Published in final edited form as:
Soc Sci Med. 2008 August ; 67(3): 389–397. doi:10.1016/j.socscimed.2008.03.013.

Church ladies, good girls, and locas:

Stigma and the intersection of gender, ethnicity, mental illness, and sexuality in relation to HIV risk

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Abstract

Inner city women with severe mental illness may carry multiple stigmatized statuses. In some contexts these include having a mental illness, being a member of an ethnic minority group, being an immigrant, being poor, and being a woman who does not live up to gendered expectations. These potentially stigmatizing identities influence both the way women's sexuality is viewed and their risk for HIV infection. This qualitative study applies the concept of intersectionality to facilitate understanding of how these multiple identities intersect to influence women's sexuality and HIV risk. We report the firsthand accounts of 24 Latina women living with severe mental illness in New York City. In examining the interlocking domains of these women's sexual lives, we find that the women seek identities that define them in opposition to the stigmatizing label of "*loca*" (Spanish for crazy) and bestow respect and dignity. These identities have unfolded through the additional themes of "good girls" and "church ladies". Therefore, inspite of their association with the "*loca*", the women also identify with faith and religion ("church ladies") and uphold more traditional gender norms ("good girls") that are often undermined by the realities of life with a severe mental illness and the stigma attached to it. However, the participants fall short of their gender ideals and engage in sexual relationships that they experience as disempowering and unsatisfying. The effects of their multiple identities as poor Latina women living with severe mental illness in an urban ethnic minority community are not always additive, but the interlocking effects can facilitate increased HIV risks. Interventions should acknowledge women's multiple layers of vulnerability, both individual and structural, and stress women's empowerment in and beyond the sexual realm.

Keywords

mental illness; stigma; sexuality; ethnic minority; HIV; gender; USA; latina women

Main text

The past 25 years of the AIDS epidemic have demonstrated that people who are vulnerable to gender inequality, racism, and stigma carry the greatest burden of disease and death (Farmer,

1997). People with severe mental illness (SMI) exemplify one such group. In the United States, HIV prevalence in samples of people with SMI is much higher than the general population (McKinnon, Cournos, & Herman, 2002). High rates of coercive sexual encounters, unprotected sex with high risk partners, and exchange sex contribute to risk for women with SMI (Meade & Sikkema, 2005). A focus on individual characteristics alone has not successfully curtailed the epidemic in vulnerable women. The need persists for HIV prevention approaches that take into account their multiple contextual risks.

The stigma related to mental illness may be another contextual factor that contributes to HIV risk. Women who develop schizophrenia, bipolar disorder, and other severe mental illness (SMI) inherit a legacy of marginalized and stigmatized sexuality. Examples at a structural level include state-sanctioned sterilization and institutional practices that prioritize reproductive control over HIV prevention (Collins, 2001; Stern, 2005). Women's internalization of stigma related to mental illness can also have grave social consequences. Expectations of rejection can lead to reduced confidence and impaired social interactions, constricted social networks, low self-esteem, depressive symptoms, unemployment and income loss (Link, Cullen, Struening, & Shrout, 1989; Link, Struening, Rahav, Phelan, & Nuttbrock, 1997; Rosenfield, 1997; Wright, Gronfein, & Owens, 2000). Individual discrimination experiences, structural discrimination in the treatment setting, and sociopsychological processes such as feeling devalued and withdrawing from others can affect options for sexual relationships (Wright, Wright, Perry, & Foote-Ardah, 2007). It is plausible that some of these options for women with SMI may lead to greater HIV risk. Given the evidence for stigma's association with low self esteem, one might expect that women with SMI would perceive themselves as less desirable, have less power in relationships, and may be more likely to engage in sexual encounters of greater risk, involving unprotected sexual intercourse. In a quantitative assessment of women with SMI, Collins et al. found a relationship between experiencing mental illness stigma and several correlates of HIV risk: using alcohol or other substances before sex, having multiple sex partners, and exchanging sex for money or goods (Collins, Sweetland, & Zybert, 2007).

Stigma, Intersectionality, and Contextual Risk

Current conceptualizations of stigma processes note that stigmatization occurs in the context of social forces that are mobilized to create and maintain specific dynamics of power (Link & Phelan, 2001; Parker & Aggleton, 2003). Feminist theorists have explored the ways in which systems of oppression related to gender, class, race/ethnicity and sexuality interact (Collective, 1983; Collins, 2000; Lorde, 1984). The concept of intersectionality has been used to understand these complex systems of multiple identities and oppressions (Crenshaw, 1994; Stewart & McDermott, 2004). Intersectionality holds that "people must be located in terms of social structures that capture the power relations implied by those structures" (Stewart & McDermott, 2004). The concept presumes that systems of power/oppression (that create differences along the axes of race, class, gender, and sexuality) are interlocking, and their effects can only be explored by taking all of these dimensions into account without prioritizing one form of oppression over another (Collins, 1999). For example, women's sexuality is limited by oppressive gender norms that propose a dichotomy of "asexual, moral women who are to be married, and their sexual, immoral counterparts…"(Collins, 2000). Ethnic minority women are further subject to sexualized stereotypes, a phenomenon described as "sexualized racism" (Collins, 2000). These stereotypes cast African American women as promiscuous or and Latinas as sexually available and desirable (Valdivia, 2000).

To determine the constellation of HIV risks for an unemployed, black, Dominican woman with bipolar disorder one must explore how and where these identities intersect to shape this woman's personal experience. Conceptualizations of stigma and intersectionality both would suggest that multiple systems of power are at work. These might include laws that determine

access to welfare, Medicaid, or housing; rules in a residential facility that govern sexual activity; traditions in a local community that privilege male sexual desire and power; or a community's reinforcement of stereotypes of women who are black and Latina with mental illness as having uncontrollable sexual urges or dangerous aggression. The question is how these intersections of race/ethnicity, gender, class, status and the stigma of mental illness influence women's sexual relationships and HIV risk.

This paper analyses the accounts of impoverished Latina women living with mental illness in New York City, many of whom are immigrants. In the women's stories, the effects of gender, race/ethnicity, poverty, and immigrant status on life experiences and behaviors cannot be meaningfully separated, thereby lending themselves to an intersectional analysis. We illustrate the intersecting effects of these aspects of identity on women's sexual lives and HIV risk through the themes *"locas"*, "good girls", and "church ladies."

METHODS

Sample

We recruited women age 18 and older from two community mental health clinics in New York City to participate in Project Wisdom, a study of HIV prevention for women with SMI. In this first phase of Project Wisdom, we conducted qualitative interviews to elicit women's perceptions of their mental illness and its impact on their sexuality. The research team visited each site and met first with the staff. We later met with women receiving services to describe the study during community meetings. We recruited a convenience sample of 32 women with serious mental illness who used services at these two sites.

Data Collection

Four female interviewers of Latina, African American and European American descent conducted face to face, qualitative interviews in English and Spanish. The team used an interview guide to ensure that the same topics were covered with each participant, including 1) women's perceptions of their mental illness, 2) and the impact of their mental illness on their (hetero)sexuality, 3) the quality of their sexual relationships, 4) experiences of stigma and discrimination, and 5) the relevance of their ethnicity to their experiences of mental illness, discrimination, and sexuality. Women were interviewed when they expressed interest in the study and had the capacity to give informed consent. A treating psychiatrist assessed women for medical and psychiatric clearance and documented their capacity to give informed consent. Participants received $20 for completing two 90-minute interviews. The majority of women completed two to four interviews totaling three hours. All interviews were audio-taped and transcribed.

Qualitative Data Analysis

We conducted a qualitative analysis of the interview data guided by a modified grounded theory approach (Charmaz, 2002; Strauss & Corbin, 1990). The transcripts were read multiple times. We developed case summaries of each interview, which enabled us to distinguish the participants' biographies and to capture the most salient aspects of the interview content. We then conducted a detailed indexing of the interviews, organizing them according to major topical areas. As we reviewed these topics, we refined the focus of the analysis to examine the relationship between the stigma of mental illness and ethnic minority membership and sexuality. We then conducted open (line-by-line) coding, accompanied by memo writing on emergent themes. We grouped themes into categories during discussions among the research team members. The data were also subjected to the constant comparative method both as a method of analysis and to increase the validity of the study results (Charmaz, 2000). Additional measures taken to increase the validity of the study results included engaging in critical peer

review and alternative interpretations (team discussions), active seeking of disconfirming evidence, a strategy entailing the rigorous examination not only of the supporting data that our conclusions are based on, but also of discrepant data and deviations from the main story lines (Maxwell, 2005). From this process we arrived at conclusions about how stigmatization experiences relating to mental illness and participants' experiences as impoverished ethnic minority women affect their sexuality. Three of the main themes that emerged from the data — "*locas"*, "church ladies", "good girls"—are presented in this article. The current paper focuses on the experiences of the 24 participants who identified themselves as Hispanic, "Spanish" or Latina.

RESULTS

Demographics

The women ranged in age from 24-64 years, with a mean age of 42.6 years. Among the 24 Latinas, 15 were Dominican, 7 were Puerto Rican, 1 was South American, and 1 of mixed ancestry. The majority of the women (79%, N=19) were first generation immigrants or migrants (in the case of some Puerto Rican participants) and primarily spoke Spanish. The remaining were born to (im)migrant parents. Seventy-five percent (N=18) of the women had children. Seventeen women (71%) lived with family members or male partners, three lived alone in apartments or supervised residences, and four lived with non-relatives. The participants were mainly unemployed and received government entitlements. Five worked part-time in mental health programs.

Eleven women were in heterosexual relationships at the time of the interview. Of those not currently in a relationship, 9 out of 13 had been previously partnered or in dating relationships. Fifty percent of the women report past physical or sexual abuse by their partners or family members, including rape. One-third of the women describe potential risk for sexually transmitted infections (especially lack of condom use with casual, non-monogamous partners and known or suspected infidelity of their current or past steady partners).

Social Context

Community mental health clinics—The interviews were conducted in two community mental health clinics located in urban neighborhoods with large Latino populations. Men and women with mental illness attended the clinics for psychiatric services, including psychotherapy, medication management, and therapeutic and educational group interventions. Many of the study participants had attended the clinics for several years and viewed the clinic staff and other patients as important members of their support system and social network. Some women attended the clinics multiple times per week to participate in day treatment programs, whereas others attended monthly for prescription renewal and supportive therapy.

Community—The community surrounding the clinics was hard hit by the crack epidemic in the 1980s. The area remains a center for drug trafficking organizations (NDICDEA, 2002). AIDS is the third most common cause of death after cancer and heart disease (NYCDOH, 2005). Nearly one-third of the residents live in poverty. Spanish is widely spoken on the street and in shops. Women's lives were largely confined to this community, and only a few women reported activities that took them outside.

(Im)Migration Experiences—Women's stories were often intertwined with (im)migration experiences. Participants or their families came from the Dominican Republic, Puerto Rico, and other Spanish speaking countries. Most had lived in poverty with limited opportunities for education. They were employed in factories or private homes as domestic workers. Others, with greater means had operated small businesses. For several women parenthood at a young

age had led them into deeper poverty; some formed partnerships with men because they offered an opportunity to emigrate. Many participants expressed dismay at the violent urban neighborhoods, social isolation, cramped apartments, and demanding work schedules of New York. An older woman lamented the loss of community and the sense of being cared for by neighbors and friends that she experienced in her home country. But the US brought advantages, also. One woman explained, "We continue being poor, but, more comfortable. There's more of an abundance of things than one had there." (Gina)

Among the resources women encountered in New York were entitlements for people with disabilities and access to community mental health care. Symptoms of mental illness kept many women out of the job market, locking them into poverty. When unable to continue working, they obtained Supplemental Security Income (SSI) and access to housing programs for people with disabilities. Yet, for those women whose dreams of a better life in the United States were derailed by the onset of psychiatric illness, the inability to work and earn money added to the pain of living with a mental illness.

For many of the migrants and immigrants, arrival to New York also brought a new status as an ethnic minority. The women resist being categorized as "delinquents" or drug users, categories they associate with minority groups in the US. When sent to a hospital outside the neighborhood, one participant complains of rude treatment and insists that she is a decent, reliable woman and not a drug addict. Another visits a church outside of her neighborhood and takes care that her own behavior is tactful and "obedient" and that she does not "go above herself." She distinguishes between the behavior of white Americans and non-white Americans and expresses shame at other Latinos from her country who do not abide by the laws of the US.

Within the community, there are local ideas of race and beauty that prize lighter skin and straight hair. Women recount stories of fathers who punished their daughters for marrying darker men or *negros;* tensions between darker, poorer branches of a family, and whiter, more affluent relatives; friends who marvel at the beauty of a child born with light skin, blue eyes and blonde hair; or perceived rejection of their own dark skin by in-laws with "good hair" (*pelo bueno*). Some reject these ideas, but admit that their relatives' ideas about race have influenced their actions in relationships. While women incorporate these experiences into their stories of relationships, few explicitly acknowledge experiencing race/ethnicity-based discrimination in New York.

Mental Illness

Psychiatric diagnoses, obtained from a review of medical charts, included schizophrenia spectrum disorders and other psychotic disorders (N=14); bipolar disorder (6); and major depression (2) with psychotic features (2). The most recent diagnosis had occurred six years before the interview, and several women had lived with their illness for 20 years or longer. Mental illness, for many, had played a significant role in the trajectories of their lives, leading both to gains and losses. We describe the theme *"locas"* and delineate three subthemes: attributions of illness, defining *"loca"*, and relationships in the setting of mental illness.

"Locas"

The onset of illness frightened and perplexed most women. They did not understand what they were experiencing, and several hid their early symptoms until the increasing severity drew the attention of friends and family. Their suicidal tendencies, paranoid delusions, and manic impulsivity evoked sympathy and protectiveness, but also impatience, avoidance, and scorn from those around them. In retrospect, women attributed their illness to the death of loved ones in adulthood; loss of relationships with, or discovery of deceit by husbands and boyfriends;

unintended pregnancy; the stress of life in the United States (lack of money and work; social isolation); the stress of (im)migration; and traumatic childhood events (being orphaned, unstable family environment). Others had been told by their doctors that the mental illness was hereditary or linked to a childhood illness. Some understood their illness as a natural result of difficult circumstances and explained that anyone in these circumstances might have formed the same psychological response.

Defining *"loca"*—The work of making sense of the illness often occurred in the context of treatment. Most women valued the treatment they received at the clinic, and strived to remain well. Regular clinic attendance and management of their symptoms distinguished them from other women perceived as crazy or *"loca"*. In contrast, they described themselves as women living with a mental illness. While *"loca"*, according to a Dominican participant, could describe a young woman who "doesn't behave well, dances a lot, goes out a lot," women particularly resented a different set of meanings that others applied to them. The *"loca"* was disorganized, messy, dirty, stupid, unpredictable, dangerous, out of control, and out of her mind. A *"loca"* was rejected and looked down upon. *"Loca"* acts as a label for a specific form of "craziness" that contradicts gender expectations. It is thus a gendered term with sexual connotations implying a status of 'less than woman'.

Susana explains the stigma of mental illness in general:

> People don't understand the illness. They think that you're *loco*, that you can burn the house down, you're an out-of-control *loco*. That's the mental illness that people know. People know mental illness in its extreme. A *loco* can shoot someone on the train…can hurt someone…People don't know the degrees of mental illness, that there are people who can control themselves when they're on their medication, that one can [live] an almost normal life. (Susana)

Women acknowledged their own experiences of loss of control, sometimes even using the term *"loca"* to describe themselves, but at the same time emphasizing the ways in which they were not *"loca"*. As *"locas"*, women were not expected to function as "proper women": to get married, to raise their children, to work, to have a career, or to maintain a home—to achieve the goals that many women immigrated for and that others expected would be part of their lives. While many believed that this was a stereotypical view of women with mental illness, others felt their lives reflected this incapacity.

Relationships and *"Locas"*—Although a small number of women believed that having a mental illness had no effect on their relationships, the majority of women believed that having a mental illness reduced a woman's opportunities for relationships and marriage. Some participants specified that this was particularly true for women with visible medication side-effects and those who "talk to themselves" or "speak foolishly". Women's personal experiences indicated that their mental illness sometimes threatened their chances to start or maintain a relationship. Women who were already in relationships when they first developed symptoms reported a range of reactions from their partners. Some men were supportive and made sure their wives adhered to their medication. During periods of acute illness they accompanied them to the hospital and visited them regularly. Others noted that men demeaned them as a result of their illness, calling them *"loca"* and dismissing their opinions.

Many who were not in committed relationships, but actively dating, believed that disclosing their illness would lead to abandonment. Linda, a 36 year-old immigrant believes that men will not consider a woman with mental illness stable enough to start a family with. She agrees with this assessment and insists that "…no man who has his five senses is going to want a situation like this for himself or for his children." Another young participant emphasizes that men have "fantasies" about women with mental illness being dangerous: "like [what] if I go to bed with

this woman one night and this woman kills me…" (Renee). Renee reveals that she has recently started a relationship with a man, but has kept her illness a secret due to fears that he might leave her, "If I told all of my lovers that I have this problem, can you imagine? Then they would leave for one thing or another. They're all going to leave…."

Women also perceived psychiatric medications and their side effects as problematic. Linda associated taking medication with being *"loca"*. She never disclosed her illness to her ex-boyfriend, but believed that the sedation and weight gain associated with her medication may have played a role in his departure. In other cases, medications took away sexual desire. Laura despaired over her inability to function "as a woman", sexually, with her husband: "…I felt nothing, nothing, nothing…and the doctor told me that's the medicine." Although her partner was supportive, she was dependent on him for her home, and she felt vulnerable in the relationship. She remarks that he has not yet "thrown her out" and that she encourages him to seek another sexual partner.

Women's psychiatric symptoms could impair judgment so that, as Laura comments, "you don't know who you're going to go to bed with." Renee describes an unsafe sexual encounter with a stranger during an episode of illness and acknowledges the role the illness played in the act: "…when you're sick you do crazy things (*se cometen locuras*). I believe this was the most serious…it was something in the moment…a spontaneous thing." Symptoms could also create tension in a relationship. Cati, a middle-aged woman, implies that her symptoms contribute to her husband's infidelity and vice-versa. She laments, "…One of the things that led to my emotional state, to going to the doctor more, was that…at the same time that he helped me, he didn't help me because he was going with all these women…I knew he was going around with women and I suffered from that." Women with more severe (psychotic) illness talked about the tendency to fight when they were ill, or the need to "keep clean," "keep your appearance up", and "be out of the hospital, feeling healthy to relate to another person." Women with depression and negative symptoms of schizophrenia, on the other hand, described a tendency to avoid social and sexual interactions.

Intentionally or unintentionally, many participants chose partners who also lived with a mental illness. Rosalie, a young, sexually active woman dates a man she met at her clinic. Her own lack of a job makes her feel vulnerable to criticism and judgment by people without mental illness. Ultimately, her approach to her relationship with her partner is pragmatic. She acknowledges that she does not want to be alone, and she tolerates his symptoms with empathy, knowing that he will also tolerate hers. Neither Rosalie nor her partner likes to use condomsgiven his already impaired sexual functioning (a consequence of his medication).

The label *"loca"* captures the stigmatizing effects of living with a mental illness. Women's sexual relationships are affected in many ways. The symptoms and stigma of the illness, as well as the sexual side effects of the medication hamper women's chances of finding a partner and maintaining a satisfying sexual relationship. Some women fear that their symptoms also drive their partners to seek sex outside the relationship, which presents a possible HIV risk. Because many of the women struggle with low self-esteem, they are hurt by the rejection they experience. Some react by withdrawing from the romantic arena altogether while others settle for a partner who will stay with them. Women's risk of HIV infection can occur in the context of active psychiatric symptoms, lack of condom use (sometimes related to a partner's mental illness), and their partners' infidelity.

Good Girls

> "In the first place a woman must learn to be a good wife, after that a good mother, and take on her responsibilities: not only keeping the house clean [but] the education of the children, their behavior, having a good image so that the society can have a

> good image of them… That should be a woman's function, and she should also prepare herself and, better still, work to help to cover expenses." (Lisa)
>
> "I'm not complete; I'm not a whole woman… a man asks a lot of a woman: that she be a woman who can give them children, and what they ask most is that the woman has children with them, this is the most important…" (Helena)

The category of "good girl" encompasses the women's beliefs about gender norms and roles and reveals the impact of stigma at the intersection of gender, class and ethnicity. Although the mental illness shapes women's experience of their relationships and forces them to recognize how others viewed them (often unfavorably), they remain deeply influenced by the ideals of womanhood from their cultures of origin. Most participants describe being raised in settings where traditional gender roles predominated. Women's lives centered on the home and they were expected to enter into heterosexual marriage with their virginity intact, bear children, and raise them. Women distinguish between good women who remain in the house and the bad behavior of women "in the street." Women in the street are sexually demonstrative (e.g. kissing boyfriends in public) and available for men's use.

In several of the relationships described, men ruled the sexual domain, and women had little control over men's sexual urges and desires. Women could either meet their partner's needs for sex or watch him go to "the street" in search of women. Laura, an immigrant, explains, "A man is a man. If there is a woman who gives him the opportunity, the man takes it." She warns, "many marriages go to the street because the woman refuses to have sex with her husband." This negative portrait of men, consistent with stereotypes of Latin masculinity, contrasts starkly with the image of the "good girl" who does not assert her sexuality. Yet, when men were emotionally abusive, some women did assert themselves, and refused to have sex with partners they believed to be unfaithful. Women also believed that mental illness amplified the likelihood of abuse. Participants explained that in the clinic women could become victims of sexual predators and were particularly vulnerable when suffering from acute symptoms.

While some participants have very clear ideas of what it means to be a "good girl," in reality, they are usually not able to live up to this ideal. Many report being used as sexual objects by men, leaving them unable to fulfill gender norms with regard to virginity. As a result, they often have sexual experiences, but are rarely treated with respect and care by their male sexual partners. Illness also affects their appearance and care-taking abilities. Although most participants had children, the majority lacked custody rights because their children had been removed during the course of their illness. Not being able to have children or being unable to care for them was a source of pain and disempowerment for many. Mental illness placed them at risk of rejection or derision. While the "good girl" ideal can, in fact, never be achieved by these women (or others) striving toward the ideal seems particularly relevant for women with SMI. It serves to maintain dignity and counteract the stereotypes of promiscuity associated with the *loca*.

Rita, a middle-aged woman describes a relationship in which she feels disrespected. Her partner is a younger man who lives with another woman and visits Rita once a month to have sex. She suspects him of lying and complains that it is "not fair" that he is not taking her out on dates to the movies, etc. In the past, she has had a number of sexual partners, but she cannot recall ever being treated like a "lady," which would include being cherished and married. "I only found bad people (...) And they use you like garbage…to have sex with them, and they leave." (Rita) Rita is very critical of men and their behavior towards her. However, she has difficulties refusing their advances when they insist on having sex with her, but she would not say that she was "forced".

Clara's illness experience leaves her yearning for an intimate partner relationship. She recalls being warned that it might be difficult to find a husband after having a psychiatric illness. She marries a man who eventually becomes abusive, unfaithful, and uses drugs. Clara experiences the relationship as an example of her failure to live up to her ideal—to "keep her dignity." Instead, by tolerating the husband's infidelity and addiction she becomes "too loose." She allows herself to fall into a lifestyle that conflicts with her values. She explains:

> Sometimes I'm kind of blind to the fact...that it's not going to work out and you just persist like it should work out, it should work out… because you want it to work out so bad. …It takes sometimes a while to see because you don't want to be lonely, without a companion... It takes a while to realize that…You feel disturbed and confused and you don't know how to say the right thing… And, then when you're having an argument… he wonders why you're acting like that--what's wrong with you--and it's hard for you to explain because you don't understand. You're in the state of symptoms and you wish you could get out of it and you don't know how… But… there's no way out. You have to go back to the doctor, pray, do something. There's no way out. (Clara)

Clara's status as a woman with mental illness leads her to believe that she may not have many opportunities for relationships, and she neglects her personal beliefs in the course of the relationship. Her "blindness" is further complicated by not knowing "how to say the right thing," and the "state of symptoms"—over which she has no control--keeps her from fully exercising that responsibility in the way she would like. She expresses deep regret for the loss of dignity that follows.

While the theme "good girls" captures women's more conservative gender norms and ideals, not all participants aspired to the values of a "good girl." One 27 year-old participant routinely defies her husband by spending time "in the street" with other women rather than remaining in the house doing domestic duties. Another woman secretly seeks and maintains a sexual relationship outside of her marriage after her mental illness creates distance in her relationship with her husband. Patricia, a participant from the Dominican Republic, is highly critical of the gender system and refuses to play a part in it:

> Dominican men are always in the street. You're not going to see a woman, you'll just see men. And where are the women?…In the house watching soap operas. The husbands with a beer watching all the behinds of the women that pass by. My God, for that [reason] I'm going to stay single. I can't put up with that. Then, the poor women, alone there slaving away with the children. At times I see women with three small children: one, two, three with a stroller, and I say where is the husband? That situation—I can't put up it that. (Patricia)

Church Ladies

How do women regain a sense of power in the midst of an illness that strips them of control? Many of the study participants asserted that personal faith, religion, or church communities provide them with a source of strength. They spoke of the healing power of prayer and mentioned the Bible as a source of moral values. The theme "church ladies" describes an identity that many of the women perform which helps them cope with the unpredictability and stigma of mental illness. Clara explains:

> …I never lost faith, I felt God helped me. 'Cause with the illness I just need God because you are alone… and people on the outside world they can't see it that way and sometimes you can't define what you are going through inside because it is so scary like sometimes you hear these evil things. You know it's just terrible, it's like

> a darkness…You can't lose faith. It's a danger to lose faith because the doctors are--they can help so much, but they can't get inside of you. (Clara)

Gina, a 59 year old woman who became severely depressed in middle age states that religious life has become the mainstay of her strength. She asserts that faith is the ultimate source of healing for mental illness declaring, "the only thing that heals is faith in God and prayers..." She attends Bible studies, recites Psalms when she needs strength, and prays for herself and the members of her family. When faced with the disorder of her illness and the humiliating infidelity of her husband, she describes her active search for support in the church as an empowering activity: "…I took care of myself…I put myself in church…and look, I'm still here…I don't know what I have [in] this bad illness, but the *only* bad thing I have is the illness of depression."

Beatriz, a 51 year old woman with chronic psychosis looks forward to the day that God will "change the system" and rid the world of mental illness. She describes the combined action of her medication and God's power in enabling her to resist the desire to kill herself or kill the man included in her delusional ideas. She comments, "…God is much bigger than he is. God made the world. Why would I go to prison for [this man]?"

For devout women, religion imposes limits on sexual behavior and provides a cloak of respectability in the chaos of psychiatric symptoms. These women eschew sexual activity and describe their commitment to God, their submission to God's will, and some describe their fear of punishment if they engage in sexual activity. Other women in the clinic perceived them as unlikely to engage in relationships with men. A 44 year old participant observed: "What I've noticed since I've been coming to the clinic, is that a lot of women…either they're too much into their religion and they can't see a man because their religion don't--it's not that they don't permit it--but, they're too much into their religion so they can't ." (Ruth)

Other women, though they describe their reliance on prayer, remain sexually active regardless of marital status. For these women, their belief in God remains a source of comfort, and their faith in prayer helps them cope with poverty and mental illness. Religious beliefs, thus, do not predict a particular approach to sexual behavior. Similarly, the relationship between this theme and HIV risk is not one-dimensional. On the one hand, religious beliefs and activities represent a source of support for the women, which may indirectly help them protect themselves from HIV-related risks (e.g. by abstaining from sex and engaging in self-care). On the other hand, for some participants, HIV risk occurs in the context of marriage to men who were unfaithful.

DISCUSSION

Our study uses qualitative interviews to explore women's perceptions of how mental illness affects their sexual relationships and the likelihood of engaging in sexual risk behavior. The data show that women's experiences of their mental illness and its meaning in the sexual realm are closely intertwined with their experiences of immigration, poverty, race/ethnicity and gender. The data thus support an intersectional analysis that takes into account the broader life circumstances and interconnected identities of the women when trying to understand their HIV risks in the context of living with mental illness. The themes, "*locas*", "good girls" and "church ladies" illustrate some of the main patterns described by the participants.

Our data show that women internalize *and* resist the stigma attached to mental illness in their communities by aligning themselves with identities that bestow dignity and respect. Most participants used faith in God and prayer as tools for coping with their difficult circumstances. Our findings are consistent with other research on religious coping among Puerto Rican women with SMI (Loue & Sajatovic, 2006). Second, immigrant status, being Latina, being poor, and espousing traditional ideas about gender roles, race, and color can add to the difficulty of

managing sexual relationships in the setting of mental illness. Women whose poverty leads them to depend on a man for housing, whose immigrant and monolingual statuses lead to relative confinement to the community, whose ethnicity leads to a preference for a relationship with a Latino man, but whose mental illness leads the man to seek sex outside the relationship, provide an example. Third, women's HIV risk occurs through a variety of situations. Sexual risk occurred when they were in monogamous relationships with men who were unfaithful; when they experienced sexual abuse; when their loneliness and desire for relationships, combined with their symptoms, prevented leaving a risky relationship; when symptoms impaired their judgment; and when they engaged in unprotected intercourse without knowledge of a partner's serostatus.

These sexual risks resemble those of other urban, impoverished women of color who do not have a mental illness (Wyatt, Myers, Williams, Kitchen, Loeb, Carmona et al., 2002). However, at this intersection of female gender, Latin ethnicity, migration experiences, and low socioeconomic status in an urban community, women's mental illness brings with it a special set of meanings and effects in the sexual realm. The stigma attached to their illness places the women in conflict with gender norms in their ethnic communities and indirectly increases their HIV risk. Due to the stigma, the women lose social standing, self-confidence, and leverage in terms of negotiating the conditions of their sexual relationships. As women with a mental illness, they are no longer perceived as able mothers and wives. Male partners are often not interested in a committed and respectful relationship with them; instead, the women describe feeling disrespected and used as sexual objects with little power to insist on safer sex. The social structures and institutions of mental health care in their urban neighborhood, however, can have protective effects in terms of HIV risks. Here, women find social support and health-related information. On the other hand, the clinic provides opportunities to meet partners who also live with a mental illness and may themselves engage in HIV risk behaviors.

The concept of intersectionality proposes that the intersections of the multiple axes of differentiation (related to gender, race/ethnicity, class, and in our case diagnosis of a mental illness) do not have additive effects. The accounts of the participants in this study suggest, however, that living with a mental illness amplifies existing power inequalities in the intersection of gender, race/ethnicity and class and weakens the status of the women within their families and relationships. In other words, women who live with a mental illness perceive their illness as a disadvantage that lowers their social standing and sense of power as compared with other women in their communities who do not have a mental illness. On the other hand, there are also non-additive, contradictory effects at the intersections. For many women the illness makes financial stability and relative independence attainable through government entitlements and housing support for disabled residents. These benefits may also allow them to live free from the influence of abusive male partners.

Limitations

Our study has several limitations: the sample size is small, and we are unable to present adequate comparisons with mentally ill women of other races or ethnic backgrounds or with women of similar immigration, gender, and ethnic experiences but without a mental illness. Furthermore, the study participants were in treatment, and most were between 40 and 60 years of age. Accounts of younger Latinas and those in less stable situations might reveal other salient themes. Nevertheless our study participants shed light on the complex interconnections between gender, race/ethnicity, class, and the stigma of mental illness and its implications for women's HIV risk.

We also noted that, while women shared many experiences related to gender inequality and the stigma of mental illness, few participants acknowledged experiencing racial discrimination. Other studies of ethnic minority groups suggest that the salience of race/ethnicity in daily life

depends on “social contact beyond the boundaries of the immediate neighborhood.” (Young, 2004). Women’s relative confinement to their neighborhoods may have reduced opportunities for discrimination based on ethnicity on a daily basis. It is also possible that women may minimize personal experiences of discrimination even when acknowledging discrimination toward the group (Crosby, 1984).

Implications for Sexual Health and HIV Prevention

Our findings suggest that HIV prevention activities conducted in mental health settings must first acknowledge women’s sexual desire; needs for respect, intimacy, and emotional support; and the barriers that gender oppression, poverty, and mental illness place before them in their communities. Ideally, prevention activities would target the institutional level (the clinic), the individual and interpersonal levels, and the community. At the institutional level, the familiar setting of the clinic can be used to create an environment that is safe and respectful of women’s sexual needs. To do so providers must be comfortable discussing women’s sexual lives and the relationships between sex, symptoms, stigma, and economic need. Barriers to such conversations must be addressed. At the individual level, behavioral interventions focused on sexual risk can include new modules on stigma and its impact on relationships as well as relational styles that gently challenge gender oppression. At the community level, participatory research and advocacy may help to initiate change.

Our research team developed the curriculum, “Ourselves, Our Bodies, Our Realities” with the goal of increasing women’s autonomy in sexual encounters by introducing female-initiated methods of HIV prevention in addition to the male condom (Collins, Geller, Miller, Toro, & Susser, 2001). Role plays facilitate negotiation skills, and participants are encouraged to share personal relationship experiences and receive support for making choices to leave abusive relationships. Culturally sensitive examples are used for discussing barriers to safer sex and group discussions are meant to foster a sense of empowerment and self-respect. Previous interventions targeting women with SMI have incorporated assertiveness skills (Weinhardt, Carey, Carey, & Verdecias, 1998). Useful additions could include sessions that enable women to assess their gender role attitudes, weigh their success in attaining their ideals, and work with their peers to reframe ideals that capture the strengths they display in their current circumstances. Similarly, sessions that utilize problem-solving around stigma management in relationships could be integrated. Stigma reduction activities that support self-esteem may help decrease women’s vulnerability to dangerous relationships. Moving interventions from the individual focus to the interpersonal by including women’s partners would permit couples to work toward satisfying and safe sexual relationships.

As the current study shows, women’s HIV risk is embedded in contextual factors that also need to change. Ensuring women’s access to economic self-sufficiency is one priority. In the community other goals would include increasing women’s power and challenging stigma related to mental illness. Creative integration of advocacy for people with mental illness into advocacy efforts of relevance to broader groups of women and immigrants might enable women with SMI to enlarge their networks of support and engage others in anti-stigma efforts. The role of faith-based organizations in advocacy efforts should be explored. Finally, access to mental health services is critical. The participants in this study received important benefits through the clinic services. These services were located in their neighborhoods, provided treatment in their language of choice, and helped women redefine themselves as people with mental illness, rather than *“locas”*.

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