, they often felt that the interpersonal communication with their PCPs was not optimal. They expected their PCPs to demonstrate active listening during the encounters and interest in other parts of their lives that could impact their health and well-being.
A trusting relationship

As we discussed above, many participants spoke of the need to have good communication with their PCP as a central component of quality care. To do so, participants spoke of needing a trusting, professional, and non-judgmental relation that allowed them to develop a personable relationship. A trusting, non-judgmental relationship was key to facilitate an open discussion of health concerns, particularly when discussing sexual behaviors, substance use, and other stigmatized behaviors.

I like to feel like a person, not a medical record number, not a case, not a diagnosis. I feel like the better interactions that I’ve had with medical providers are where I feel they recognize like my dignity, even when they’re maybe giving me a rectal exam. I felt like authentic concern for me as a person, not necessarily like risky behavior, what I’ve been doing. (LA Focus Group, English)

At the same time, a non-judgmental relationship did not imply avoiding open discussions on harmful behaviors. Instead, participants felt that when they were able to trust and to disclose to their PCPs without fear of judgement, they could find solutions to their health concerns in a collaborative manner.

I like to have sex a lot of times. So, I told him that, and he said that he was going to watch for sexually transmitted diseases. And he does. He doesn’t judge me. He doesn’t meddle in my personal life, but he does his work as a professional. (LA Focus Group, Spanish)

He always clears my doubts or he tells me, “You have to take better care of yourself. Stop drinking so much alcohol. Lower your cholesterol.” And there is this trust, I mean that is how he tells me things. I don’t feel ashamed. I like that he is direct. (NYC Focus Group, Spanish)

On the other hand, a trusting relationship was hindered by poor communication and hasty consultation time as earlier described. Overall, participants highlighted the importance of a trusting and non-judgmental relations with their PCPs for being able to address health concerns related to stigmatized behaviors.

Joint decision-making

As mentioned earlier, participants spoke of the need to feel like a person during the interaction with their PCPs rather than as a medical record number, a case, or a diagnosis. In addition to having quality communication and a trusting relationship, many participants wanted to feel a part of the process through participation in the decision-making process. A central aspect of the patient-PCP relationship was the ability of the PCP to engage the patient in the medical decisions through a collaborative approach. Quality communication between the patient and PCP resulted in joint decisions about treatment.

He treats me wonderfully. He asks me, I ask him, and we communicate. When I had to switch medication to the one I use now, he asked me. And he showed me on the computer what it was. And I said, “Let’s switch, then.” So, we communicate. That’s very important. (NYC Focus Group, Spanish)

I decided to change clinics, and I’m currently satisfied with my clinic. I feel fine because I talk to my doctor – I check everything with him, I ask for his opinion and we always reach an agreement because he listens to me and he takes me into consideration. And I also feel good because if I have any specific problem, he refers me with the adequate specialist. I feel satisfied with him. (LA Focus Group, Spanish)

As a component of a collaborative approach to care, participants spoke of PCPs actively providing health information so patients could make their own health decisions.
Every time I need to make a change, I talk to her or I send her a message and she be very good at doing that. She explains everything to me very well and she tells me, “Do you actually want to do this?” (LA Focus Group, English)

However, some participants felt that decisions about medication were made without their input, including polypharmacy, a major concern for many Latinos living with HIV.

My doctor listed all of my refills, and she told me every single one that she was going to stop prescribing, but she never told me why, nor asked if I wanted to. She just wanted to eliminate medicines to reduce refill or medicine expenses. (LA Focus Group, Spanish)

Nonetheless, the burden of developing a collaborative approach was not left to the PCPs alone. Some participants preferred a more proactive approach regarding medication by conducting their own research and getting more involved in the decision-making process.

Research about new medicines and all of that! It’s your life, so you need to be interested – you shouldn’t leave everything in the hands of the associations, or doctors. You need to do research, you need to have suggestions and options for the doctors so that they make the right decision with you. (LA Focus Group, Spanish)

When their PCPs proposed solutions rather than commanding them, participants saw this approach as an effective utilization of consultation time.

I think that a good appointment is when the doctor comes and has the right knowledge the second he steps in the room. He knows about your case. He talks to you about the options you have. And also, in a good appointment you get the chance to help each other. The patient and the doctor help each other to make good use of the time you have. (LA Focus Group, Spanish)

Focus group participants described the importance of adopting a collaborative approach to health care in order to ensure that patients are part of the decision-making process, and, ultimately, achieve positive health outcomes.

Taking a pro-active role

Participants saw good communication as a key facilitator for obtaining quality care and described several strategies to ensure adequate communication with their PCP by taking a more proactive role. This proactive role included “educating” PCPs about symptoms, screenings, side effects, and treatment options. Some participants also stressed the responsibility of the patient to ensure that their PCPs listened to and understood their pressing needs.

Sometimes you have to educate them because they don’t know what you’re feeling; they don’t know your side effects, your stuff. Sometimes they want to prescribe me something that I’ve had before and I’m like no, I don’t like that. It’s not good for me. It’s good that they listen, because I have the last word, not them. (Miami Focus Group, Spanish)

When I come here for a visit I always have a list of questions so I don’t forget to ask them when I am in front of him. And I always make suggestions like, “Doctor, it’s time I get my prostate checked or to see if I have any UTIs.” They recently started doing this test for contagious
diseases like herpes, gonorrhea, syphilis and they are doing that here. But when you are in front of your doctor you are responsible for making him listen to you. (LA Focus Group, Spanish)

Taking a proactive role also meant treating PCPs as a team member and opening up to PCPs, even when it could lead to embarrassment. Several other participants spoke of proactive strategies for ensuring a more productive interaction by preparing lists of questions prior to the appointment.

And as a patient you can’t have any restrictions with your doctor. You have to tell him everything that is going on with you because he is the one that is going to help you have a better process. And if you don’t feel well and you’re like, “He will scold me if I tell him.” You have to tell him. You can’t be quiet. You have a little lump here or there. You have to show him because you don’t know the consequences that this small lump can have. So, you have to bare your soul before your doctor. (NYC Focus Group, Spanish)

I write down a list of everything that I want to talk with him, and the things that he can recommend because I want to know what’s wrong with me this year – because I want to stop taking those medicines. Maybe the HIV medicines are hurting me. So, I’m waiting to see him on the 6th, and I already have my list to see if he can refer me. (NYC Focus Group, Spanish)

Focus groups participants spent considerable time discussing the importance of a good patient-PCP relationship and describing key components of such relationship, including authentic listening, easy to understand health information, and trust and acceptance. They also stressed the importance of a collaborative approach to care that included joint decision-making and a proactive role of the patient.

Treatment adherence and continuity of care

Participants reported a variety of facilitators and barriers to treatment adherence and continuity of care, from the individual to the interpersonal to the structural level. For instance, some participants spoke of the reasons behind “forgetting,” including alcohol use and treatment exhaustion.

I used to forget. I didn’t forget. I would do it on purpose. I would be like, “I am not going to take it today. I don’t think I will die today. I am not going to take it today and I will take it tomorrow. Okay, I will not take it today but I will take it tomorrow.” And this was because I was drinking alcohol. (LA Focus Group, Spanish)

In my case, it’s because I work nights and sometimes I am so tired that I take a shower, and I forget about the pill. It’s not that I don’t want to but - [inaudible] But it’s not like I took it today and I stopped taking it for three days. Or if I go walking and I return late at night. No, I am always stable but it has to be on my nightstand. (Miami Focus Group, Spanish)

Participants also reported the ways in which housing instability impacted their engagement in care and treatment, including confidentiality concerns about storing their medication at home or when taking their medication in public.

I didn’t want my roommates to know. We were not family. We were just roommates. I had to hide it in my clothes. I am not going to lie. I didn’t take the medication. When the next month came and I had to go collect more medication, I had to throw all of that in the trash. And every month, every month it was the same. Nobody knew. (LA Focus Group, Spanish)

Among the main barriers to treatment adherence, substance use and the physical and emotional toll of taking HIV medication for life were two central topics.
**Substance use**

Substance use was often mentioned in connection with lack of HIV treatment initiation or adherence. As reported by a participant, initiation in HIV treatment could take many years for active users.

So, I was diagnosed in 2003, and then it wasn’t till 2008 when I became a tweaker. And that’s when I went downhill and that’s when I definitely wasn’t taking my medication. And then I finally got on medication in 2014. (LA Focus Group, English)

Participants also reported intermittent adherence to treatment due to relapses. Some active users reported on recurring instances in which they had unintendedly skipped their medications for a short time because of heavy use.

And there was a time where… the last week I was shooting up so much and I just fuckin’ just disappeared from – I turned off my phone, I fuckin’ cut off all communication with everybody and just, like, tweak. (LA Focus Group, English)

Yes, when I go out, or I’m at home drinking – I do remember sometimes [to take medication], but not so much when I’ve had alcohol. I do remember sometimes, but when I’m very drunk, I don’t remember. (LA Focus Group, Spanish)

On the other hand, some participants spoke of negotiating their substance use and the adherence to treatment, including developing strategies for taking their HIV medication while using drugs, stopping treatment temporarily, or abstaining.

Me, lately, I don’t take it when – when I drink. And when I say "when I drink" it’s because I’m like really drunk, because I don’t like to mix it – I don’t like to mix it, because the next day, the medication itself make you so dehydrated, with the hangover. (LA Focus Group, English)

But then, when I was taking the HIV, they told me that if you take the HIV and you drink, it won’t be effective, so, I’m like, "I’m going to stop drinking." So, that’s only recently I stopped drinking because I want my medication to work, and the only way is to stop drinking. (LA Focus Group, English)

While substance use clearly impacted treatment adherence, the connection between substance use and treatment adherence was nuanced. Some participants had developed strategies for engaging in substance use while trying to adhere to treatment. Others had opted for sobriety and abstinence as their only effective strategy.

**Physical and emotional burden of taking medication**

In addition to substance use, many participants spoke of the physical and emotional burden of taking HIV medication for the rest of their lives. Their concerns ranged from the burden of regimen changes, to polypharmacy, to short and long-term side effects. Several participants expressed the emotional burden of taking medication.

I am constantly taking medication after medication, after medication and you think you are about to finish that bottle and then boom, another bottle comes. And then you finish that bottle and boom, another comes. (LA Focus Group, Spanish)
I would like to hear other people’s experiences with the medications and all that, because you get stressed or you can even traumatize yourself, and you think that you’ll be living with this all your life and it affects you. (LA Focus Group, Spanish)

Many participants spoke of the side effects of medication, which for some were terrifying, as they impacted their general well-being, sleep patterns, or ability to concentrate at work. In some cases, participants also expressed hesitance to take additional medications due to concerns about the long-term impact on their health, particularly if they were feeling healthy.

Dreams. Horrible dreams, you can’t sleep because you’re more awake than asleep, so much so that you feel like – well, in my case it feels like you’re on some kind of ride when suddenly you fall off a cliff, and you jerk awake because you feel like falling down. And besides it happening constantly – you wake up, have a glass of water, wash your face, and all of that, you go back to sleep and you fall off again. You keep falling down. (LA Focus Group, Spanish)

While participants in the focus group did not discuss at length the relation between mental health and engagement in care and treatment adherence, a few participants reported on the impact of depression and “being in a bad place.”

The longest I went without meds was maybe a three or four-month time period where I was in a really, really bad place and I wasn’t practicing very much self-care, and I just stopped taking care of my meds. (LA Focus Group, English)

Many times, we’re in depression, and depression leads to, “I don’t want to take medication. And I really don’t care if I live or die.” (NYC Focus Group, Spanish)

As mentioned above, participants reported on the need to address stigmatization of mental illness and integrating much more mental health services within HIV care. They describe how accessing therapy resulted in greater engagement in HIV services.

So, I wasn’t taking care of myself. One of those ways I was neglecting was I didn’t do a refill one month and I didn’t care and then another and another. It was like two or three months. But I went to go get labs. When I saw the doctor, I let her know, “I need to talk to someone about how I’m feeling.” I saw a therapist, godsend, amazing person. The very first thing I did was I refilled my prescription and then I kept taking it since. (Los Angeles Focus Group, English)

Throughout the discussions at the focus groups, participants described a variety of barriers to accessing care. Nonetheless, two particular barriers were central in the discussions about treatment adherence and continuity of care - substance use and the physical and emotional burden of taking medication.

Strategies for engagement in care and treatment adherence

As described above, some participants had developed strategies for managing substance use and treatment adherence. Participants also described a variety of strategies to increase or ensure their engagement in care and treatment adherence. Many participants reported engagement with technology to schedule appointments, get reminders of upcoming appointments, self-registration at clinical settings, and checking their lab results.
I think that to have a good visit is to have a good relationship with the doctor. The other one is My Chart, which is also – in my case, it has facilitated it for me much more. I don’t have to ask for prescriptions. Everything comes up online and everything. I communicate with the doctor. (NYC Focus Group, Spanish)

At the same time, some participants described a technological gap based on age differences and advocated for greater attention to those with difficulties utilizing these technologies.

Unfortunately, we are very ignorant. In my personal case, right?, regarding technology, and all of that. So, they shouldn’t assume that you are going to be able to use all of that. (LA Focus Group, Spanish)

Participants also discussed their own strategies for increasing treatment adherence. As reported by some participants, integrating medication intake within daily routines helped them the most. Others used pills holders and/or carried their daily doses with them or relied on electronic reminders, including those from third parties.

I get up at 6:45 to get my roommate’s son ready for school, so I go and smack him awake, and then I go make some coffee, and then I just take my pill when I’m up, every day, like at 7:00. And it’s habit now. (LA Focus Group, English)

I always carry my pill organizer with my pills in it because I have to take two pills for diabetes in the morning, one in the afternoon and then another two when it starts to get dark. Just for diabetes I have to take five pills. I don’t want to take insulin. (LA Focus Group, Spanish)

I always tell people to put an alarm on their phones because we are kind of now attached to this contraption. I would say put a little alarm that goes off every day around the same time and put a little icon that only you know what it is, put a penguin on it, whatever. That will hopefully help you. (LA Focus Group, English)

The strategies to increase engagement in care and treatment adherence described above were aligned with other group discussions on the importance of adopting a pro-active role within the clinical encounter and treatment decisions.
Discussion

The main goal of this exploratory study was to examine key factors shaping patterns of engagement in HIV care and HIV treatment adherence among Latino GBM/MSM in three major metropolitan areas, New York City, Miami, and Los Angeles. The vast majority of participants had a regular health provider (93.6%), had seen a health care provider for HIV treatment in the previous 12 months (94.3%), were in treatment (93.9%), had taken their HIV medication in the previous 4 weeks (93.7%), and had been told by their PCP that their viral load was undetectable (88.5%).

Perhaps as a result of the connection of participants to HIV organizations, the overall sample of survey participants reported outcomes along the continuum of care slightly higher than some epidemiological reports. However, outcomes along the continuum of care were not the same across Latino subgroups by age and place of birth. Older and foreign-born participants tended to present better outcomes along the continuum of care than younger Latino GBM/MSM and those born in mainland U.S. and Puerto Rico. In addition, older participants were experiencing health and social needs that went beyond HIV-related services, including multi-morbidities and polypharmacy.

Younger Latino GBM/MSM

The younger participants in this study were more likely to experience delay or lack of HIV care than their older counterparts. They were less likely to have a regular health provider, have visited a PCP in the previous 12 months, report being in HIV treatment, and to have taken their medication in the previous 4 weeks than their older counterparts. Younger participants reported more difficulty adhering to treatment than their older counterparts. Not surprisingly, younger participants were less likely to report having been told that they have undetectable viral load.

The younger participants also reported some differences from their older counterparts related to HIV in general. Younger men were more likely to live with their families and have worries about disclosure (HAT-QOL domain). Older participants had lived with HIV for a much longer time (mean 11.78 years vs. 4.85 years) which might have shaped their relationship to HIV treatment. For instance, older participants were less likely to report medication worries and disclosure worries, and more likely to report HIV mastery (HAT-QOL domains) than their younger counterparts. In 2017 NYC, almost 1 in 5 (18%) of Latino GBM/MSM born in mainland U.S. and living with HIV were under 30 years of age. In contrast, among foreign-born Latino GBM/MSM living with HIV, 1 in 10 (11%) were under 30 years of age.

Latino GBM/MSM born in mainland U.S. and Puerto Rico

Some differences related to engagement in care and treatment adherence were also found based on place of birth. Participants born in Puerto Rico were less likely to have a regular provider and less likely to report undetectable viral load than those born in mainland U.S. and foreign-born participants. Those born in mainland U.S. were less likely to be in treatment and have taken medication in the previous 4 weeks than the other two groups. Participants born in Puerto Rico and mainland U.S. were more likely to forget their medication than other groups and no take the medication as prescribed. Similar findings can be found elsewhere.

For instance, in 2017 in NYC, viral suppression among foreign-born Latino GBM/MSM was 82% but 75% for those born in Puerto Rico.
Immigrant Latino GBM/MSM

Foreign born and Puerto Rico born Latino GBM/MSM share with the other subgroups a variety of factors hindering their ability to achieve undetectable viral load. However, they also reported specific challenges to remain in care and adhering to treatment, including lack of Spanish-speaking PCPs, health coverage limitations, and concerns over their immigration status.

For many, lack of Spanish-speaking PCPs constituted a critical barrier to quality care for some participants. Specifically, participants reported feeling frustrated with the medical appointment as they were not able to effectively communicate their health needs and understand the information about their medical conditions or treatment.

As foreign-born participants age, their health and social needs increase and require a broader range of services besides those directly related to HIV. Those who depended on ADAP and Ryan White Services also reported on the challenges of accessing comprehensive and long-term health services to effectively address multi-morbidity and polypharmacy issues.

In addition to language barriers and health coverage limitations, foreign-born participants reported on their fears and concerns about utilizing programs and services that could have a later detrimental impact in their ability to obtain permanent residency or citizenship. In fact, participants reported on stress, anxiety and depression symptoms over their current immigration status and their ability to feel safe accessing services.

Aging population

While older participants presented better HIV outcomes, they were more likely to experience multi-morbidities than their younger counterparts. Overall, survey respondents presented high levels of multi-morbidity. Sixty nine percent (69%) of participants reported one more health condition besides HIV, and 1 in 5 (21.1%) reported 3 or more conditions. For instance, older participants were more likely to have been diagnosed with diabetes, hypertension, high cholesterol, arthritis, cancer, AIDS, and HCV.

These findings are consistent with other studies showing that the probability of multimorbidity increases by age and number of years living with HIV. Despite the presence of multi-morbidities, focus group participants reported their HIV primary care providers were not attending to their multiple needs, particularly because of the emphasis on HIV clinical markers with the HIV care. For some Latino GBM/MSM who have already stabilized their HIV care and become undetectable, HIV has become less pressing than other health and social needs.

Despite ART advances, life expectancy in well-treated OPLWH is still lower than in the general population. Prior co-infections, severe immunodeficiency issues, lifestyles, persistent inflammatory response, and long-term exposure to ART may accelerate aging advancement among PLWH. The probability of multimorbidity and polypharmacy increases by age and number of years living with HIV. Furthermore, non-HIV morbidities are more common in PLWH, even after adjusting for age, ART, and other risk factors.

Out of the estimated 1,173,900 people living with diagnosed or undiagnosed HIV, aged 13 and older living in the U.S., 32.3% were 55 years of age and older. While the HIV epidemic continues impacting younger Latinx, the number of older Latinx living with HIV will continue increasing. Out of the 242,500 Latinos living with diagnosed or undiagnosed HIV, aged 13 and older living in the U.S., 35,000 (14.4%) were 55 years of age and older and 57,000 45 to 54 (23.6%). As the population of Latino GBM/MSM ages, they will require pre-screenings, aging-related prevention interventions, specialty care, and geriatric care. These emerging needs will most likely require changes to the standard HIV care approach which focuses on HIV viral suppression as the chief outcome.

Substance use

In addition to the aforementioned barriers, participants reported individual behaviors that might have hindered their ability to fully engage in care and adhere to treatment. While over half of the sample engaged in alcohol and drug use, younger and mainland-born participants were more likely to report drug use than foreign born.
In fact, current substance use was inversely correlated with having been told to have undetectable viral load. While substance use may impact treatment adherence, the connection between substance use and treatment adherence is nuanced as reported by the focus group participants. Active users of drugs and alcohol reported on recurring instances in which they had skipped their medications because of heavy use.

On the other hand, some participants spoke of negotiating their substance use and the adherence to treatment, including developing strategies for taking their HIV medication while using drugs or stopping treatment temporarily. There were also some who had opted for sobriety and abstinence as their only effective strategy.

**Stigmatization of HIV and sexual orientation**

Stigma was a central theme of the focus groups. Fear of stigmatization and rejection prevented many of the participants from disclosing sexual orientation and HIV status to people in their social networks who may provide emotional, instrumental and social support. Many participants were concerned about the synergistic double impact of stigmatization due to their sexual orientation and HIV status. Those who had already experienced stigmatization due to their sexual orientation were hesitant to add another source of stigmatization by disclosing their HIV status.

Within a cultural context that blamed their sexual orientation as the reason for acquiring HIV, many participants withheld information about both their sexuality and HIV status for fear of their family’s reactions. These concerns about the negative consequences of disclosure were not unfounded. For some participants, disclosure of their HIV status resulted in housing instability, loss of social support, and financial and emotional stress.

Multiple sources and experiences of stigmatization increased isolation and decreased social integration among people living with HIV. They also impacted their ability to engage in services and make healthier decisions. The impact of stigma on the sexual health of GBM/MSM has been long documented. Gay men and men who have sex with men avoid or delay access to health care because of concerns about disclosure and, of those accessing health care, a large number will not disclose their sexual orientation or sexual practices to their primary health care providers.

**Strategies for increasing engagement in care and treatment adherence**

Participants in the focus groups also reported on medication burden. For many, having to manage HIV, multi-morbidities, and polypharmacy took a physical and emotional toll. This physical and emotional toll was often experienced in isolation as they felt hesitant to disclose their sexual orientation or HIV status to their social networks for fear of stigmatization.

Some focus groups spoke vividly and emotionally about the struggle to pass the denial stage and...
to become more engaged in care and treatment as they recognize the necessity and benefits of treatment. Focus group participants also reported on strategies they had developed or adopted to manage the challenges of living with HIV and engaging in quality care.

Many participants also reported the use of pill reminders and engaging with technology to schedule appointments, get reminders of upcoming appointments, self-registration at clinical settings, and checking lab results.

At the same time, some participants described a technological gap based on age differences and advocated for greater attention to those with difficulties utilizing these technologies.

A recurring theme in the focus groups was quality of the relationship between the primary care providers and patients. The patient-PCP relationship was often evaluated in terms of the quality of the interpersonal communication. Focus group participants reported on the engagement and treatment benefits of PCPs who listened to their concerns, explained complex health information in a non-judgmental manner, helped them understand and manage side effects, engage them in the decision-making process, created a trusting relationship to discuss stigmatized behaviors, and demonstrate authentic concern beyond HIV clinical markers. At the same time, participants spoke of the need for patients to take a proactive stance in the relationship and suggested strategies for engaging more in the care and treatment process. This proactive role included “educating” PCPs about symptoms, screening requests, and discussing side effects and treatment options.

Study Limitations

This study has several limitations. First, we used a convenience sampling strategy to recruit participants for the survey and the focus groups, many of whom were connected to service organizations. Furthermore, the demographics of survey respondents were not representative of the Latino GBM/MSM in New York City, Miami, or Los Angeles. For instance, over half of our sample for the survey resided in New York City; almost three quarters were between 30 and 49 years of age; 90.5% of respondents identified as gay; and immigrants from the several Caribbean and Central American countries were underrepresented. Similarly, focus group participants were overwhelmingly Spanish speaking as nine of the thirteen focus groups were held in Spanish, and no focus groups in English were held in New York City. Over three quarters of the participants had been born outside mainland U.S., and the mean age was 40.5 years of age (SD=8.1).

Second, the findings are based on self-reported data, increasing the risk of socially desirable responses. Particularly, participants in the focus groups might have felt compelled to minimize stigmatizing behaviors such as substance use or exaggerate socially approved ones such as treatment adherence. Because many focus group participants were connected to service organizations, they might have been embarrassed or hesitant to report negative information that they thought could impact their access to services. Finally, the length of the survey and the associated burden on the respondent’s time might have prevented some participants to engage fully with the surveys, leading them to answer questions in a hasty manner.

Thus, these findings, while pointing toward critical issues, should not be taken as representative of the entire population of Latino GBM/MSM living in the U.S. In particular, this study did not assess the needs and life experiences of people who are under 29 years age, are disconnected from services and care, live outside major metropolitan areas, or identify as heterosexual, bisexual or transgender.

At the same, some of the study features support the internal validity of our findings for these particular sub-samples. First, the surveys were voluntary, and the questions did not ask for any identifiable information. Second, focus group transcriptions showed the willingness of participants to agree and disagree with each other and disclose sensitive and stigmatizing information. Transcripts also showed a similarity of themes emerging across the 13 focus groups as well as differences based on the demographics of the group participants. Finally, these features combined with similar findings in other studies increase the possibility that similar findings may apply to other Latino GBM/MSM in large urban areas.
Greater attention to the needs of Latino GBM/MSM born in mainland U.S. and Puerto Rico

There is a lack of intervention research disaggregating differences based on place of birth, immigration experience, or cultural attachment relating to issues such as sexual risk, substance use, family and social support, racial/ethnic intersectional identities, and stigmatization of HIV and sexual orientation. HIV interventions need to include services that are culturally and linguistically responsive to the needs of English-speaking Latino GBM/MSM, including young immigrants, as well as those born in Puerto Rico.

Greater attention to the specific needs of Latino young GBM/MSM, particularly those born in mainland U.S.

There is a need to develop new tailored and nuanced programs for young Latino GBM/MSM, particularly those born in mainland U.S., that consider their particular lived experiences, including the challenges of disclosure of HIV status and sexual orientation, denial of HIV diagnosis, and substance use. While the lapse between diagnosis and treatment initiation has reduced, there is a need to increase HIV treatment education for newly diagnosed youth in order to increase their ability to manage side effects and treatment regimens (HIV mastery). Furthermore, programs must capitalize on social media strategies and expand the use of technology-based interventions as a means to reduce disparities in clinical outcomes among young individuals, including eHealth (healthcare practice supported by electronic processes and communication) and mHealth (technologies like smartphone and tablet apps enabling consumers to manage their own health data).

Greater attention to the specific needs of immigrant Latino GBM/MSM, particularly those who are undocumented

There is a need to conduct a critical assessment of the successes and limitations of current health care systems to serve immigrant Latino GBM/MSM. While many interventions have been somewhat successfully tailored to immigrants, there is a need to develop and provide services within a language justice framework and with particular attention to cultural and linguistic differences and commonalities across Latinx subgroups.

Given the current limitations of the health system to address immigrant health, there is a need to increase the capacity of service providers to develop and provide culturally and linguistically appropriate services. This could require educational and professional support of sexual and racial/ethnic minorities to increase their presence in the medical workforce, as well as policies to enhance the capacity of health organizations serving immigrant and monolingual communities.

While many foreign-born Latino GNBM/MSM have achieved undetectable viral load, there is a need to extend primary and preventative health coverage to Latino GBM/MSM irrespective of documentation status.

Recommendations
of immigration status. Preventative health is particularly important in light on their growing aging health-related needs. Similarly, immigrant Latino GMB/MSM are in great need of long-term and low-cost behavioral health services to address the overlapping stigmatization and discrimination related to social and structural racism, homophobia and xenophobia.

Greater attention to the non–HIV health and social needs of aging Latino GBM/MSM

The emerging health and social needs of older Latino GBM/MSM require changes to the standard HIV care approach, including the need for additional aging-related screenings, polypharmacy reconciliation, specialty care, and geriatric care. There is also a need to provide greater attention to their social integration needs, particularly as their social networks become smaller and their isolation is exacerbated by issues of mobility. This must include an examination of key social and cultural views on aging and geriatric care among Latino communities.

Continue efforts to address stigmatization of sexual orientation and HIV

We must continue our efforts to address the impact of stigma among Latino GBM/MSM living with HIV. For instance, there is a need to increase the cultural and linguistic capacity of service providers to identify and address concerns about disclosing stigmatizing information in the consultation room as well as to support patients’ assessment of the benefits and risks of disclosure to social networks and family members. Moreover, there is a need for partnering with non-traditional organizations such as Latino-led churches, immigrant worker organizations, and businesses to enhance the community knowledge of HIV and dispel rooted misconceptions about HIV and homosexuality. In addition to large social marketing campaigns to address negative cultural perceptions and norms about HIV and sexual orientation, we must develop and implement community-level and structural interventions to address multiple sources of stigma, including xenophobia, ageism, and racism.

Obtain better information on those not achieving viral suppression

There is a need for a deeper understanding of the reasons for differences in engagement in care and treatment based on place of birth and immigration experience, particularly for younger Latino GBM/MSM. Given the over-representation of Latino GBM/MSM among those living with HIV, the Centers for Disease Control and Prevention, the National Institutes of Health, the U.S. Department of Health and Human Services, local and state departments of health, and research institutions must disaggregate data collection to fully understand and address the long existing health disparities across racial/ethnic groups and within Latino sub-populations. If we are to achieve the Ending the Epidemic goals for 2030, there is a need to improve and integrate data collection at the local, state, and federal level to understand the heterogeneity in the Latino experience, particularly among those subgroups who have limited access to quality care, are not engaged in quality care, or struggle adhering to treatment.
References


