Research

Lessons learned from syndemic HIV research in an immigrant, latinx sexual and gender minority community

Nicholas Metheny[1] · Dalton Scott[2] · Sandor Santana[3] · Rosa Pache[3]

Abstract

The HIV incidence rate in Miami-Dade County is among the highest in the United States, with Latinx sexual and gender minority (SGM) groups experiencing a disproportionate burden. Despite extensive efforts by both private and public sectors to curb transmission and improve pre-exposure prophylaxis (PrEP) uptake, Latinx SGM groups continue to have high rates of HIV and low PrEP uptake compared to SGM groups overall. Using data collected from a biobehavioral study of the socio-structural factors affecting HIV susceptibility and PrEP uptake among Latinx SGM subgroups in Miami-Dade County, this paper shares lessons learned and provides concrete recommendations for tailoring survey research and biospecimen collection among a largely immigrant, socioeconomically disadvantaged community that is especially vulnerable to HIV. By drawing inferences from study data and contextualizing these with community partners, we learned: (1) Large parts of the target community may be unfamiliar with the underlying constructs captured in important HIV-related measures; (2) Cash incentives may shift motivation from intrinsic to extrinsic and lead to poorer data quality; (3) Deviations in Spanish go beyond vocabulary used in different Latin American countries, and more formal Spanish may relay concepts in unfamiliar ways that are unapproachable; and (4) community members may be unfamiliar with survey data collection processes and the protections in place to ensure confidentiality. These lessons and associated recommendations may help improve recruitment, study design, analysis, and community engagement in future studies, building trust and ultimately reducing the burden of HIV in these communities.
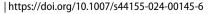
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1 Background

Despite comprising approximately 1% of the US population, Latinx sexual and gender minority people (SGM- those who identify as gay, lesbian, bisexual, queer, and/or transgender) account for approximately one in four (24%) new HIV infections in the United States [1]. Miami-Dade County, the only Latinx-majority (70.2%) metropolitan area among the nation's 10-largest, experiences some of the highest HIV incidence rates in the United States [2]. Home to the cities of Miami and Miami Beach, Miami-Dade County has a diverse Latinx community in terms of race, socio-economic status, immigration status (over half of Latinx residents are foreign-born), and other social determinants of health [3].

✉ Nicholas Metheny, Nick.metheny@emory.edu; Dalton Scott, dls122@miami.edu; Sandor Santana, ssantana@survivorspathway.org; Rosa Pache, rpache@survivorspathway.org | [1]Nell Hodgson Woodruff School of Nursing, Emory University, 1520 Clifton Road NE, Atlanta, GA 30322, USA. [2]School of Nursing and Health Studies, University of Miami, Coral Gables, FL 33155, USA. [3]Survivors' Pathway, 33 SW 2nd. Ave Ste. 901, Miami, FL 33130, USA.

In 2022, Miami-Dade County recorded 1038.6 cases per 100,000 people- a rate more than twice that of Florida (557.9 per 100,000) and nearly 100 times greater than the US incidence rate of 11.5 per 100,000 people [2].

Minority Stress Theory [4, 5] maintains that sexual and gender minority people face stigma that accompanies their subaltern position in a heterosexist society [5, 6]. This sexual orientation-related stigma manifests in stressors that include internalized homophobia, anticipated stigma, and enacted discrimination, which are thought to be fundamental causes of many of the health disparities facing SGM, including HIV [7]. For Latinx SGM, belonging to multiple marginalized identities (i.e., Latinx and SGM) compounds the stressors of each and result in stress-response health behaviors that result in mutually reinforcing epidemics (i.e., a syndemic [8]) of HIV-related health outcomes than Latinx or SGM communities alone[9–11]. For example, in a sample of more than 24,000 Latin American MSM, Mimiaga and colleagues found that recent intimate partner violence (IPV) was significantly associated with a greater odds of condomless anal sex, while IPV in addition to other syndemic factors such as drug use and poor mental health was significantly associated with greater odds of condomless anal sex and HIV infection [12]. Qualitative work with Hispanic MSM in South Florida corroborates a mutually reinforcing syndemic with substance abuse, HIV risk behaviors, and poor mental health [13] that combine to negatively impact health outcomes in this population. Structural barriers such as xenophobia and a largely English-language health system (even in Miami), as well as syndemic health outcomes can also lead to downstream factors such as mistrust toward government- and academia-sponsored HIV prevention efforts, which is likely one reason for the continually high incidence of HIV in this community. Despite widespread local efforts to provide PrEP cheaply and conveniently [14], many Latinx sexual and gender minority communities are reticent to take advantage of these programs. In fact, rates of PrEP uptake fell in 2023 from 2020 levels [15]. Medical mistrust is shown to be a key mediator in the relationship between perceived discrimination and PrEP uptake in this population [16]. Much of this mistrust stems from concerns about undocumented immigration status (for themselves or family), limited English proficiency, low health literacy, unfamiliarity with the healthcare system, and perceived discrimination in the health care sector [16, 17].

Another reason for persistent disparities in HIV-related outcomes is the propensity for HIV researchers to treat Latinx communities as a monolith, ignoring the tapestry of diversity in race, socio-economic status, country of origin, immigration status, acculturation, gender identity, sexual orientation, and language that differentiate components of this community [18]. Previous research [18, 19] has attempted to draw attention to these issues and their implications for HIV research, yet the majority of this work focuses on overcoming barriers (e.g., mistrust) to recruitment. In contrast, little research has been conducted to provide concrete recommendations for ways to improve the data quality and assuage widespread concerns regarding confidentiality after recruitment takes place among immigrant Latinx SGM.

Using data collected from a study of the socio-structural factors affecting HIV susceptibility and PrEP uptake among Latinx SGM in Miami-Dade County, the aim of this paper is to share lessons learned *after* successful recruitment of such marginalized communities- in the survey development, informed consent, reimbursement, and biospecimen collection spaces. Rather than providing results of the study itself, the current study aims to assess patterns of response and non-response to key variables and uncover potential drivers of these patterns. By providing specific recommendations for reaching, recruiting, and collecting data with Latinx SGM, we aim to provide researchers, policy makers, and social service providers with additional tools to approach Latinx SGM in culturally safe ways. These lessons may help improve study design, analysis, and community engagement in future studies, building trust and ultimately reducing the burden of HIV.

2 Methods

2.1 Overview of the parent study

The Adelante study is a cross-sectional, exploratory study of syndemics and HIV risk among Latino sexual minority men (LSMM) and transgender women residing in South Florida. Its primary aim is to identify the mechanisms by which sexual minority stressors, syndemic factors (i.e., intimate partner violence, substance misuse, poor mental health), and Latino cultural factors (e.g., machismo, acculturation stress) are associated with inflammatory biomarkers of HIV susceptibility in the rectal microbiome and PrEP adherence. The study was approved by the Social and Behavioral Sciences Institutional Review Board at the University of Miami (IRB #20210666).

2.2 Parent study research site

Participants were recruited from May 2022 to April 2023 via client referrals from Survivors' Pathway, a local justice and healing center focused on improving access to HIV-related care, mental health resources, and trauma-informed care related to domestic abuse and human trafficking. The focus of Survivors' Pathway on recently arrived LGBTQ + Latinx immigrants allowed the research team to easily reach and recruit members of the LGBTQ + community who may otherwise not participate in research studies.

2.3 Participants

A total of 161 Latinx SGM were recruited as participants in this study. Eligible participants were cisgender LSMM or Latinx transgender women 18 years of age or older, able to speak and read either Spanish or English, lived in Miami-Dade County, and were HIV-negative via a rapid test conducted immediately prior to the study at Survivors' Pathway. Since the aim of the parent study is to understand the associations between the socio-structural factors outlined above and HIV risk via inflammation in the rectal biome, participants must have self-reported no antibiotic use in the past three months and self-reported anal sex (insertive, receptive, or both) with a cisgender man in the past 6 months. Potential participants were excluded if they were HIV-positive, reported antibiotic use, or were unable or unwilling to provide informed consent.

2.4 Recruitment of parent study participants

Respondent-driven sampling [20] and the collaborating organization's extensive network were used to recruit participants. Survivors' Pathway's client base provided seed participants. Participants who were eligible via an online screener came to Survivors' Pathway to complete an electronic informed consent form for both survey and biospecimen collection procedures in the presence of Survivors' Pathway staff, who further explained the study and answered any questions from potential participants. To assuage fears surrounding breaches in confidentiality, staff at Survivors' Pathway reassured participants that the same privacy protocols would be followed as when conducting HIV testing (a process with which most participants were familiar) and conducted all data collection in a private area of the office. If they agreed to participate, they completed an electronic survey hosted via RedCap and provided biospecimens. Those who completed both received $100 cash. Adelante participants were incentivized $10 each to recruit up to three members of their social networks using personalized referral cards, making the total potential renumeration $130.

2.5 Data collection processes

The survey was available in English and Spanish and hosted on RedCap, a password-secure data management software [21, 22], and designed to be completed in 30 min or less. For investigator-derived measures and those without psychometrically validated translations, Spanish versions were obtained where available and, where unavailable, were created using the World Health Organization's process of translation and adaptation of research measures. This includes blind forward and back translation by native speakers [23]. The measures below were adapted from previously tested protocols of successful HIV-related studies with sexual minority communities in South Florida [24, 25]. All study procedures were conducted in accordance with ethical standards as laid down in the 1964 Declaration of Helsinki.

2.6 Measures of interest in the current study

2.6.1 Sociodemographic data

Sociodemographic data collected and utilized in this analysis were age, nativity, income, homelessness, and education level. A "prefer not to answer" level was added to each sociodemographic variable. Only participants who answered at least three out of five of the sociodemographic questions (n = 95) were included in the current analysis.

2.6.2 HIV and sexually transmitted infection (STI) susceptibility

PrEP uptake was assessed using items asking about use (e.g., "*Have you ever been prescribed HIV medications (e.g., Truvada) for use as PrEP (Pre-Exposure Prophylaxis)?*") and adherence (e.g., "*During the past month (30 days), did you miss any of the*

PrEP medication doses you planned to take before or after sex?"). Questions regarding sexual behavior (e.g., "*During the last 3 months, with how many men have you had receptive anal sex (you were the bottom?*"; "*Of these men (the ones with whom you bottomed), how many were without a condom for at least part of the time you were having sex?*") were also asked. Questions on STI testing history and recency measured recent STI testing and results for chlamydia, syphilis, and gonorrhea.

2.6.3 Minority stress

The Multiple Discrimination Scale was used to capture different forms of discrimination experienced by participants [26]. In this sample, internal consistency was α = 0.96. Minority stress was assessed using widely used measures of anticipated stigma [27], enacted stigma [28], and internalized homonegativity [29]. Sexual identity silence and disclosure (e.g., "outness") was measured using a two-part measure and has previously been used to assess sexual identity disclosure in Latinx SGM [26, 30–33]. All minority stress measures included have been validated among Latinx SGM and had Cronbach's alpha above 0.90, though alphas may be inflated due to data missingness and should be interpreted with caution.

Substance use was measured using the Alcohol, Smoking, and Substance Involvement Screening Test (ASSIST) [34, 35]. Depression was assessed via the Center for Epidemiologic Studies Depression Scale 10-item measure (CES-D-10; α = 0.93) [36]. Intimate Partner Violence (IPV) was measured using the 20-item IPV-GBM scale [37]. Familism was assessed using a five-item scale (α = 0.96) [38]. Machismo was measured using the Machismo Measure, a 20-item scale (α = 0.91) that has previously been used in samples of Latinx SGM [39]. Biospecimens were collected using standard methods recommended by the Substance and Mental Health Services Association (SAMHSA) [40].

2.7 Analysis

Recall the aim of the current study is to better understand patterns of response and non-response to key socio-demographic and outcome variables in the Adelante study. To this end, descriptive statistics summarized differences in the sociodemographic makeup of the sample and scale response rates. Only participants who answered three out of five of the sociodemographic variables were included in the reporting of key variable response rates and subsequent analyses. This was done to better reflect whether the sociodemographic attributes of participants who chose to respond to the majority of sociodemographic questions were related to item non-response or "prefer not to answer" choice selection on other measures. Response rates were calculated using the number of items answered versus not-answered by the sample. The cutoffs (see Table 1) were set at 70–75%% of the items in each measure. Only root items of each measure were included in determining cutoffs; subsequent questions from branching logic were not factored into response rates. Chi-square tests were performed to determine if there were significant differences in item response (versus non-response) by category of selected sociodemographic variables (see Table 2). For statistically significant tests, we then examined the differences between observed and expected frequencies for each combination of categories to understand the nature of these associations. The Flesch-Kincaid [41] reading scale was used to determine reading grade level for measures in English and the Fernández-Huerta reading scale was used for Spanish reading grade level [42]. A Pearson correlation was performed to determine how response rates were correlated with reading levels for the measures in English and Spanish. All analyses were performed using an alpha of 0.05 and a 95% confidence interval. To contextualize the results of these analyses, we asked two staff members of Survivors' Pathway (RP and SS), who collected much of the data and have deep roots and experience working with SGM Latinx immigrant communities, to review the results and provide insights.

3 Results

3.1 Descriptive statistics

Descriptive results (Table 1) showed 18.7% did not answer the age item and 21.1% did not answer the homelessness item. Few (1.2%) did not answer the nativity, education (7.5%), and income (14.9%) items. Nearly 90% were born outside of the United States (87.6%; a plurality from Cuba [33.5%] and Venezuela [27.4%]), and 73.3% made less than $25,000 per year. More than one in five (22.4%) reported ever experiencing homelessness.

Most respondents answered the STI susceptibility (91.6%), sexual behavior (61.1%), and PrEP uptake (95.8%) items. The response rates for the minority stress measures were lower. Fewer than half answered the multiple discrimination

Table 1 Sample characteristics

Variable groups	n (%)	English reading grade level	Spanish reading grade level
Sociodemographic characteristics			
Age	161	–	
Prefer not to answer	30 (18.7)		
18–23	17 (10.6)		
24–29	42 (26.1)		
30–35	28 (17.4)		
>35	44 (27.3)		
Data collection language	161		
Spanish	129 (80.1)		
English	32 (29.9)		
Immigrant status	161	–	
Prefer not to answer	2 (1.2)		
Foreign-born	141 (87.6)		
US-born	18 (11.2)		
Country of origin	161	–	
Prefer not to answer	4 (2.5)		
US-born	18 (11.2)		
Brazil	3 (1.9)		
Chile	1 (0.6)		
Colombia	7 (4.3)		
Cuba	54 (33.5)		
Ecuador	2 (1.2)		
El Salvador	3 (1.9)		
Guatemala	1 (0.6)		
Honduras	13 (8.1)		
Mexico	3 (1.9)		
Nicaragua	20 (12.4)		
Paraguay	1 (0.6)		
Dominican Republic	3 (1.9)		
Venezuela	28 (17.4)		
Income	161	–	
Prefer not to answer	24 (14.9)		
<$9,999	66 (41.0)		
$10,000–24,999	52 (32.3)		
>$25,000	19 (11.8)		
Ever experienced homelessness	161	–	
Prefer not to answer	37 (21.1)		
No	91 (56.5)		
Yes	36 (22.4)		
Education	161	–	
Prefer not to answer	12 (7.5)		
Did not complete high school	37 (23.0)		
Completed high school	67 (41.6)		
Completed college	45 (28.0)		
STI Susceptibility			
STI Testing	95	1	5
Answered 2 out of 2	87 (91.6)		
Sexual behavior	95	4	8
Answered 2 out of 2	58 (61.1)		

Table 1 (continued)

Variable groups	n (%)	English reading grade level	Spanish reading grade level
PrEP Uptake	95	4	7
Answered 2 out of 3	91 (95.8)		
Minority stressors			
Multiple discrimination	95	6	8
Answered 7 out of 10	45 (47.4)		
Sexual Minority Stress	95	7	7
Answered 7 out of 9	46 (48.4)		
Anticipated discrimination	95	4	7
Answered 7 out of 9	46 (48.4)		
Internalized homonegativity	95	5	9
Answered 4 out of 5	46 (48.4)		
Sexual Silence	95	1	5
Answered 2 out of 3	87 (91.6)		
Syndemic factors			
Substance use	95	9	9
Answered 10 out of 13	82 (86.3)		
Depression	95	4	6
Answered 7 out of 10	49 (51.6)		
Intimate partner violence victimization	95	4	7
Answered 17 out of 22	86 (90.5)		
Intimate partner violence perpetration	95	5	6
Answered 17 out of 22	85 (89.5)		
Cultural factors			
Machismo	95	2	6
Answered 15 out of 20	46 (48.4)		
Familism	95	3	7
Answered 4 out of 5	46 (48.4)		
Biospecimen collection	161		
Completed collection	161 (100.0)		

US United States, *STI* Sexually Transmitted infection

scale (47.4%), the sexual minority stress scale (48.4%), the anticipated discrimination scale (48.4%), and the internalized homophobia scale (48.4%). However, 91.6% answered the sexual silence scale.

Regarding syndemic factors, 86.3% answered the substance use scale, and approximately nine out of ten answered the IPV victimization (90.5%) and perpetration (89.5%) subscales. However, only half answered the depression scale (51.6%), less than half answered the machismo (48.4%) and familism (48.4%) scales. All participants (100%) provided biospecimen samples.

Reading grade levels for multi-item measured are also presented in Table 1. Response rates did not differ by grade level for English or Spanish measures.

3.2 Response rates by sociodemographic variables

Chi-square tests of independence were performed to examine the relationship between each sociodemographic variable and instrument or item response rates.

Regarding minority stress measures, response rates were significantly different by income category on the internalized homonegativity scale (X^2 (6, N = 95) = 24.85, $p < 0.001$), intersectional anticipated discrimination scale (X^2 (6, N = 95) = 24.85, $p < 0.001$), sexual minority stress scale (X^2 (6, N = 95) = 20.86, $p < 0.002$), and multiple discrimination scale (X^2 (2, N = 95) = 11.98, $p = 0.002$),. Observing the counted and expected frequencies by category (see Table 3), it is likely that participants with a higher income had response rates that were significantly higher than those with lower incomes.

Table 2 Chi-square results of item response and sociodemographic characteristic

Variable groups	Sociodemographic characteristics				
	Age	US-born	Education	Homelessness	Income
STI susceptibility					
Sexual behavior	0.804	0.401	0.073	0.224	0.128
PrEP uptake	0.557	0.437	0.098	0.772	0.748
STI testing	0.964	0.271	0.260	0.707	0.870
Minority stress					
Sexual silence	0.110	0.991	0.395	0.241	0.245
Internalized homonegativity	0.510	0.462	0.056	0.125	<0.001**
Anticipated discrimination	0.510	0.176	0.127	0.055	<0.001**
Sexual minority stress	0.510	0.176	0.034*	0.275	0.002**
Multiple discrimination	0.614	0.040*	0.061	0.429	0.002**
Syndemic factors					
IPV					
Perpetration	0.466	0.791	0.682	0.910	0.573
Victimization	0.172	0.885	0.666	0.526	0.577
Depression	0.524	0.263	0.097	0.119	0.002**
Substance use	0.542	0.748	0.231	0.946	0.613
Cultural factors					
Familism	0.207	0.176	0.182	0.275	<0.001**
Machismo	0.271	0.462	0.012*	0.515	<0.001**

US United States; *STI* Sexually transmitted infection, *PrEP* Pre-exposure prophylaxis, *IPV* Intimate partner violence

*=statistical significance level <0.05

**=statistical significance level <0.005

Response rates were also significantly different by education level on the sexual minority stress scale (X^2 (2, N=95)=6.77, p=0.034). Participants with a higher education level likely had significantly higher response rates than those with lower levels of education. Those who were foreign-born had significantly higher-than-expected response rates on the multiple discrimination scale (X^2 (1, N=95)=4.21, p=0.040) than US-born participants, though the small number of US-born participants mean this should be interpreted with caution.

Regarding syndemic factor measures, response rates were again significantly different by income category. Participants with incomes greater than $25,000 per year had higher-than-expected response rates to the depression measure(X^2 (6, N=95)=21.35, p=0.002).There were no other significant differences by sociodemographic variable.

Those with a higher income also had significantly higher-than-expected response rates on the familism measure (X^2 (6, N=95)=26.10, p<0.001) and participants with more education (X^2 (2, N=95)=8.77, p=0.012) and higher incomes (X^2 (6, N=95)=26.10, p<0.001) had significantly higher-than-expected response rates on the machismo measure. Pearson correlations were not statistically significant for English (r(12)=0.00, p=0.991) or Spanish (r(12)=0.33, p=0.246).

4 Discussion

The purpose of this study was to critically analyze response rates and data quality in a community-based, biobehavioral study to explicate better ways of engaging a highly marginalized Latinx SGM community in survey research. Unlike most research with highly marginalized communities, recruitment was not an issue in Adelante. In fact, the study reached its recruitment goals ahead of schedule. However, during spot-checks of data quality during recruitment, the team noticed high rates of participants indicating "prefer not to answer" on a majority of items for specific measures. Despite efforts to improve data quality via offering assistance from Survivors' Pathway employees during survey completion, many participants continued to select "prefer not to answer". This led to a greater exploration of the underlying reasons for these patterns.

Table 3 Expected and Observed for measures with greater than 70% completion by select sociodemographic characteristics

	Income		
	< $9,999	$10,000–24,999	> $25,000
Internalized Homonegativity			
Answered 4 out of 5 questions			
Expected/Observed	21.8/20	15.5/11	8.1/15
Anticipated discrimination			
Answered 7 out of 9 questions			
Expected/Observed	21.8/20	15.5/11	8.7/15
Sexual minority stress			
Answered 7 out of 9 questions			
Expected/Observed	21.8/18	15.5/13	8.7/15
Multiple Discrimination			
Answered 7 out of 10 questions			
Expected/Observed	21.3/19	15.2/11	8.5/15
Depression			
Answered 7 out of 10 questions			
Expected/Observed	23.2/22	16.5/12	9.3/15
Familism			
Answered 4 out of 5 questions			
Expected/Observed	21.8/18	15.5/13	8.7/15
Machismo			
Answered 15 out of 20 questions			
Expected/Observed	21.8/18	15.5/13	8.7/15
Education			
	No HS	HS	College or more
Sexual minority stress			
Answered 7 out of 9 questions			
Expected/Observed	10.7/6	21.8/22	13.6/18
Machismo			
Answered 15 out of 20 questions			
Expected/Observed	10.7/5	21.8/23	13.6/18
Nativity			
	US-born	Foreign-born	
Multiple discrimination			
Answered 7 out of 10 questions			
Expected/Observed	39.3/36	5.7/9	

HS high school

While response rates differed by various sociodemographic variables and underlying constructs being measured, these alone were not sufficient to explain the low response rates on many measures. Sociocultural measures, including measures for machismo, familism, internalized homophobia, anticipated discrimination, sexual minority stress, and multiple discrimination, had the lowest response rates. The overall low response rates by the largely non-US-born sample suggests a level of mistrust in filling out surveys, which in South Florida, may be attributed to the chilling effect of recent anti-immigrant laws [43, 44] and the syndemic health outcomes mentioned previously. Additionally, participants who were US-born were more likely to answer questions regarding multiple discrimination, suggesting this construct may not be as salient in the Latin American countries from which the majority of the sample emigrated (i.e., Cuba, Venezuela). Further, participants with higher educational attainment were more likely to answer questions regarding sexual minority stress and machismo, and participants with higher incomes were more likely to answer questions regarding internalized homophobia, anticipated discrimination, sexual minority stress, multiple discrimination, depression, machismo, and familism, suggesting that those with lower educational attainment may be unfamiliar with these constructs and alternative measures that are more culturally salient and/or more thorough introductions to these constructs before

answering the questions may be warranted (Lesson 1). Overall, these results are congruent with extant literature show-ing people with higher educational attainment yield higher response rates [45]. Among the participants we sampled, we speculate that this may be the case as higher education and income may be associated with both literacy level and being more attuned with the potential benefits of participating in scientific research. Secondly, we may have under-estimated the financial insecurity many participants in this community consistently face, making the money collected through this study a significant source of income for many respondents. While we do not feel the amount was coercive, it may have shifted the motivation of some participants from one of intrinsic motivation for improving HIV-related care in their community to one that was more externally motivated by monetary incentives. Previous research with non-SGM Latinx communities suggest that reliance on such extrinsic motivation, as well higher levels of certain individual cultural factors (e.g., machismo) can affect item non-response and tendency to select response scale endpoints such as "prefer not to answer"[46]. Carefully crafting recruitment materials and intake processes to improve intrinsic motivation among potential participants may improve response rates in future studies with this community (Lesson 2). Best practices in improving intrinsic motivation for SGM communities is evidenced by The PRIDE Study and could be adopted for Latinx-specific communities [47]. These include tailoring recruitment materials to highlight the positive influence participation will have for the community, using high-touch outreach (e.g., regular texts and emails), and providing a sense of com-munity for participants via a PRIDE study newsletter and regular updates on findings.

Third, even though the measures were either validated in Spanish or professionally forward- and back-translated by native speakers who were employees of the Principal Investigator's institution, there likely remain discrepancies between the more formal Spanish spoken by these highly educated staff members and colloquial Spanish spoken by many of the participants. This could have contributed to confusion and perceived redundancies in questions, leading to item non-response. Previous work recommends purposefully leveraging the social capital of trusted community members to increase overall response rates in Latinos [48]. Extending this to survey design by using members of the community with whom the study is to be conducted to conduct or review measure translations, and adapting as needed, may help improve data quality in future studies (Lesson 3).

In contrast to the sociocultural measures, participants unanimously provided biospecimens and largely responded to measures capturing constructs that were often stigmatized, such as STI testing, sexual behaviors, PrEP uptake, sexual silence, substance use, and IPV. It is plausible that since the community partner offers routine HIV and STI testing to this community, the participants trusted the organization with their biological data and were more willing to answer the (potentially more familiar) questions that are often asked on official forms required by County government regarding PrEP uptake and HIV risk. This would be consistent with research showing that community organizations are trusted sources of health information for the LSMM community [49]. Survey data, on the other hand, is rarely collected among this community and many are likely unfamiliar with how and why this data is collected, as well as with whom it is shared. Moreover, our online data collection method (while hosted by REDCap and confidential) was unfamiliar to many partici-pants, and some participants were concerned that their confidentiality would be breached. Careful communication from a trusted community member- over and above the requirements stipulated in an informed consent document- may help assuage these fears and lead to improved data quality (Lesson 4). Similarly, using a syndemic approach to understanding the holistic nature of HIV risk in this community may be helpful in ensuring the research, recruitment, and data collection processes are appropriately tailored to this community. Understanding both the socio-structural drivers (e.g., minority stress, Latinx cultural norms) and syndemic outcomes (e.g., substance use, poor mental health) as potential reasons for poor data quality in a socio-economically disadvantaged community is imperative for ensuring next steps are inclusive of the needs of participants.

5 Limitations

This study regarding the lessons learned in collecting data for the Adelante study has some important limitations to note. First, by design, the assessment of response via "prefer not to answer" limits the ability to draw concrete inferences as to the reasons participants chose not to respond to specific instruments. There are likely reasons not covered by our analysis that are important to understand for future data collection efforts. Ongoing collaboration with Survivors' Pathway will help to uncover best practices in working with this community. Second, the cutoff for response versus non-response for multi-item instruments was set at 70–75%%, which means that even those who are coded as "responding" may not have fully answered all the items in a given instrument. Further inquiry into which specific items within each instrument were the most likely to receive "prefer not to answer" may uncover additional lessons learned. Third, the reading scales

Table 4 Lessons learned and recommendations

Lesson	Recommendation
Large parts of the target community may be unfamiliar with the underlying constructs captured in important HIV-related measures	Pilot testing measures (even when previously validated in similar communities) may shed light on ways the measure should be introduced in the survey prior to data collection
Cash incentives, while not inherently coercive, may shift motivation from intrinsic to extrinsic and lead to poorer data quality	Intentional recruitment with trusted community members with intrinsic motivation to improve health outcomes in their community and crafting recruitment materials that speak to the improvements in health outcomes the research may lead to may improve data quality
Deviations in Spanish go beyond vocabulary used in different Latin American countries, and more formal Spanish may relay concepts in unfamiliar ways that are unapproachable	Working with members of the target community to forward and back-translate measures and edit instruments previously validated in the target language to make them more approachable may improve data quality
Community members may be unfamiliar with survey data collection processes and the protections in place to ensure confidentiality. Reviews of informed consent documents may not be sufficient	Intentional and approachable communication on the basics of survey data collection and the protections afforded to participants may be needed to assuage fears of personal data breaches- especially for those who are undocumented

used to analyze comparisons of English and Spanish-language items may not be directly comparable. In spite of these limitations, inquiry into the data quality of the Adelante study provided valuable lessons for subsequent data collection efforts with this community.

6 Recommendations

Based on our quantitative analyses and qualitative contextualization, we have derived four main lessons learned from working with this highly marginalized community (see Table 4). Such recommendations for future improvements to the data collection process may help improve data quality in future studies of similar communities.

7 New contribution to the literature

Given the HIV-related inequities present among Latinx SGM in Miami-Dade County, there is an urgent need for rigorous, effective approaches to reaching this marginalized community. While previous research provides guidance on potential ways to improve recruitment and response in Latinx communities generally, the unique makeup of South Florida's Latinx community as well as the specific needs of Latinx, SGM immigrants means that more tailored approaches are needed to achieve quality data collection. By critically analyzing the strengths and weaknesses of our data collection approach in this highly marginalized population, we hope to provide researchers with four concrete recommendations to improve their own survey designs and outreach protocols, allowing for a more complete understanding of the needs and strengths of this vibrant and resilient community.

Author contribution NM retained the funding for the study from which this manuscript is derived, conceptualized the manuscript, and NM and DS wrote the initial drafts. RP and SS contextualized the findings, made meaningful contributions to the writing, and edited the manuscript for accuracy. All authors reviewed the manuscript and approved its submission.

Data availability As the study is still ongoing, data from the Adelante study are not yet publicly available. However, data supporting this research are available from the first author upon request.

Declarations

Competing interests The authors declare no competing interests.

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