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## Substance Use and HIV Risk in a Sample of Severely Mentally Ill Puerto Rican Women

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### Abstract

Latinos, and Puerto Ricans in particular, have been disproportionately impacted by HIV/AIDS. Severe mental illness (SMI) is associated with an increase in HIV risk. Relatively little research has focused on the role of SMI among Puerto Rican injection drug users (IDUs) and non-IDUs in susceptibility to and transmission of HIV and there are few published reports on HIV risk among Latina SMI. We conducted a longitudinal mixed methods study with 53 Puerto Rican women with schizophrenia, bipolar disorder, or major depression to examine the cultural context of HIV risk and HIV knowledge, beliefs, and behaviors among a larger study with Puerto Rican and Mexican women with serious mental illness (SMI). There was a high prevalence of past and current substance use and a high prevalence of substance use-associated HIV risk behaviors, such as unprotected sexual relations with an IDU. The violence associated with substance use frequently increased participants' HIV risk. Choice of substance of abuse depended on cost, availability, and use within the individual participant's network. Participants attributed their substance use to the need to relieve symptoms associated with their mental illness, ameliorate unpleasant feelings, and deaden emotional pain. HIV prevention interventions for poorer Puerto Rican women with SMI must target the individuals themselves and others within their networks if the women are to be supported in their efforts to reduce substance use-related risk. The content of any intervention must address past and current trauma and its relationship to substance use and HIV risk, as well as strategies to prevent HIV transmission.

### Keywords

Latinas; HIV; Severe mental illness; Substance use

## Introduction

Hispanics/Latinos are disproportionately impacted by HIV. Comprising just 13% of the U.S. population [1], Latinos account for 16% of the estimated 952,629 AIDS cases diagnosed through 2005 [2]. Puerto Ricans, in particular, have been impacted by the disease as the result of injection drug use (IDU) and high risk heterosexual contacts [2].

Data from the combined 2000 and 2001 National Household Survey of Drug Abuse suggest that the prevalence of illicit drug use is higher among Puerto Ricans 12 years of age (9.2%), compared with those of other Latino ethnicities (3.6%) [2, 3] and that the prevalence of illicit drug use in Puerto Rico (PR) is lower than that among mainland Puerto Ricans and other Latinos [4–6]. However, a household study of substance use disorders in PR found low sensitivity of respondents' self-reports of heroin and cocaine use compared to testing results, indicating that illicit drugs use is higher than reported [7]. In PR, IDU accounts for one-half of all AIDS cases [8], compared with 24.3% of AIDS cases on the mainland [9].

Compared to Blacks and Whites, Puerto Rican IDUs have the highest monthly mean frequency of both injection and injection of cocaine and heroin together (“speed-balls”). They are more likely to inject in a shooting gallery [10], a somewhat sheltered location where individuals can buy—often previously used—injection paraphernalia and use their drugs. These factors are associated with an increase in the likelihood of HIV transmission. Women may be at especially high risk; one study found that female Puerto Rican IDUs are more likely than men to exchange sex for drugs or money and to have multiple sexual partners [11, 12].

Higher levels of risk have been observed among IDUs in PR [13, 14] and those who are newcomers to the mainland [15]. Those in PR have been found to (1) obtain a greater proportion of their syringes from “syringe sellers” and a much smaller proportion from syringe exchange programs (SEP); (2) be less likely to be referred by a SEP to drug treatment and/or HIV and TB testing services [16]; (3) engage in higher levels of needle-sharing [17, 18]; and (4) be more likely to inject speedballs, which may account for the greater frequency of injection among PR-residing IDUs [11, 18, 19].

Severe mental illness (SMI) may play a role in the elevated risk of HIV. Studies of HIV seroprevalence among sample SMI populations found that HIV seroprevalence ranged from 4% to 22.9% [20–29]. HIV transmission risk is elevated among persons with SMI due to sexual relations with multiple sexual partners [30, 31] and a high prevalence of both sexual intercourse with an IDU [32, 33] and trading sex for drugs [34, 35]. Women with SMI may be at particularly high risk of HIV infection [36] due to illness symptoms that decrease their ability to refuse unreasonable requests, solve problems effectively, and negotiate risky situations [37]; heightened risk of partner violence [38]; and the impact of poverty and unemployment on their survival [39, 40]. HIV prevalence among Hispanic SMI has been found to be three times that among whites, suggesting that ethnicity may be important in the relative risk of exposure to HIV [41]. Nevertheless, relatively little research has focused on the role of SMI among Puerto Rican IDUs and non-IDUs in susceptibility to and transmission of HIV and there are few published reports on HIV risk among Latina SMI.

We report here our findings from a longitudinal, mixed-methods (quantitative and qualitative) study designed to examine the cultural context of HIV risk and HIV knowledge, beliefs and behaviors among Puerto Rican and Mexican women with SMI. We confine our discussion here to the Puerto Rican women, the context of their substance use, and its implications for HIV risk. All procedures described below were approved by an institutional review board.

## Methods

### The Study Site

Puerto Rican women were recruited from a six-county area of northeast Ohio. Compared to non-Hispanic whites in this region, the Puerto Rican population is relatively poor, with a substantial proportion living under the poverty level [42–46] and a large proportion experiencing multi-generational unemployment [47].

In Cleveland, the 39th largest city in the U.S., Hispanics account for 4% of the population, the vast majority of which is Puerto Rican. The HIV prevalence rate of 1,061.4 per 100,000 among Hispanics in Cleveland is higher than that among any other racial/ethnic group. Estimates suggest that fully 1% of Cleveland's Hispanic population are HIV-infected [48–50], compared to an estimated 0.6% prevalence within the general U.S. population. Unprotected heterosexual intercourse remains the predominant mode of transmission for Puerto Rican women, both nationally and in Cuyahoga County, in which Cleveland is situated. In Cleveland, 48% of all Hispanic females currently living with HIV/AIDS were infected through unprotected heterosexual intercourse, with the remainder having been infected through injection drug use, maternal transmission, and unknown routes [48–50].

### Participants

Participants had a diagnosis of major depression, schizophrenia, or bipolar disorder and were between 18 and 50 years at the time of enrollment. Mental illness diagnosis was verified with the Structured Clinical Interview for Axis I DSM-IV Diagnoses (SCID). The SCID has been used with various populations in numerous countries, has been translated into Spanish, and has been found reliable and valid for use with Spanish-speaking patients [51]. All participants provided informed, voluntary written consent to their participation.

### Data Collection

**Quantitative Measures**—Following the confirmation of the diagnosis and enrollment into the study, we conducted the baseline assessment, which consisted of a semi-structured qualitative interview and standardized quantitative measures designed to assess substance use, acculturation, and HIV-related knowledge and behaviors. We supplemented and verified the results obtained with quantitative measures against the qualitative data that we gathered through the semi-structured part of the interviews and from the non-continuous participant observation. The structured instruments allowed us to maximize and standardize the information that we received and to provide a context against which that information could be measured. Trained bilingual staff conducted all of the interviews and ethnographic observations.

We assessed the severity of each participant's substance use with the Addiction Severity Index (ASI) [52]. Acculturation was assessed with the use of a short acculturation scale developed for use specifically with Latinos [53]. Lower levels of acculturation have been associated with erroneous beliefs relating to HIV transmission, lower levels of HIV knowledge, greater reluctance to use condoms, lower levels of HIV disclosure to others, and risk behaviors for various other diseases [54]. A 12-item true–false scale was used to measure practical knowledge about HIV, risk behaviors, condom efficacy, perceived risk, barriers to condom use, partner attitudes towards condom use, peer group use of condoms, barriers to HIV testing, barriers to clean needle use, and HIV prevention behaviors during the previous year [55, 56].

**Qualitative Tools**—We conducted a semi-structured interview with each participant once a year for each of 2 years. We used ethno-graphic methods to “shadow” each participant for

up to 100 h over a 2 year period, that is, we observed them living their daily lives in settings common to all participants, as well as those that may have been particular to specific women. Typical settings across all participants included physician visits, family events, interactions with sexual/romantic partners and, for those women with children for whom they retained custody, interactions with children. Other shadowing situations, which depended on the circumstances of the individual participant, included hospital visits, appointments with mental health care providers, church gatherings, parties, nightclubs, their own and/or partners' injecting behaviors, and interactions with sexual clients. We also conducted semi-structured interviews each year for 2 years with a health care provider and a "critical other" designated by each participant. These interviews focused on their knowledge of the participant's circumstances, including her romantic and sexual partners; substance use; mental illness symptoms; use of prescribed medication; friendships; sources of support; and ability to manage the affairs of daily living.

Our use of these varied methods of data collection and our reliance on multiple sources of data allowed us to triangulate the data. We tape recorded these shadowing activities, with the exception of those in which the safety of the participant, the ethnographer, or others could have been compromised. In such situations, the ethnographer tape recorded the observations that she had during the visit after she had left the location of the shadowing. All study procedures were approved by the local institutional review board.

## Data Analysis

All tape recordings were transcribed in their original language; they were translated into English if they were originally recorded in Spanish. We established a codebook, based on both predetermined themes noted in the previously published professional literature and on perspectives that arose from the data, and assigned codes on a line-by-line basis using Atlas.ti 5.0 software. We created codes on a concurrent basis and assigned every paragraph in every transcription as many codes as was necessary to describe the contents of that paragraph accurately. This approach allows for an examination of the data for patterns, themes, and categories developed by the participants [57].

We utilized data from both our qualitative and quantitative approaches ("mixed methods") to understand the context in which our participants lived. Our mixed methods data analysis process incorporated data reduction, data display, data transformation, data correlation, data consolidation, data comparison, and data integration [57]. Data reduction involved exploratory thematic analysis of the qualitative data and descriptive analysis of the quantitative data. Data display involved describing the data pictorially using charts and networks for the qualitative data and tables and graphs for the quantitative data. We converted our qualitative data into numerical codes in order to represent the data statistically, that is, we *quantitized* the qualitative data [58]. The data correlation stage involved the correlation of qualitative data with any *quantitized* data. In the data consolidation stage, the quantitative and the qualitative data were combined to create new variables and a dataset for analyses. Finally, data comparison involved comparing data from the qualitative and quantitative data sources and data integration provided a means to integrate the two types of data into a coherent whole [57].

## Results

Table 1 displays the demographic and clinical characteristics of the participants. A few statistically significant differences were evident between those who are current substance users and those who are not. Individuals who are not current substance users were more likely to be Spanish-language dominant or monolingual in Spanish ( $p = 0.03$ ). They were less likely to report lifetime use of alcohol ( $p = 0.001$ ) or drugs other than cocaine, crack,

marijuana, or heroin ( $p = 0.03$ ). Consistent with their current nonuse of substances, their addiction severity score was significantly less for alcohol ( $p < 0.001$ ) and for drugs ( $p = 0.002$ ) compared to current substance users.

Although the ASI provides information regarding the severity of substance use, it does not say anything about personal experience or cultural context. Qualitative data analysis revealed two major themes: (1) women's explanations for their use or non-use of substances and (2) the relationship between substance use, violence, and HIV risk. These themes are reflected in the representative segments below. We use only pseudonyms in order to safeguard the participants' privacy and confidentiality.

### Use and Non-Use of Substances

At the time of the study, 51% of the women reported current use of alcohol or other substances. However, related questions on multiple assessment tools, shadowing, and observation of participants during interviews revealed that 58.5% were using alcohol and/or other substances at the time of their entry into the study. The frequency of participants' use ranged from rare use to daily consumption, while the quantity of their use also varied as widely.

No longitudinal trends in substance use were noted during the course of the study. In general, the women who were engaged in substance use at the time of their entry into the study continued to use during the course of the study, although the frequency, amount, and drug of choice may have varied depending on drug availability. Similarly, women who were not using substances at the beginning of the study remained nonusers throughout the study. One individual who had not been using heroin at the beginning of the study resumed its use during study participation. A second individual who had been using multiple drugs at the beginning of the study ceased all drug and alcohol use when she became pregnant.

Over the course of their lifetimes, 71.7% of the women reported ever using any substance; more than one-half had used marijuana and almost one-quarter of them had used cocaine and/or crack. (See Table 1). Four (7.5%) of the women had ever shared injection equipment with others and 1 (1.9%) had shared equipment during the 90 days preceding her interview. Ten of the women (18.9%) reported that during the 90 days preceding their baseline interview, they had had unprotected sexual relations with a man who they believed to have injected drugs or they had had unprotected sexual relations with multiple partners; 31 women (58.5%) reported having these experiences over the course of their lifetimes. Of the 35 women who completed all questions on the HIV knowledge questionnaire, 85.7% correctly recognized that cleaning needles with water was inadequate to protect against HIV transmission when sharing injection equipment. Almost one-quarter of the women (24.5%) had at some time been diagnosed with substance abuse or dependence.

More than one-half of the women (58.5%) had ever had unprotected intercourse with a partner who they believed may have injected drugs. Many of the women attributed their own substance use or that of their sexual-romantic partner to the influence of others around them. Hermosa and Wera are illustrative examples. Hermosa was a middle-aged, divorced woman with two children. Hermosa had few employment possibilities open to her as a non-English speaker with less than a high school education who was suffering the symptoms of bipolar disorder. Consequently, Hermosa subsisted on disability income. She had ceased her use of heroin approximately 1 year prior to her enrollment in the study, but began using again. She attributed her resumed heroin use to her new boyfriend's influence; he had encouraged her to use the drug with him. Crying, Hermosa said.

He was the one who gave it to me ... I thought nothing would happen and I would be clean in the morning. I am going to die soon. I am using and have liver problems ... 1 bag of heroin a day and 1 pipona [40 ounces of beer].

Like Hermosa, Wera had been born in Puerto Rico and was primarily Spanish speaking. A mother of two with little more than a high school education, Wera had been able to find and maintain part-time employment despite her diagnosis of major depression. Wera explained why her boyfriend was unlikely to stop using heroin:

It would be really hard [to stop using heroin] because almost his entire family uses ... When Agustin was a youngster he only smoked weed once in a while. On one of his birthdays his brother had him try heroin. Desde eso esta huckiao. [Ever since that he has been hooked.] From his own brother.

Wera did not recognize that, even though she did not inject drugs herself, she remained at increased risk of HIV infection due to her unprotected sexual relations with her boyfriend, who regularly injected and shared equipment with others. Hermosa, in contrast, was at risk both as a result of her own sharing of injection equipment and her unprotected sexual relations in exchange for drugs and/or money.

Many of the women talked about using substances as a way of alleviating the anxiety that was a part of their mental illness. Examples include Katia, a middle-aged woman who had been diagnosed with bipolar disorder many years previously. Katia explained, “*Weed [marijuana] calms me down so I won't get into shit. Coke [cocaine] gets your teeth all fucked up and I used to get paranoid when I did coke.*” Another participant remarked, “*Beer calms me down, so that is why I am drinking*”.

Others appeared to use drugs to avoid painful emotions. Katia attributed her drug use to her mother's relinquishment of her after her mother's boyfriend tried to kill her:

What mess me up is my mom giving me away. She doesn't love me. I love her ... Yes, she gave me away 'cause of her boyfriend. He wanted to kill me ... I went to the streets and started using drugs.

Some of the women realized that involvement with drugs, whether it was their own involvement or that of a partner, would only worsen their situation. Laurita, diagnosed with major depression, may have gained this insight as a result of her interaction with the larger world through her part-time employment, her 3 years of college, and her participation in her five children's activities. She observed about a friend of her then-current partner: “Ricardo has a friend that comes over. He injects drugs and I don't like that stuff ...It's stupid. You are never in reality. You are eating your brains out”.

### Substance Use and Violence

Two-thirds (68%) of the women had suffered partner violence during the course of their lives and almost one-third (32%) had suffered partner violence during the course of the study [59]. Partner violence interacted with substance use in ways that we had not anticipated. Osana had been diagnosed with major depression even before she became the target of partner violence. She had used drugs and alcohol herself at one time, but that was way in the past. The symptoms of her depression and her inability to speak much English stood as barriers to finding any kind of employment, and she relied on her social security checks to pay for her rent. Osana explained how her boyfriend had beaten her when she initially refused to withdraw money from her bank account so that he could buy a fix. Although she relented and withdrew the money for him, he nevertheless forced her to accompany him while he made the drug buy. Osana recounted that she tried to get away after he injected the drug, but he caught up with her and continued his violence:

He stabbed me with the needle on my hands and thighs. When I felt him stabbing me I thought about the lady he shared the needle with. I thought of her and how I would get AIDS. He already used the needle, had blood contact with this third person and now it's in my blood.

For many of the women, HIV risk was heightened as a result of the violence associated with substance use. Julieta, a young adult with a child of her own, recounted the events that led up to her rape and potential exposure to HIV:

Well, I went out to the bar and had a couple of drinks. I remember leaving the bar and going to my friends' house. Next thing you know I don't remember anything ... Thank God all the tests came back fine and I don't have anything. I went out with a group of friends and they said I was messed up ... They found condom residue so I'm glad a condom was used. Doctors gave me pills to prevent any STDs ... I don't remember anything.

## Discussion

This study utilized both quantitative and qualitative methodologies to identify and characterize substance use among SMI Hispanic women. Use of this type of combined data collection can not only identify the prevalence of substance use and its severity, but can also shed light on how clinicians and researchers can begin to address the enormous problem of substance use and HIV risk in this vulnerable population. This is the strength of the mixed methods approach; while the quantitative data indicate the existence of a problem, the qualitative data provide greater insight into how the problem might be addressed. The relatively high prevalence of substance use among our participants is consistent with previous research findings: up to one-half of all individuals with SMI may develop substance abuse or dependence at some point during their lives [60, 61]. Estimates suggest that 14.5% of individuals with bipolar disorder, 10.1% of people with schizophrenia, and 4.1% of those suffering from major depression also abuse substances [62].

It has been suggested that the use of substances may relieve the symptoms of mental illness that are inadequately controlled by medication, reduce the uncomfortable side effects of medication, facilitate the experience of emotions when they are lacking or muted, or help to control confusing emotions [63–65]. Several of the narratives provided here illustrate the widespread use of substances among our participants to relieve the symptoms associated with their mental illness, ameliorate unpleasant feelings, and deaden emotional pain.

Why an individual uses a particular substance depends on various factors, including cost and availability, the individual's income, the effort required to obtain and sustain the substance's use, and the degree to which others in the individual's network use that substance [66]. Our participants' choice of substance depended on the availability of particular drugs within the local area and the choice of drug(s) by their "critical others." Marijuana, crack, and heroin, widely available and relatively cheap, were the preferred drugs among those in our participants' networks.

The relative stability of participants' use or non-use of substances is likely attributable to the convergence of multiple factors, although the factors specific to each individual participant may vary. First, as indicated previously, there is a high prevalence of substance use among individuals diagnosed with severe mental illness [60–62]. The reasons for this have not been definitively identified, but may include inadequate control of mental illness symptoms. Additionally, the overall pattern of participants' life circumstances, such as the presence or absence of poverty, unemployment, ubiquitous violence, and social support, remained relatively constant during the course of the study. A trend towards greater or lesser

substance use might have been evident had there been a change in these factors that have been associated with use or non-use of substances.

Our findings are limited by a small sample size and a focus on relatively poorer participants situated in one geographical area. Nevertheless, they suggest that HIV prevention interventions for poorer Puerto Rican women with SMI must target both the individuals themselves and others within their networks if the women are to be supported in their efforts to reduce substance use-related risk. This suggests a role for interventions and approaches that target and are implemented in community-based rather than mental health or specialty settings, where stigma and access may limit opportunity to reach families and larger groups of individuals that make up the social support networks of Hispanics with SMI. Finally, the content of any intervention must focus not only on strategies to prevent HIV transmission, but must also address past and current trauma and its relationship to substance use and HIV risk.

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**Table 1**  
Demographic characteristics of a sample of severely mentally ill Puerto Rican women (N = 53)

Characteristic	Current substance use (n = 31) <sup>a</sup>		No current substance use (n = 22)		p-value
	N	%	N	%	
<b>Diagnosis</b>					
Major depression	13	41.9	17	77.3	
Bipolar disorder	14	45.2	3	13.6	
Schizophrenia	4	12.9	2	9.1	0.82
<b>GAF score<sup>b</sup></b>					
Median (range)					
<40	3	9.7	1	4.6	
40–49	2	6.5	0	0.0	
50–59	11	35.5	5	22.7	
60–69	5	16.1	10	45.5	
70+	10	32.3	6	27.3	0.47
<b>Present age</b>					
18–29	6	19.4	2	9.1	
30–39	11	35.5	7	31.8	
40–49	9	29.0	9	40.9	
50+	5	16.1	4	18.2	0.89
<b>Education</b>					
Median (range)					
Less than 12	18	58.1	10	45.5	
Completed high school	8	25.8	3	13.6	
Some college	5	16.1	9	40.9	0.25
<b>Marital status</b>					
Never married	7	22.6	4	18.2	
Married or living with partner	19	61.3	16	72.7	
Divorced or separated	5	29.0	2	9.1	0.90
<b>Number of children</b>					
None	3	9.7	2	9.1	

Characteristic	Current substance use ( <i>n</i> = 31) <sup>a</sup>		No current substance use ( <i>n</i> = 22)		<i>p</i> -value
	<i>N</i>	%	<i>N</i>	%	
1-3	19	61.3	15	68.2	
4-8	9	29.0	5	22.7	0.91
Employment status					
None	20	64.5	14	63.6	
Part-time	5	16.1	4	18.2	
Full-time	6	19.4	4	18.2	0.95
Primary source of income					
SSI or other public source	21	67.7	13	59.1	
Employment	8	25.8	7	31.8	
Partner/family member income	2	6.5	2	9.1	0.95
Place of birth					
Mainland U.S.	11	35.5	1	4.6	
Puerto Rico	19	61.3	21	95.5	
Other country	1	3.2	0	0.0	0.06
Primary language					
English	10	32.3	1	4.6	
Spanish	13	41.9	18	81.8	
English and Spanish equally	8	25.8	3	13.6	0.03
Lifetime substance use <sup>c</sup>					
Alcohol	27	87.1	8	36.4	0.001
Cocaine	8	25.8	5	22.7	0.41
Crack	5	16.1	6	27.3	0.76
Heroin	5	16.1	1	4.6	0.10
Marijuana	22	71.0	8	36.4	0.17
Other	5	16.1	0	0.0	0.03
Addiction severity <sup>d</sup>					
Drug range					
0-3	18	58.1	22	100.0	
4-6	10	32.3	0	0.0	

Characteristic	Current substance use (n = 31) <sup>a</sup>		No current substance use (n = 22)		p-value
	N	%	N	%	
7-9	3	9.7	0	0.0	<0.001
Alcohol range					
0-3	15	48.4	22	100.0	
4-6	10	32.3	0	0.0	
7-9	6	19.4	0	0.0	0.002

<sup>a</sup>Based on congruence between participant self-report and interviewer assessment

<sup>b</sup>Refers to Global Assessment Functioning, assessed by interviewer observation<sup>c</sup> scores derived from *Diagnostic and Statistical Manual*

<sup>c</sup>Percentages total more than 100 because of participant use of multiple substances

<sup>d</sup>Derived from interviewer's assessment of need for treatment on Addiction Severity Index, using a scale of 0-9. 0 signifies no use; 9 signifies situation is life threatening