# DEVELOPING A CULTURALLY SENSITIVE HIV PREVENTION INTERVENTION FOR SEVERELY MENTALLY ILL PUERTO RICAN WOMEN

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## HIV PREVENTION, SEVERELY MENTALLY ILL LATINAS PRIMARY OBJECTIVES

- To describe the HIV risk and prevention behaviors of Puerto Rican and Mexican SMI women ages 18 to 50 living in northeast Ohio and San Diego County, California
- To describe the context in which these behaviors occur

## HIV INFECTION AMONG SEVERELY MENTALLY ILL (SMI)

- Carey et al., 1995: study aggregating results across studies: 5% female SMI HIV+, 10% male SMI HIV+.
  - Estimated rate in general population 0.24-0.35% (Rosenberg, 1995)
- Carey et al., 1995; Cournos & McKinnon, 1997: rates among SMI range from 3%-23%, 8-70 times higher than national rates
- Among SMI, women at increased risk (Otto-Salaj et al., 1998)
- Literature suggests that Latinos among SMI may be at increased risk (cf. Cournos & McKinnon, 1997)
- 1993: NIMH declared SMI "AIDS risk group of particular concern"

#### FACTORS RELATED TO RISK AMONG SMI

- Severity and symptomatology of psychopathology
- Use of alcohol and drugs prior to sexual relations
- Relatively low levels of HIV-related knowledge
- Inaccurate perceptions of HIV risk
- Environmental factors influencing choices/decisionmaking

## SEVERITY AND SYMPTOMATOLOFY OF PSYCHOPATHOLOGY

- Severe cognitive deficits
  - Lower severity increases likelihood of being sexually active
  - Greater severity may reduce desire for sexual activity but increase likelihood of survival sex due to inability to manage resources; increase vulnerability to coercion (McKinnon, Cournos, Herman, 2001)
- Affective instability
- Behavioral impulsivity
  - Correlation between higher excited symptoms and number of sexual episodes (McKinnon, Cournos, Herman, 2001)

#### PERCEPTIONS OF HIV RISK

- Little fear of HIV (Sacks et al., 1990)
- Low perception of personal risk (Carey et al., 1997)

#### **ENVIRONMENTAL FACTORS**

- Homelessness, as high as 45% (Kalichman, 1994)
- High prevalence among homeless SMI, as high as 19% (Susser et al., 1993)
- Sexual relations transient, casual, offered in exchange for shelter, food (Kalichman, 1996)

#### STUDY DESIGN

- 75 women of PR ethnicity from northeastern Ohio (Ashtabula, Cuyahoga, Geauga, Lake, Lorain, Medina Counties):
- Diagnoses of schizophrenia, bipolar disorder, major depression
- 15 women of Mexican ethnicity from San Diego County
- 50 women of Mexican ethnicity from northeastern Ohio, matched to SD women by diagnosis, age +/- 7 years
- Recruitment through social service organizations, social clubs, participant referral, vocational programs, churches
- Baseline interview with each participant
- Each year for 2 years
  - Interview with participant
  - Interview with "Critical Other" identified by participant
  - Interview with key informant in provider network identified by participant
- Up to 100 hours shadowing each participant over 2 year period; critical events

#### SOURCES OF DATA

- Shadowing with participants, including shadowing during interactions with providers
- Interviews with critical others
- Provider interviews

#### DATA ANALYSIS

- Shadowing activities tape recorded, transcribed, translated, coded (80-85% agreement on assigned codes)
- Data examined for patterns, themes, and categories that were both preformulated and that arose from data

#### DEMOGRAPHIC FINDINGS

- 75.5% born in Puerto Rico
- Mean age = 32.6 years
- 52.8% has <12 years school</li>
- 52.8% depression, 35.8% bipolar disorder, 11.3% schizophrenia
- 64.2% unemployed
- 54.7% SSI as primary source of income
- 54.7% Spanish as primary language

#### RESULTS

- 35.8% listen to music regularly
- Four themes:
  - The importance of music
  - The use of music to reflect emotion
  - The use of music to change energy level, mood, or thought pattern
  - Type of music preferred

#### **EXAMPLES**

- The importance of music
  - "One thing I love is music. I love music. I can't live without music." (Participant 118)
- The use of music to reflect emotion
  - "I listen to a song called 'Se me rompe el alma ['My soul is breaking'] all the time because that is how I feel." (Participant 102)
- The use of music to change energy level, mood, or thought pattern

Purchase of nature CD to help relax (Participant 135)

- The type of music preferred
  - Spanish
  - Salsa; Younger participants preferred reggaeton
  - High volume

#### CONCLUSIONS

- Music may be an important coping resource among Puerto Rican women with SMI
- Music may allow individuals to articulate emotion and facilitate emotional processing
- Music volume and content may assist in increasing energy levels and optimizing functionality
- Findings consistent with past research demonstrating improvement of core symptoms of mental illness with use of music
- Integration of culturally appropriate music into HIV prevention program for SMI Puerto Rican women may
  - Modify affect and facilitate the expression of feeling and interaction
  - Permit verbal processing of the effect of music
  - Apply musical experience to issues of concern in daily lives
  - Facilitate the expression of personal experiences and emotion in order to promote learning and enhance insight into risky behaviors

#### **CONCLUSION 2.**

- The majority of HIV prevention interventions developed to date for Latinos have not integrated critical aspects of the relevant culture into their approach.
- HIV prevention interventions developed for SMI populations have generally not considered cultural elements as components of the intervention approach.
- We recommend that HIV prevention interventions for SMI populations be tailored specifically to encompass cultural elements and to address the unique learning needs of individuals with SMI, in an effort to reduce disparities related to HIV risk within a population that is dually impacted.

#### LIMITATIONS

- Small sample size
- Limited geographic area
- Focus on severely mentally ill of particular ethnicity and with lower levels of education