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A Cross Cultural Perspective of Adherence for Racial/Ethnic Minority Women with HIV, Living in the United States

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ABSTRACT

HIV persists as a global public health tragedy, as more than 36 million lives have been lost to HIV/AIDS. A diagnosis of HIV can be treated as a chronic disease, for those who adhere to their medication regimens and other health recommendations. However, for racial/ethnic minorities living in the United States, many of whom face a multitude of barriers, adherence to medications and medical appointments can be a challenge. For racial/ethnic minority women, specifically, gender roles, HIV stigma, racism, inconsistent access to healthcare, financial and food insecurity are just a few of the barriers they experience, which may interfere with their ability to adhere to medical treatment. For immigrant women, low language literacy, which is linked to health literacy, may further exacerbate these lives where staff and services provide culturally and linguistically competent services. This paper reports parts of a larger mixed-methods inquiry. The goal is part of larger study to develop an intervention for racial/ethnic minority women with HIV, living in the Southeastern region of the United States.

Keywords: HIV, Women, Health Disparities

Manuscript Abbreviations

ARV:	Anti-retroviral medication
EMR:	Electronic medical record
VL:	HIV viral load
PLWH:	Persons living with HIV
PrEP:	Pre-exposure prophylaxis
PHQ-9:	Patient Health Questionnaire
HHS:	HIV Stigma Scale -
CD-RISC25:	Connor-Davidson Resiliency Scale-

A Cross-Cultural Perspective of Treatment Adherence for Racial/Ethnic Minority Women with HIV, Living in the United States

To date, 36 million lives have been lost to HIV, and 37 million people are currently living with HIV/AIDS (WHO, 2022a). However, with adequate and regular treatment, HIV is a manageable as a chronic disease, as treatment in the form of anti-retroviral medications (ARV) are effective in reducing the HIV viral load (VL) (Samji et al., 2013). With an undetectable viral load, the chances of spreading the virus to intimate partners and to newborns, for pregnant women with HIV, are greatly reduced, and the life expectancy of persons living with HIV (PLWH) is significantly increased. An extension of anti-retroviral medications ARV is pre-exposure prophylaxis (PrEP) treatment, which is prescribed to HIV sero-negative persons and protects against acquisition of HIV, when taken regularly by non-HIV intimate partners of PLWH (WHO, 2022b). Whether taken to prevent HIV acquisition or prevent the replication of the virus for persons already living with HIV, it is important to understand the barriers to the uptake and maintenance of HIV anti-retroviral medications (WHO, 2022b).

Adherence to anti-retroviral medications ARV is key to ensuring good clinical outcomes for PLWH; however, even in the developed world, where access to subsidized medications and medical care are more widely available, maintaining viral suppression for certain population subgroups, like persons living in poverty and communities of color (Earnshaw et al., 2013), may be challenged by structural and individual level barriers. Structural level barriers include consistent access to HIV care and anti-retroviral medications ARV. Individual level barriers, such as mental health diagnoses and substance use are faced by marginalized communities (Myhre & Sifris, 2022), including women of color in the US (Dale et al., 2014).

In the United States (US), racial/ethnic minority groups, such as self-identified African-Americans and Hispanic-Americans, share an increased burden of new HIV infections—and, for those living with HIV, worse health outcomes (CDC, 2021). This burden is more notably observed in the Southeastern US, where the greatest rate of new HIV infections and poor health outcomes in PLWH occur (CDC, 2021). The purpose of this study was to explore multiple barriers and facilitators of HIV care adherence, among a group of self-identified African-American and Hispanic-American women living with HIV, who spoke English and Spanish, and were receiving care in a public clinic in the Southeastern US. The intervention as described in Duthely et al. (2020) is predicated on the Health Belief Model, which entails characterizing and acting on the individual-level barriers and facilitators that influence health behavior change (Glantz et al., 2008).

From the larger study (see Duthely et al., 2020), we first conducted the quantitative inquiry, where we compared participants' baseline and clinical characteristics, while summarizing healthcare mistrust (Duthely et al., 2021a), resiliency and adherence to HIV care (Duthely et al., 2021b). The study cohort resided in a region that shares the greatest

burden of new HIV infections and poor health outcomes for PLWH. The quantitative findings are summarized below.

Prior Findings—Linguistic Group Comparisons

Participant demographic profile, mental health history and clinical profile, which was compared by linguistic group, was previously reported (Duthely et al., 2021a). An overwhelming majority (93%) were racial/ethnic minorities. Two-thirds (67%) of the cohort were English-speakers; one-third (33%) were Spanish-speakers; 89% of English speakers were African-American and of Black race, and 93% of Spanish speakers were Hispanic-American and of White race. English speakers were significantly younger, compared to Spanish speakers ($M = 44; 38$ vs 53 years old; $SD = 12.7$; $p = 0.0019$). Regarding psychosocial history, while non-significant, a higher proportion of English speakers had a recent history of substance use compared to other groups (19% vs 8%, $p = 0.65$); a significantly higher proportion of English-speakers had a recent history of clinically-confirmed depression or another psychiatric diagnosis compared creole and spanish speakers (54% vs 25%, $p = 0.039$). A higher proportion of Spanish-speakers were VL suppressed at the clinically-accepted threshold of 200 copies/mL; the difference by linguistic group, however, was not confirmed statistically.

Prior Findings—Racial/Ethnic Group Comparisons

Previously published data from this cohort (Duthely et al., 2021b), summarized here, examined the relationships between several mental health constructs—namely, depression using the Patient Health Questionnaire-9 (PHQ-9) (Kroenke et al., 2001); HIV-related stigma using the HIV Stigma Scale (HHS) (Berger et al., 2001); and resiliency using the Connor-Davidson Resiliency Scale (CD-RISC25) (Connor-Davidson, 2003). Medians scores were further subdivided by VL suppression group, for the two racial/ethnic groups, namely African-American and Hispanic-American. Overall, higher depression and HIV-related stigma were found among those not VL suppressed, compared to the VL suppressed group; and higher levels of resiliency were related to VL suppression. However, significant differences were reported, when comparing VL suppression (vs not suppression) among the Hispanics for HIV stigma (100, IQR=29; vs 111, IQR=50; $p = 0.043$) and comparing VL suppression amongst the African-Americans for resiliency (86.5, IQR=14; vs 64.5, IQR=41; $p = 0.039$).

Current Study

This research briefly summarizes data focus groups conducted in the English language or in the Spanish language. The purpose of the focus groups was to understand from the

participants barriers and facilitators that hindered or facilitated adherence to taking HIV medications and attending HIV appointments.

Figure 1.

A Word Art Representation of Challenges Faced by Racial/Ethnic Minority Women With HIV in the United States. Artist: Sneha Akurati



Methods

Participants

This inquiry is part of a larger study to design a technology-based intervention for African-American, African-Caribbean and Hispanic-American minority women living in South Florida, US. Patients were recruited in a public HIV clinic, to participate in the study patients were required to have a diagnosis of HIV and be at-risk for falling out of HIV care, determined by recent history of not complying with the clinic recommendations, or “non-adherence”. Non-adherence was defined as missing HIV-related medical appointments, as documented in the electronic medical record (EMR), or not taking ARV as prescribed—either missing

doses of ARV (self-report or electronic medical record) or prescribed- and not taking ARV (self-report or electronic medical record).

In the US, population census categorizes individuals by five major races (Black, White, Asian, Pacific islander, Other), and two ethnicities (Hispanic/Latin, Other). In our study, to characterize the diversity of patients followed in our clinic, we also collected information on ethnic background and country of birth, via self-report. We used a hierarchical method to consolidate the multiple race and ethnicities to provide more meaningful comparisons. Participants were characterized as the following: Black/African-American, Caribbean, Hispanic, other. The clinic population includes women of self-identified Black race, who are mostly African-American and Caribbean-American., Hispanic-American women overwhelmingly self-identified as White. The clinic population consists of native, US-born women, and also first- and second-generation women from the Caribbean Islands, Central and South America. The research team consisted of seven native and non-native, English-Spanish bilingual speakers, of varying ethnic-cultural groups, including Caribbean-American, South American, and North American.

Procedures

This current study consists of a content analysis of focus group data. The quantitative data was previously published (Duthely et al., 2021b). and included self-administered assessments and electronic medical record data (EMR). Participants were assessed for depression, HIV-related stigma, and resilience. Qualitative data were collected from a subset of participants, who agreed to 90-minute semi-structured interviews in the form of focus groups. The first focus group consisted of English-speakers. Approximately one month later, the second focus group was held with Spanish-speakers. Bilingual Research Assistants coordinated the focus group date and time, contacted and reminded participants of the interviews, and facilitated the group meeting. Participants who were not offered consent for participation prior to the focus group meeting were instructed to arrive early and consent was taken in a private room, prior to the commencement of the focus group.

Participants were offered compensation for their participation. Participants were reimbursed for their time with grocery gift cards and Lunch was provided at the end of focus group. As the clinic serves a population of low-income, uninsured, or under-insured women, and some women had travelled for more than 90 minutes to reach the clinic's location, participants were also offered a light breakfast upon arrival, as they waited for the focus group to begin. Transportation vouchers (i.e., round trip public bus or train pass; onsite parking) were provided either in advance, if needed, or the day of the focus group. Participant permission was first obtained to audio-recorded focus group interviews. During the study design phase, the research team created a codebook, which was based on previously published studies reporting known barriers to HIV adherence to care for racial/ethnic minorities, women (Cook et al., 2018; Dombrowski et al., 2015; Earnshaw et al., 2013; Kuchinad et al., 2016; Levison et al., 2017).

Qualitative Data Analysis

Through several iterations, recordings were reviewed, then transcribed. English language focus group text were coded by two separate coders, independently. The study principal investigator and (lead author), reconciled the differences. The Spanish language focus group recording was first independently transcribed into Spanish text by two native Spanish speakers, who were Spanish-English bilingual. The next step was to translate the Spanish transcript into English by two bi-lingual Spanish-English speakers—one native, one non-native. The data from both focus groups were coded using the English text.

The data were coded manually by two separate coders. Using a thematic analysis approach (Braun & Clarke, 2006), the text was analyzed recursively and manually coded. The steps, as prescribed by Braun and Clarke (2006), include data familiarization, identifying keywords and phrases, collating codes, collating codes into relevant themes, and defining and naming the themes. Initial instances of text related to known barriers and facilitators of HIV care adherence were identified. Additional, salient instances, as agreed upon by the research team, were included as well. The instances were then aggregated into overarching themes (see Table 1).

RESULTS

Qualitative Assessments

English Language Speakers

From the English language focus group, which was previously published (Duthely et al., 2021b), 24 instances were reduced to seven overarching themes related to barriers or facilitators to adherence to appointments and adherence to ARV.

Examples of coding from the transcripts is as follows: English Participant #5 expressed that caregiving responsibilities was one barrier to medication adherence: “I got six kids to worry about; so my needs [i.e., taking medications] will always get pushed [aside]”. Caregiving responsibilities was also a promoter of adherence. English Participant #1 expressed, “It’s [because of] my kids. I said I would be there for them”. English Participant #4 expressed faith/religion as a promoter of adherence: “God won’t put on you more than you can bear”. Finally, concurrent alcohol use was another reason that emerged as a factor that interfered with adherence: “If I am drinking, I’m not going to take ... medicine. Because you can’t mix [alcohol and HIV medications] it” (see Table 1).

As demonstrated in Table 1, responsibilities as a caregiver, substance use, and competing priorities were the most common reasons English-speaking women identified for not taking their medications or missing medical appointments. Examining the data to identify what helped them stay in care, 10 instances were identified, which generated 4 overarching themes. Faith / spirituality and routinization to avoid side effects, were the top promoters of adherence. Caregiver role and medication side effects were both a barrier and a promoter of adherence to care (see Table 1 and 2). English-speakers were predominantly African-

American.

Table 1.

Barriers of Adherence for the English and Spanish Language Speakers

English Language Speakers		Spanish Language Speakers	
Barriers to Adherence (N=8 WLWH ; N=24 instances)	n (%)	Barriers to Adherence (N=4 WLWH; N=11 instances)	n (%)
Caregiver Role (ARV and Appointments)	6 (25)	Personal (e.g. forgetful, hiding medications) (ARV)	4 (40)
Concurrent Alcohol Use (ARV)	5 (21)	Structural (e.g. Clinic Transportation): Appointments	3 (30)
Schedule/ Busy (ARV and Appointments)	3 (13)	Other Circumstances (ARV and Appointments)	2 (20)
Other Circumstances (ARV and Appointments)	3 (13)	Medication Side Effects (ARV)	1 (10)
Structural (e.g Clinic/ Transportation): Appointments	3 (12)	Schedule/ Busy (ARV and Appointments)	1 (10)
Medication Side Effects (ARV)	2 (8)	Caregiver Role (ARV and Appointments)	-
Personal (e.g forgetful, hiding medications) (ARV)	2 (8)	Concurrent Alcohol Use (ARV)	-
Total	24	Total	11

Table 2

Promoters of Adherence for the English and Spanish Language Speakers

English Language Speakers		Spanish Language Speakers	
Promoters of Adherence	n (%)	Promoters of Adherence (n = 2 instances)	n (%)
Avoid Side Effects (i.e., take ARV with meals)	3 (30)	Avoid Side Effects (i.e., take ARV with meals)	2 (100)
Faith/ Religion/ Spirituality	3 (30)		-
Caregiver Role (i.e responsibility for children)	2 (20)		-
Trust in Medical Personnel	2 (20)		-
Total	10		2

Notes: ARV - anti-retroviral medication

Spanish Language Speakers

From the Spanish language focus group, which was first transcribed into English, 11 instances related to barriers and facilitators to adherence, were identified. Through an iterative process, the 11 instances were further reduced and generated seven overarching themes. Examples of this reduction are presented here: Spanish Participant #1 expressed that one challenge with adherence to appointment was wanting to change provider: "... and I said no more ... I begged, I inquired until they made the appointment for me with Dr.

[ABCD]”. This was initially coded as “discontent with clinic”, which was then combined with other codes to a more general category of: “structural: clinic “, “structural (clinic/transportation”. In another example, Spanish Participant #2 expressed: “ ... yes, I forget ... I forget my appointment[s].” This was assigned to “forgetfulness”, then collapsed into a general category of “personal” (see Table 1).

Personal factors (e.g., forgetfulness) and structural issues (e.g., related to the clinic, transportation challenges) were the reasons endorsed most by the Spanish-speakers ($n = 4$) for missing appointments and missing doses of their medications. Routinization to avoid side effects, was the only promoter of adherence identified by Spanish-speakers (see Table 2).

Discussion

This study explored the multiple and intersecting factors related to HIV care adherence, for racial/ethnic women living in a Southern US State—the State of Florida. We summarized qualitative data generated from focus group interviews, among a group of African-American and Hispanic-American women, who were at-risk of being lost to HIV care. Participants were interviewed in the language of their choice. From previously published quantitative assessments, comparing participants in the larger group by language, the majority of English speakers self-identified as African-American, were significantly younger, and had a recent history of substance use and depression or other psychiatric diagnosis. Spanish speakers, the majority of whom identified as Hispanic, were significantly older, and had significantly higher rates of VL suppression (Duthely et al., 2021b). In the US, younger age is associated with lower adherence and VL non-suppression (CDC, 2022). It has been reported in other US Southern states that depression and substance use frequently co-occur among people with HIV (Felker-Kantor et al., 2019).

In the larger study, Hispanic-Americans were overall more resilient, and endorsed lower levels of HIV stigma and depression, compared to the African-Americans (Duthely et al., 2021b). In the South Florida region, Hispanic-Americans are a minority-majority, predominantly of White race, and the Spanish language is spoken by the majority of households in the region. Duthely et al. (2021b) proposed that the majority status of the Hispanic-American women is a plausible reason why the Hispanic-Americans endorsed higher mental health status and lower health risk behaviors, compared to the African-Americans. Our findings (current study) concur with the quantitative findings that English speakers, who were predominantly African-American, expressed more risk behaviors (substance use), structural barriers and caregiver responsibilities as barriers to adherence; whereas the most Spanish speakers, the majority of whom were Hispanic-American, identified personal reasons, such as forgetfulness as barriers to adherence.

From the larger quantitative study, higher depressive symptomatology was associated with VL non-suppression, which has been reported among US, clinic-based populations (Kelso-Chichetto et al., 2018), and amongst women living outside the US (Regan et al., 2021). The data on the positive relationship between resilience and, both, medication

adherence and viral suppression was similar to what was reported by Fletcher et al.'s (2020) mixed methods work. In their study, the relationship was statistically significant amongst those with lower levels of depression, compared to those with higher levels of depression (Fletcher et al., 2020). The mechanism, as proposed by Fletcher et al. (2020), is that the relationship between resilience and adherence could be moderated by depression. Jaiswal et al.'s (2019) qualitative evaluation found that, despite social and economic exclusion experienced by their study participants, greater resilience contributed to HIV-related adherence for their population of persons of color.

In examining the relationship between stigma and VL suppression, higher levels of stigma for the current study population was associated with VL non-suppression, across both racial/ethnic groups, however, statistically significant differences were found amongst the Hispanics, only (Duthely et al., 2021b). These findings could be explained by what has been shown in the literature regarding strong social support reported by Hispanics in the US (Mulvaney-Day et al., 1982), which is linked to better health, and an environment that fosters disclosure of HIV status to friends and family (Kalichman et al., 2003). PLWH who have disclosed their HIV status are less likely to conceal their HIV medications from others, take medications as prescribed and attend their HIV medical visits (Katz et al., 2013). Amongst the women in parent study, there was also a statistically significant difference amongst the African-Americans, where higher resiliency was associated with VL suppression (Duthely et al., 2021b). African-Americans in the US have experienced centuries of racism, which filters into healthcare (Feagin et al., 2014), and so it is plausible that resiliency becomes a way of life, and African-Americans with the lowest levels of resilience may be the most marginalized and vulnerable individuals.

Participants interviewed attended the focus groups in their language of choice. English speakers, who were predominantly African-American, expressed barriers differently than the Spanish speakers—specifically, substance use and other psychological factors were the themes most frequently endorsed by the African-Americans, which impeded their ability to adhere to their HIV care. Quantitatively, substance use and mental health diagnoses were endorsed more frequently by the African-American women in our parent study (Duthely et al., 2021b). Gwadz et al.'s (2016) qualitative study revealed the multi-faceted challenges PLWH who use drugs face, which interfere with their ability to adhere to ARV. Substance use and mental health diagnoses often co-occur among women with HIV in the US (Cook et al., 2018).

One approach that explains the complexity of certain diseases is the “syndemic” approach, which considers the unique intersection of social conditions and factors that exacerbate the spread HIV (Singer, 1994). The syndemic paradigm also explains the unique, often negative, health outcomes of marginalized communities, including persons living in poverty and minoritized populations, such as racial/ethnic minorities. Minorities are more vulnerable to multiple and co-occurring diseases like COVID-19 and HIV, together (Cao et al., 2020; Williams & Vermund, 2021). The substance use, HIV/AIDS and violence syndemic, which is also inclusive of experiences of trauma and abuse (Meyer et al., 2011), explains the increased burden of HIV infections and poor health outcomes amongst women of color in the US with HIV, which is fuelled by the SAVA syndemic. Following the SAVA

framework, it is plausible that the higher substance use and depression we found amongst the African-American women in this cohort, compared to the Hispanic-American women, could be explained by these interrelated and deleterious factors that contribute to poorer health outcomes.

Comparing the qualitative data by linguistic groups, the top priorities for the Spanish speakers related to structural issues, such as challenges with the clinic or transportation barriers, and personal challenges, such as forgetfulness. It is possible that the women who elected to be interviewed in Spanish, had limited fluency in the English language, which may have contributed to the issues related to the clinic and transportation, which they expressed. Other help in the household may have alleviated the caregiver burden that was expressed by the English speakers. Levison et al. (2017) qualitative inquiry amongst Latino migrants and immigrants, reported that stigma, social support, patient-provider relationship, competing priorities, like food and transportation, religion/spirituality and unaddressed substance use either impeded adherence or facilitated adherence to HIV care. The Hispanics/Latinos in our study were a mix of native and non-native, immigrants/migrants, and so it is plausible that some bilingual participants, regardless of nativity, elected to be interviewed in Spanish, were longer time established in the US, and not subject to the challenges faced by newer immigrants who have newly arrived into the US. Also, as mentioned previously, in Southern Florida, Hispanics/Latinos are a minority-majority and the Spanish language is spoken by a majority of the population.

Several study limitations are noted here. First, the number of English speakers who participated in the focus groups was double the number of Spanish speakers, which may explain why there were differences in the number of themes that emerged for each language group. Second, there was more homogeneity amongst the Spanish-speakers, where an overwhelming majority self-identified as Hispanic ethnicity and White race; there less homogeneity amongst English-speakers, which included both native and non-native women from the Caribbean islands, as well. Our findings are, therefore, not generalizable to the population racial/ethnic minority women with HIV, living in the US.

Another limitation of our findings is that although we did query the women to reflect generally, on promoters of adherence, we did not ask specifically about resilience; however, overall, the Spanish-speaking women were generally older in age, and so it is plausible that Spanish speakers had developed this resiliency over time, and were not affected by day-to-date challenges. Also, as presented previously, the majority status experienced by the Spanish speakers, shields them from the negative experiences endorsed by the English speakers in our study, the majority of whom were of Black race.

Despite these limitations, our study is perhaps the only study, which included both racial/ethnic group and linguistic group comparisons, to examine qualitatively facilitators and barriers to care and treatment for women with HIV, living in the US. We sought to understand the different challenges faced by this racially, ethnically and linguistically diverse cohort of women, with the ultimate goal of designing effective interventions to improve health-related outcomes.

Conclusion

Among a clinic-based cohort of racial/ethnic minority women with HIV living in the US, who were at-risk of falling out of care, women identified several co-occurring psychological and social factors that were related to missing doses of HIV medications and missing medical appointments. Patients identified barriers and facilitators to adherence, which mapped onto both structural factors, such as issues with the clinic, and personal factors, such as forgetfulness, that interfered with adherence.

Several differences emerged by linguistic and racial/ethnic group. Although limited in scope, our previously reported quantitative findings (see Duthely et al., 2021b) were that Spanish speakers, who were mostly of White race, encountered fewer barriers and fared better health outcomes, compared to the African-American women, who were all of Black race and endorsed more barriers, compared the Hispanic-American women. These differences could be explained by the historical context of racism, particularly for persons of Black race, who have endured centuries of discrimination in the US, and the cultural context of social support that Hispanics in the US, who are newer immigrants, relatively, and who identify racially as White/Caucasian, maintain from their home countries. Hence, among racial/ethnic minority populations it is important to consider race/ethnicity, as well as language, when designing interventions that address health care disparities among heterogeneous populations, living in the US.

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