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## Perceived mental illness stigma, intimate relationships and sexual risk behavior in youth with mental illness

Katherine S. Elkington, Ph.D.<sup>1</sup>, Dusty Hackler, MA<sup>2</sup>, Tracy A. Walsh, BA<sup>1,4</sup>, Jessica A. Latack, MS<sup>3</sup>, Karen McKinnon, MA<sup>2</sup>, Cristiane Borges, MD<sup>2</sup>, Eric R. Wright, PhD<sup>5</sup>, and Milton L. Wainberg, MD<sup>1,2</sup>

<sup>1</sup>HIV Center for Clinical and Behavioral Studies, New York State Psychiatric Institute (NYSPI) and Columbia University, NY, NY

<sup>2</sup>Columbia Mental Health HIV Training Project, New York State Psychiatric Institute, NY, NY

<sup>3</sup>Department of Psychology, State University of New York at Stony Brook, NY

<sup>4</sup>Mailman School of Public Health, Columbia University, NY, NY

<sup>5</sup>Department of Public Health, IU School of Medicine, Indiana University-Purdue University Indianapolis, IN

### Abstract

The current study examines the role of mental illness-related stigma on romantic or sexual relationships and sexual behavior among youth with mental illness (MI), including youths' experiences of stigma, the internalization of these experiences, and the behavior associated with managing stigma within romantic and sexual relationships. We conducted in-depth interviews with N=20 youth with mental illness (MI) (55% male, 16-24 years, 75% Latino) from 4 psychiatric outpatient clinics in New York City. We conducted a thematic analysis to investigate shared experiences of MI stigma and its impact on youth's sexual or romantic relationships and associated behaviors. Our analysis revealed four main themes: 1) societal perceptions of those with MI as partners (societal stigma); 2) individual experiences of stigma within relationships (individual level); 3) internalized stigma of self as a partner (social-psychological processes); and 4) managing a stigmatized identity, of which some of the behaviors directly placed them at increased risk for HIV. We found that just under half of the sample (n=9/20) endorsed all themes, including engaging in HIV/STI sexual risk behaviors as a method to manage a stigmatized identity, which suggests that MI stigma and sexual risk may be linked. We discuss differences by gender and diagnosis. Findings provide new information for providers and researchers to address on the role of stigma experiences in the romantic and sexual behavior of youth in psychiatric treatment. Implications for stigma and HIV/STI prevention interventions are discussed.

### Keywords

youth; psychiatric disorders; mental illness-related stigma; romantic relationships; sexual risk behavior

Adolescents and young adults are at serious risk for acquiring HIV. In the US between 2006 and 2009, rates of HIV among persons aged 15-24 continued to increase whereas rates for other age groups decreased in the same period (Centers for Disease Control and Prevention [CDC], 2011). Youth of this age also account for over two thirds of STIs each year (CDC, 2010). Adolescents with mental illness (MI) are at substantially greater risk for acquiring HIV compared to their counterparts without MI (Brown, Danovsky, Lourie, DiClemente, & Ponton, 1997a; Donenberg & Pao, 2005; Smith, 2001). Compared to adolescents in the general population, adolescents with MI report earlier age of sexual debut, more inconsistent condom use, and a greater likelihood of having multiple partners (Brown, Reynolds, & Lourie, 1997; Brown, Shari, Lourie, Ford, & Lipsitt, 1997; Donenberg, Emerson, Bryant, Wilson, & Weber-Shifrin, 2001). Despite this risk, the nature of the association between mental illness and the high rates of sexual risk behaviors among adolescents is not well understood.

Mental illness has been linked to various sexual risk behaviors in youth, though not consistently. Externalizing symptoms and disorders (e.g., ADHD, conduct disorder, impulsivity) have been associated with increased sex- and drug-risk behaviors (Loeber, Farrington, Stouthamer-Loeber, & Van Kammen, 1998; Ramrakha, 2000; Tubman, Windle, & Windle, 1996), whereas internalizing symptoms or disorders (e.g., depression, anxiety, hopelessness) have been associated with both increased risk behaviors (Brown et al., 2006; Shrier, 2001; Whitbeck, Conger, & Kao et al., 1993), and *decreased* sexual activity (Tubman et al., 1996). One study found no relationship between symptoms and sexual risk for girls but did for boys (Lehrer, 2006). These studies show a complex relationship between psychiatric symptoms and risk behavior, and suggest that factors aside from psychiatric symptoms or disorders may also increase sexual risk behaviors among youth with MI (Donenberg & Pao, 2005).

One potential contextual factor that may increase risk among adolescents with MI, but which has received scant attention in the literature, is MI-related stigma. Stigma is defined as an attribute or mark that has been identified within a given social context as being deeply discrediting to the individual (Goffman, 1963; Jones et al., 1984). Link and Phelan (2001) proposed a model of stigmatization that describes a process whereby the individual who is stigmatized is labeled and identified as being distinct from the norm - those with desirable characteristics - by individuals, the community, and/or the larger government (*societal stigma*). This labeling results in the individual's being devalued; and the loss of status leads the individual to be discriminated against. Link and Phelan describe discrimination at both the individual level - where individuals are directly and overtly discriminated against - and at the structural level - where practices at the institutional level work against the disadvantaged person. They additionally describe the *social-psychological processes* involved, which reflect how the stigmatized individual perceives the cultural stereotypes of the undesirable characteristic, what s/he expects to happen as a result of the negative cultural stereotype, and how s/he manages his/her perceptions and expectations and responds to discrimination.

This model, developed for adults, has not been used to examine experiences within the sexual interpersonal sphere. However, an emerging literature among adults with MI suggests that the social response to individuals with MI (e.g., discrimination, mistreatment, and social rejection) may contribute to both increased risk-taking and decreased risk avoidance or prevention. A handful of recent studies have found that perceived MI stigma is associated with HIV risk behaviors in adults with MI (Collins, Elkington, Sweetland, & Zybert, 2008; Elkington et al., 2010) and affects beliefs that they can choose their partners, establish relationships, and negotiate safer sexual behaviors (Wainberg et al., 2007; Wright & Gayman, 2005). In contrast, we have a limited understanding of the experiences of MI stigma and its influence on intimate relationships or sexual behaviors among youth in psychiatric treatment.

The few MI stigma studies of adolescents suggest that youth with MI believe that those without MI hold pejorative views about them. Moreover, many of these youth have had individual experiences of stigma across several domains (Elkington et al., 2012; Moses, 2009, 2010a), including experiences of direct rejection by friends and family, as well as indirect rejection such as tacit, disparaging messages from teachers and the larger socio-cultural context (Chandra & Minkovitz, 2006; Elkington et al., 2012; Lindsey, Joe, & Nebbitt, 2010). One study found such experiences and messages were internalized as a sense of shame, a belief of being “less than,” and a general fear or expectation of rejection by others; these youth engaged in several coping behaviors to manage their stigmatized identity, such as refusing to tell others about their diagnosis, withdrawing from others in anticipation of rejection, or denying their own illness (Elkington et al., 2012). Furthermore, prior research finds experiences of stigma among youth in treatment are not uniform, varying instead by gender and diagnosis (Chandra & Minkovitz, 2006; Elkington et al., 2012; Moses, 2010a). As such, gender and diagnosis must be considered when examining the influence of stigma on intimate relationships or sexual behaviors among youth in psychiatric treatment,

Adolescence and young adulthood is a period characterized by identity development and consolidation, independence from family, need for social acceptance within peer groups, desire for and involvement in romantic relationships, and increased sexual activity (Erikson, 1959; Collins, 2003; Roisman, Masten, & Tellegen, 2004). The difficulty of these tasks may be compounded for youth receiving psychiatric treatment who have been “labeled” as mentally ill and who are particularly susceptible to the negative evaluation from peers or others in their environment (Elkington et al., 2012; Moses, 2010a, 2010b). The effects of MI stigma may have considerable ramifications for an individual’s developing identity (Rappaport & Chubinsky, 2000), and may impose challenges to developing a healthy self-concept, engaging in romantic and intimate relationships, and practicing safer sex behaviors. Drawing from Link and Phelan’s model (2001), we anticipate that experiences of stigma at individual and structural-levels via rejection from peers, family, and the larger community may lead to social-psychological processes by which these youth internalize pejorative messages that they are undesirable as sexual or romantic partners due to their MI or that they are unable to choose their partners. As a result, these youth may become involved in relationships with unequal power dynamics and respond less assertively to their partners’

demands, including demands for unsafe sexual behavior, as a way to avoid rejection and abandonment.

In sum, adolescence is a critical period for intervention with stigma as well as sexual risk behaviors. Understanding how MI stigma may impact romantic or sexual relationships among adolescents in psychiatric treatment can increase our understanding of ways to promote healthy sexuality and reduce risk behaviors among this population. However, to our knowledge, there are no studies that examine the effect of MI stigma on behaviors in romantic or sexual relationships among youth with MI. Building on our earlier work of stigma in youth with MI (citation removed for review) and extending Link and Phelan's model of stigmatization in adults (Link & Phelan, 2001), we examined the experience of MI stigma and its influence on the romantic or sexual relationships and related behaviors of N=20 male and female youth with MI in psychiatric outpatient treatment. Using qualitative methodology, the current study sought to understand the impact of stigma on romantic or sexual relationships, including youth's experiences with stigma, the internalization of these experiences, and the behavior associated with managing stigma within romantic and sexual relationships.

## Methods

### Participants and Sampling

As part of a larger study to develop an instrument for measuring mental illness stigma and sexuality in adolescents and young adults receiving outpatient psychotherapy, we recruited 24 participants from four outpatient mental health facilities in New York City (citation removed for review). These facilities provide psychiatric care and support services for youth and young adults with MI. Recruitment took place from October 2007 to May 2008. Participants were included if they (a) had been diagnosed with a DSM-IV Axis I disorder, (b) spoke English, (c) were between 13 and 24 years old, (d) were capable of providing assent/consent, and (e) were currently receiving psychiatric services at the clinic. Youth were excluded if they (a) had a current diagnosis of eating disorder, pervasive developmental disorder, or Mental Retardation, (b) were diagnosed with a psychiatric disorder as a direct result of substance use, withdrawal, or intoxication, or (c) were currently acutely suicidal or psychotic.

The original sample size (N=24) was determined based on saturation of the data; interviews were conducted until the coders determined that themes were being repeated and that no new themes, categories, or subcategories were emerging (Power, 2002). Given that sexual development and activity differ by age (CDC, 2010), we limited the sample in the current analysis to youth aged 16-24 years to capture those with experiences with romantic or sexual relationships and those at an age who are beginning to make decisions about sex and relationships (Brooks-Gunn & Paikoff, 1997). Thus, the current paper excludes four youth (2 male and 2 female), none of whom reported lifetime sexual activity, resulting in a final sample N=20.

To ensure a full range of experiences, we stratified our sample by gender and diagnostic group given the influence of these variables on stigma experiences and sexual activity

(Andersen & Cyranowski, 1994; Auslander, Rosenthal & Blythe, 2005; Brooks-Gunn & Paikoff, 1997; Elkington et al., 2012; Link, Cullen, Frank, & Wozniak, 1987; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001). We divided the sample into two diagnostic “groups:” psychotic disorders (e.g. schizophrenia, bipolar disorder, schizoaffective disorders, psychosis NOS) and non-psychotic disorders (e.g. major depression without psychosis, generalized anxiety disorder, panic disorder), as the adult and youth literatures suggest that stigma is related to severity of diagnostic symptoms, particularly psychosis (Link et al., 1987; Link et al., 2001; Elkington et al., 2012). This stratification was also used to guide the analysis (see Data Coding and Analysis). We did not stratify by race/ethnicity given that the geographic location of the clinics where participants were recruited was predominantly Latino. Consequently, given the race/ethnic homogeneity in the current sample (17/20 youth were Hispanic or Hispanic plus another race/ethnicity), we were unable to distinguish differences in the experiences of these youth by race/ethnicity; we discuss the influence of race/ethnicity on findings where relevant.

## Procedures

We used a purposive sampling method (Patton, 1990) to recruit participants based on both gender and diagnostic group. Participants were recruited by their clinicians who were asked to describe the study to all patients who were clinically stable and eligible to participate (i.e. not acutely psychotic or suicidal) to prevent clinician bias. Clinicians informed patients of the study’s purpose, which was to understand how being in treatment for a mental health problem may affect their experiences and relationships with important people in their lives such as friends, family members, and boyfriends/girlfriends. All participants who were eligible based on inclusion criteria agreed to participate in the study.

For each participant under the age of 18, we obtained written informed caregiver consent and child assent; for participants 18 years and older, we obtained written informed consent from the youth only. All participants were interviewed in private rooms in the clinic where they were receiving services. Interviews were conducted by one of three trained female interviewers with at least a master’s degree in psychology or related field. Interviews lasted about 45 minutes, were audio-recorded and transcribed. Participants received \$24 in compensation for their time. All study procedures were approved by the Institutional Review Board of the New York State Psychiatric Institute.

## Assessments

**Demographic and clinical background information**—We collected demographic data (age, gender, current or last grade completed, employment, and current residence), current and past psychiatric diagnoses, modalities of treatment (type, length, and frequency), and use of medication using a self-report, nine-item questionnaire.

**The qualitative interview protocol**—Team members experienced with this population created a qualitative semi-structured interview protocol based on Link and Phelan’s (2001) model of stigmatization, to draw upon subjective experiences of stigma by youth receiving outpatient psychiatric care and to elicit their attributions about the effects of stigma on romantic and sexual relationships. Because prior studies have suggested that adolescents and

adults may have difficulty using the term *mental illness* to describe themselves, in large part due to issues around societal and internalized stigma (Moses, 2010a, 2010b; Mowbray & Holter, 2002), we used alternate terms in the interview protocol in order to avoid stigmatizing our participants and to create better rapport during interviews (e.g., *being in treatment or care*). Medical directors at each study site reviewed the interview guide for appropriate content and wording, and the interview guide was then pilot-tested.

Early in the interview, interviewers built rapport by asking participants to describe themselves, their families and friends, and their schools and/or communities. Interviewers then asked participants about their perceptions of stigma within various domains, initially asking general questions about experiences and then, if not elicited, asking questions about stigma experiences within sexual or romantic relationships. Specifically, interviewers inquired about societal stigma toward those with MI (e.g., How do you think people who are not receiving care at a clinic like this one think of other people who do? Do you think other people would want to go out with or mess around with people who get care in a clinic like this one? Why/why not?) as well as their individual experiences of stigma, including their experiences of discrimination and rejection by peers, romantic/sexual partners, and family members (individual level) (e.g. .... I'm wondering if xxxxxx [people just described] acted differently towards you, either in a good or bad way, after you began receiving treatment in this clinic?... What about sexual or romantic partners or people you were interested in --did anything change with them?), and separation from mainstream groups at school; and denial of club or group membership (structural level). The interview then examined participants' social-psychological processes related to stigma, such as internalized stigma, self-devaluation, poor self-concept, and coping mechanisms (e.g. Sometimes when people go to a clinic like this one it affects how they feel about themselves. What do you think changes and why? What about for you? .....Does receiving care in a clinic like this one affect the way you see yourself as a girlfriend/boyfriend or as a sexual partner? Why?). Questions within this domain targeted participants' behaviors and roles, including their ability to negotiate and assert themselves in romantic and sexual relationships; participants' need for intimacy and use of intimate or romantic relationships to meet intimacy needs; and participants' fear of rejection/abandonment in romantic and sexual relationships (e.g., Do you think it's harder, easier or the same for people receiving care in a clinic like this one to tell their partners about using condoms? Why?).

Finally, when inquiring about participants' social-psychological processes related to stigma we also used a series of four vignettes, developed by the authors, to elicit perceptions of stigma. All participants were asked to comment on the vignettes regardless of their endorsement of other stigma experiences. We used vignettes to examine social-psychological processes, as these were deemed more sensitive and open to defensive responding by participants. Vignettes allow for the exploration of youth's perceptions that might otherwise be missed by the use of questions directed towards the youth's own thoughts, feelings, or actions. Vignettes provide participants the 'freedom' to respond in less socially desirable ways when describing perceptions of a vignette character as opposed to answering directly about themselves (Barter & Renold, 2000). We used vignettes after inquiring about individual and structural experiences of stigma. We presented hypothetical

situations of male and female youth with MI in particular situations with sexual or romantic partners, for example: Sarah is a girl who, because she's receiving care in a clinic like this one, thinks that guys don't like her. She has a boyfriend but she's not totally down with him. She goes out with him anyway. Why do you think Sarah goes out with someone she doesn't like? Table 1 presents vignettes in the order they were asked. We asked participants to comment on the attitudes and actions of the subject of the vignette, eliciting reasons for subject's behavior. We then asked the youth if s/he had experienced something similar and to describe how s/he did or would feel in such a situation and what s/he did or would do next in the same situation.

### Data Coding and Analysis

All interview transcripts were entered into *NVivo 9*, a qualitative data software package. The central research question focused on understanding how the experiences of MI stigma among youth in psychiatric outpatient treatment affected their sexual or romantic relationships and sexual risk behavior. We conducted a thematic analysis of the interview texts, employing inductive and deductive approaches, to investigate shared experiences of mental illness-related stigma and its impact on youth's sexual or romantic relationships and associated behaviors (Braun & Clarke, 2006). From verbatim transcriptions of the interviews, coders conducted close readings of those passages containing accounts of or references to experiences of MI stigma, romantic or sexual relationships, sexual encounters or behaviors, or sexual or romantic partners (including consideration of one's qualities as a romantic or sexual partner).

The initial coding scheme focused on the three broad main domains of stigma in Link and Phelan's (2001) model which emerged as central in our earlier work (citation removed for review): 1) societal stigma, 2) individual discrimination, and 3) social-psychological processes of stigma. As our prior work indicated that youth did not endorse experiences of structural stigma, we omitted exploration of this domain in the current analyses. First, we defined a typology of codes and definitions created from the interview guide and aforementioned broad domains. Then we organized the data by emerging themes. We continually defined and redefined emerging concepts, the larger themes they represented, and the relationships among these themes. From stories of youths' experiences with stigma and subsequent internalization of stigma messages and beliefs, we identified the youth's response to these experiences within romantic or sexual relationships and identified the elements of stigma experiences that influenced their romantic and sexual (risk) behavior. We then conducted analytic cross-case analyses comparing and contrasting major themes by gender, age, and diagnostic group.

When analyzing the data, we first explored themes within the participants own lived experience. We then analyzed themes that emerged from the vignettes. As anticipated, we found some participants were more forthcoming about social-psychological processes of stigma (such as expectations of rejection from non-MI others or fear of rejection or abandonments) when responding to vignettes and identifying the experiences and emotions of a hypothetical person with mental illness as opposed to endorsing their own experiences (Barter & Renold, 2000). For all of the vignettes, themes that emerged underscored or

echoed themes from the youths' lived experiences and are presented here to provide additional evidence of important themes.

## Results

### Sample Characteristics

Just over half the 20 participants were male (n=11), 15 were Hispanic (75%), 2 were non-Hispanic white (10%), 1 was African American (5%), and 2 were mixed race/ethnicity (10%) (Hispanic and white). The mean age was 19 years (SD=2.8 years). The majority of youth were in school (75%, n=15), 1 had dropped out of school (5%), 2 had graduated high school, and 2 had completed some college; two participants stated they were currently employed (10%; missing data on 4 youth). Data on economic indicators were not collected, but the average adjusted gross income in the community where the clinics were situated was \$27,909, with approximately 26% of residents living below the poverty line (<\$25k for NYC; <http://www.city-data.com/zip/10040.html>). Almost all youth (95%) resided with family members, and one youth reported living with his partner. Fifteen youth (75%) reported initiating services at the clinic within the past year, 2 (10%) began treatment at their clinic within the past 5 years, and 12 (60%) reported taking psychiatric medication. Five youth (25%) were diagnosed with a psychotic disorder: 1 had schizophrenia (5%), 2 had bipolar disorder, type I, (10%), and 2 had schizoaffective disorder (10%). Non-psychotic disorders were: major depressive disorder (without psychosis) or dysthymia (n=10, 50%); generalized anxiety disorder (n=1, 5%); ADHD (n=1, 5%); panic disorder (n=1, 5%); adjustment disorder (n=1, 5%); and mood disorder NOS (without psychosis) (n=1, 5%). All but one youth had been in a romantic relationship, 8 (40%) were currently in a relationship, and 16 (80%) had ever had sex. There were no differences in romantic or sexual behavior by age, gender or by diagnostic group.

### The effect of stigma on youths' romantic and sexual relationships

Our analysis of the youths' experiences revealed four main themes: 1) societal perceptions of those with MI as partners (societal stigma); 2) individual experiences of stigma within relationships (individual level); 3) internalized stigma of self as a partner (social-psychological processes); and 4) managing a stigmatized identity (social-psychological processes). We examined differences in major themes by gender (males vs. female), diagnostic group (psychotic disorder vs. non-psychotic disorder), and age (>17 vs. <18), and note differences where appropriate. We present findings by youths' own experiences followed by responses to vignettes where relevant.

### Societal perceptions of those with MI as partners

Just over half of all participants (n=12 or 60%) perceived that, in general, people without MI did not want to be in a relationship with those with MI. In particular, some youth expressed beliefs that partners without MI do not consider those with MI as "*dependable*" and as a result would not want to date them or be with them. These youth considered mental illness as something that partners would not want to deal with or manage, and that over time the partner would come to consider the mentally ill person to be a burden in the relationship



It might scare them, too. It's like, "Oh crap, now I'm going to be with this person that has mood swings, and...the mood swings might scare them...or knowing that they're suicidal all the time. It drags you...because you could be strong in a relationship for a long time, but then it just – that [mentally ill] *person becomes dead weight*. (Male, age 20, Hispanic, non-psychotic)

Participants' responses to vignettes clearly underscored the beliefs that those without MI viewed those with MI as undesirable romantic or sexual partners. For example, in response to a vignette of a boy who receives psychiatric treatment and struggles to tell a girl he likes her, one female with psychotic illness responds:

R: Because he's scared of judgment?

I: You think he's scared of judgment?

R: He's scared that when she gets to know him, maybe she'll feel like he's in therapy, because he's crazy. (Female, age 20, White, psychotic)

Overall, concerns related to the negative perceptions about those with MI as partners held by those without MI emerged in the interviews regardless of the youth's gender, age, or diagnostic group (i.e. psychotic versus non-psychotic).

### Individual experiences of stigma within relationships

A few youth (n=4 or 25%) described direct experiences of rejection by partners, or following a change in the nature of their relationships after revealing their diagnosis to their partner.

Like, the last time, for Valentine's Day, I hooked up with this guy, and then after the whole deal, I was lying down, and it was like yeah, you just fxxked a bipolar chick. He was like, yo, you better not start flipping out on me.....I guess that's what his conception is about bipolar people, they just flip out. (Female, age 24, Hispanic, psychotic)

For these youth, the general perception that those without MI saw those with MI as undesirable partners was personalized by these direct experiences. We found both boys and girls reported direct experiences of rejection within relationships, but almost all youth (n=3) who described individual experiences of stigma were those with a psychotic disorder and youth who were older (i.e. >17).

### Internalized stigma of self as a partner

Almost half the sample (n=9 or 45%) described expectations of rejection by non-MI others and an internalization of stigma either through their own personal experience or by vignette. All 9 youth described either negative societal perceptions of those with MI as partners or had experienced individual experiences of stigma within relationships. These youth appeared to have internalized their experiences and the beliefs of the larger society that they themselves do not make good partners, and some described being undeserving of romantic or sexual relationships.

Like sometimes I would think like I don't deserve to be with this person because look how independent he is and look how funny he is and look at me. Like most of the time I am depressed and boring...like I don't deserve to be with that person. Like that person is too good for me! (Female, age 20, Hispanic, non-psychotic)

Furthermore, some of these youth described internalized beliefs that because they were not desirable as partners, they had limited ability to choose their own partners or had limited choices of partners.

I: Do you feel like you can choose who you go out with, or who you were intimate with?

R: I don't think [so]. They choose you, you know? I: Why is that?

R: I don't know, 'cause they seem to like -- not understand a mentally ill person. (Male, age 23, Hispanic, psychotic)

Some youth (n=3 or 15%) only described sentiments about being undesirable, having limited partner options and a need to accept any partner in hypothetical vignettes or when discussing the behavior of their friends with MI, indicating that expectations of rejection by non-MI others were present:

...Because they feel they can't find anyone else; they feel that it's too hard to find anyone else, because they have therapy. Like I said before, with [friend's name], he feels that they won't accept him...he feels like that's the only person he'll get. (Female, age 20, White, psychotic)

In contrast to accepting any partner, one white female, aged 24, who had never had a relationship, stated that because she believed she had '*no options*' with respect to partners, she had avoided relationships entirely. As with recognition of societal stigma, we found no differences by gender, age, or severity of illness with respect to youth reports of internalized stigma.

### Managing a stigmatized identity

Over half the sample (n=13 or 65%) described engaging in specific behaviors in the service of managing or reducing the impact of stigma on their romantic or sexual relationships; all 9 youth who had provided responses indicating internalized stigma of themselves as a partner described engaging in these behaviors. Several of these coping strategies directly or indirectly increased the youth's risk of HIV/STIs.

In some instances, youth used relationships (romantic or sexual) as a way of avoiding rejection or to distance themselves from the lower status associated with having a mental illness.

R: So it depends on the person. If I'm really trying to push him away, I'll tell him all sorts of shit. But if it's somebody I like, I wouldn't tell him that I have a mental illness.

I: Why wouldn't you tell him?

*R: Because that's [having a mental illness] a vulnerability. (Female, age 24, Hispanic, psychotic)*

Furthermore, once relationships were established, some youth described changing their behavior and being less assertive as a way to maintain the relationship and avoid being rejected or abandoned by a partner.

*R: [People with MI] feel less than their partner, so they're always trying to accommodate.*

*I: What might happen if they don't, do you think?*

*R: Might lose a partner.*

*I: Is that something that you struggle with, is that true for you?*

*R: Yeah, I'm pretty accommodating.*

*I: And is it for those reasons that you think if you don't your boyfriend might leave you?*

*R: Yeah, I really do. (Male, age 21, other race/ethnicity, psychotic)*

Fear of rejection and abandonment because of having a mental illness transformed itself into sexually passive behavior for a few youth. For example, a male youth with bipolar disorder described struggling to request condoms because he believed it sent a message to his partners of promiscuity, fulfilling the stereotype about people with bipolar disorder and hyper-sexuality. This same youth also stated that he became sexually involved with multiple partners for a short time following a break-up with his partner in order to ensure he was still wanted despite his having bipolar disorder.

In one extreme, a participant described trying to get his girlfriend pregnant in order to maintain the relationship, despite not wanting to be a father. This same participant earlier described a belief that due to his mental illness he could not choose his romantic/sexual partners but instead must be chosen.

*I: Do you think people who have a mental illness do things so that their partners won't leave them?*

*R: Yeah.*

*I: Do you do anything so that your girlfriend won't leave you?*

*R: I try [sic] getting her pregnant.*

*I: Does she want another baby?*

*R: Yeah.*

*I: And do you think that's a good idea?*

*R: No. She's not ready.*

*I: She's not ready for that. Are you ready?*

*R: No, not ready.*

I: Not ready, so why are you trying to do it then?

R: *Just to keep her.* (Male, age 23, Hispanic, psychotic)

In response to vignettes, the idea again emerged that in an attempt to maintain a relationship and avoid rejection or feelings of being unwanted, youth with MI might maintain a relationship with partners they did not particularly like or struggle to put demands on a relationship and ask for condoms because they feared the partner would leave them.

[Responding to a vignette about a female with MI going out with someone who she does not really like].

I: Why do you think she goes out with someone that she doesn't really like?

R: So she won't be alone, and so she won't feel bad about herself. So she won't think that nobody wants her because of any issues that she has. (Male, age 16, Hispanic, non-psychotic)

[Responding to a vignette about a teenager (same sex as respondent) with mental illness asking his/her partner to use condoms]

R: To be honest with you, yeah, they would have, like, a problem, and they will be like, "Oh, baby." You know, like they don't have -- because they want their boyfriend to love them and care for them. (Female, age 18, Hispanic, non-psychotic)

Although youth engaged in potentially risky coping strategies to manage the effects of stigma, a few of these youth also described receiving assistance in managing stigma and its negative effects on their romantic or sexual relationships. Specifically, these youth noted that being in therapy had helped them to stay safe as they would be able to get advice from their therapist on how to manage difficult situations, or "receive condoms for free."

[Therapists] are like 'here, protect yourself.' They do that.... I think it would be easier because they encourage you to like -- they talk to you about HIV and stuff like that, like diseases, sexually transmitted diseases. (Female, age 20, Hispanic, non-psychotic)

When examining differences in behaviors used to manage a stigmatized identity, we found that the majority of youth who described engaging the HIV/STI sexual risk behaviors were those youth who had a psychotic illness and who were older (i.e. >17). We found no differences by gender.

A subgroup of youth (n=4 or 25%) who reported engaging in behaviors consistent with managing a stigmatized identity did not articulate recognition of societal stigma report individual experiences of stigmatization in relationships, or describe internalized stigma. Although these youth may not have articulated experiences with mental illness stigma, their behaviors indicate that stigmatization and/or feeling less-than as a partner due to their mental illness was likely part of their experience. This group of youth included both boys and girls, but was composed exclusively of youth with non-psychotic illness and youth who were younger (i.e. <18).

### The 'absence' of stigma

Finally, our analysis also revealed small group (n=4) that did not describe acknowledgement of either societal stigma towards those with MI as partners or individual experiences of stigma. These few youth also denied that stigma or having a mental illness had any impact on their relationships or their view of themselves as a partner, and subsequently did not report engaging in any behaviors to manage their stigmatized identity. These youth who did not apply the stigmatizing label to themselves were both male and female, were younger (i.e. <18 years), and all had non-psychotic disorders.

### Discussion

Youth with psychiatric disorders are at increased risk for HIV/STI due to intra and interpersonal factors (Donenberg & Pao, 2005; Elkington, Bauermeister, Brackis-Cott, Dolezal, & Mellins, 2009). The current study is one of the first to extend Link and Phelan's theory of stigma and discrimination and examine the potential relationship between mental illness-related stigma and HIV/STI risk in youth with psychiatric illness. We identified four key themes 1) societal perceptions of those with mental illness as partners; 2) individual experiences of stigma within relationships; 3) internalized stigma of self as a romantic or sexual partner; and 4) managing a stigmatized identity, which included engaging in HIV/STI risk behaviors. We found that just under half of the sample (n=9/20) endorsed all themes, including engaging in HIV/STI risk behaviors as a method to manage a stigmatize identity, which suggests that MI stigma and sexual risk may be linked. Such findings may guide stigma reduction programs as well as HIV/STI intervention preventions tailored to the specific needs of youth with psychiatric illness, offsetting or eliminating the long-term effects of stigma that are so profound and deleterious in adulthood (Hinshaw & Cicchetti, 2000; Link & Phelan, 2001).

Over half the sample described either societal stigma — recognizing messages from the larger cultural context that those with mental illness are perceived as less desirable as partners — or individual stigma experiences of rejection by romantic or sexual partners. The majority of youth who endorsed societal or individual experiences of stigma appeared to have internalized those messages and experiences that they were not desirable romantic or sexual partners. This internalization was expressed via negative beliefs suggestive of a stigmatized or negative sexual self-concept, such as being unworthy of romantic or sexual relationships, having limited partner options, or fearing/expecting rejection or abandonment by partners. The sexual self-concept has been variously described as comprising a youth's sexual self-efficacy or agency, sexual self-esteem, sexual arousal, and sexual affect (Breakwell & Millward, 1997; Buzwell & Rosenthal, 1996). All youth who described internalizing stigma reported engaging in behaviors in an attempt to manage this stigmatized identity or self-concept, some of which directly (e.g., difficulty negotiating condoms) or indirectly (e.g., maintaining unwanted relationships to avoid rejection) placed them at increased risk for HIV.

Prior research in other populations, including Latino youth, has found that youths' sexual self-concept plays an important role in sexual behavior, providing a context that guides and defines youth decisions around sexual practices and behaviors (Breakwell & Millward,

1997; Buzwell & Rosenthal, 1996). In the current study, the negative beliefs about themselves as sexual or romantic partners held by youth with psychiatric disorders appeared to drive their stigma management behaviors within the context of these relationships. The process of managing a stigmatized identity is consistent with Link and colleague's (1987) Modified Labeling Theory, which states that individuals who are socialized to accept negative stereotypes about mental illness are primed to accept and internalize those messages, and are, thus, susceptible to a negative self-concept once they themselves are labeled as mentally ill. The internalization of negative messages and resulting negative self-concept then contribute to the use of coping strategies or behaviors aimed at protecting the self (e.g., withdrawal and isolation), but often tend to be self-defeating (Moses, 2009).

Youth in the current study described various passive coping strategies or behaviors that served to avoid rejection or offset the perceived lower social or sexual status associated with having a mental illness and being undesirable. These passive behaviors included maintaining and being committed to unwanted sexual relationships, engaging in unwanted sex or other unwanted reproductive behaviors, or failing to request condoms. Although prior research examining sexual self-concept and sexual behaviors in youth has shown mixed results (Breakwell & Millward, 1997; Buzwell & Rosenthal, 1996; Winter, 1988), youth with negative or lower sexual self-concepts but with higher relationship commitment—similar to youth described in the current study—are more likely to engage in risk behaviors within the context of a main or primary relationship (Buzwell & Rosenthal, 1996). Further research is warranted to identify how perceived MI stigma and associated experiences of rejection affect the sexual self-concept of youth with MI, and in turn how sexual self-concept is moderated by specific factors (e.g., relationship commitment) to influence sexual risk behaviors. Such research can further elucidate the connection between a negative sexual self-concept and sexual risk and inform much needed interventions designed to reduce HIV risk behaviors among these vulnerable youth.

There were a few youth who described engaging in behaviors to manage a stigmatized identity (e.g., non-disclosure to partners or maintaining relationships to avoid rejection/lower status) without acknowledging negative societal views about those with mental illness or articulating negative beliefs that would suggest internalized stigma. These youth were both male and female, and all had a non-psychotic disorder. It is possible that such youth may be struggling to incorporate the aspect of being someone with a mental illness into their larger identity or self-concept, and therefore deny or fail to endorse such experiences, beliefs, or perceptions. These findings are consistent with our prior work (citation removed for review) in which youth with non-psychotic disorders tended to deny overall stigma, despite engaging in various coping strategies (e.g., silence, withdrawal) to manage a general stigmatized identity. While their behaviors suggest internalized stigma, additional research is necessary in order to understand the role of stigma in the sexual and romantic behaviors of these particular youth.

More youth with a psychotic disorder reported direct experiences of rejection and discrimination from sexual or romantic partners than youth with a non-psychotic disorder. This finding is consistent with our prior work in which youth with psychotic disorders reported more direct experiences of non-sexual rejection from friends, family members and

their community (citation removed for review). However, given the limited number of youth with a psychotic disorder in the sample, further research is required to determine if the differences in experiences of stigma in sexual and romantic relationships differ by diagnosis as seen in studies of adults with serious mental illness (Collins et al., 2008; Wainberg et al., 2007; Wright & Gayman, 2005). Differences in age seen were largely confounded by diagnosis such that youth with psychotic disorders were all older (i.e. > 17 years). Again, additional research is warranted in order to understand the influence of stigma as youth move through adolescence.

Interestingly, one quarter of the sample reported no experiences with stigma, and did not appear to internalize negative beliefs or engage in behaviors to manage a stigmatized identity. These findings are somewhat inconsistent with some prior studies that found a majority of youth were unconcerned with stigma and behaved accordingly (Moses 2009, 2010a, 2010b), yet are consistent with other studies that found adolescents to be pre-occupied with stigma, particularly when related to seeking services (Chandra & Minkovitz, 2006; Elkington et al., 2012; Lindsey et al., 2010; Boldero & Fallon, 1995; Yeh, McCabe, & Hough, 2003). Such inconsistencies in the literature underscore the complex nature of stigma, including the influence of measurement or sampling/cohort differences on findings, and suggest continued research on mental illness stigma in youth is warranted. For example, youth who did not endorse or experience stigma in the current study all had a non-psychotic illness, suggesting that some youth with less severe illness may not be affected by mental illness stigma and discrimination. There may be significant protective factors within their larger socio-cultural environment that were beyond the scope of our study (e.g., social support from family members, friends and clinical providers) that serve to offset the negative effects of stigma. Alternatively, other stigmatized identities, such as being a minority or residing in a poorer urban area, may have had a more prominent influence on the lives of these youth than MI stigma (Collins et al., 2008; Elkington et al., 2012). Although we were able to examine differences by diagnosis, we did not gather information on psychiatric symptoms and functioning. Less severe symptoms or less functional impairment as opposed to diagnosis may minimize experiences of stigma; this link requires further examination. To date, all studies of youth have focused on the negative outcomes associated with stigma. A better understanding of resiliency to stigma in youth with psychiatric disorders will inform programming that promotes positive youth development as well as programming specifically designed to reduce the effects of stigma in youth.

It is also important to consider the cultural influences on the experience of these youth. Given the predominantly Latino sample in the current study, the effects of mental illness stigma for youth may have been heightened due to several factors. These youth may experience stigma related to mental illness in tandem with discrimination related to their race or ethnicity, and thus may be particularly susceptible to the negative evaluations of others, including their partners. Furthermore, cultural context can play an important role in shaping an individual's view of mental illness and related stigma. For example, there is some evidence to suggest that mental illness-related stigma is more prevalent in minority groups of adults than whites (Alvidrez, 1999; McKay, Nudelman, McCadam, & Gonzales, 1996). Studies have also found that Hispanic adults compared to white adults are more reluctant to seek professional assistance regarding their own or a child's mental health

problems and may struggle to acknowledge their child's difficulties in terms of a psychiatric illness (Wells, Hough, Golding, Burman, & Karno, 1987; Gonzalez, 1997; Cabassa & Zayas, 2007). Within such a cultural context of heightened stigma around mental illness, youth in the current study may have been more motivated to engage in behaviors to manage a stigmatized identity or deny the experience of stigma entirely as a method of distancing themselves from a group highly stigmatized within their own culture. In the absence of information on minority youth, additional research is therefore necessary to explore more closely the effect of culture and race/ethnicity on the influence of stigma on youth sexual and romantic relationships.

This study has a number of limitations. First, this analysis relies on data collected from a sample of predominantly Latino youth seeking outpatient treatment in an impoverished neighborhood of New York City and may not be representative of youth of differing race/ethnic backgrounds, differing socio-economic statuses, other types of psychiatric treatment, or in other parts of the country. Stigma is a function of cultural norms and the majority of this sample belongs to a minority ethnic group for whom the meaning of mental illness and of seeking treatment may not generalize to other ethnic communities. Findings from this sample of youth already seeking treatment may not be generalizable to the many youth with unidentified or untreated mental illness, for whom reasons not to seek professional help may be numerous, including highly stigmatized beliefs about mental illness. We also did not capture data on youth's socio-economic status; youth in different socio-economic strata may have different perceptions or experiences of stigma (Bird & Bogart, 2001; Moses, 2009). However, all youth in the sample resided in the same economically impoverished area of New York City, and it is likely that a vast majority of the youth were from the same socioeconomic class. Given the sample size, our ability to contrast experiences and perceptions of stigma gender, diagnosis, and age was limited and warrants replication in a larger sample. Finally, these experiences of perceived stigma rely on self-report. We did not seek corroborating evidence from other sources such as family members or peers, which should be the focus of future study. We also did not measure depressed mood at time of interview, shown to be related to perceived stigma experiences in youth (Lindsey et al., 2010). Furthermore, youth behavior in relationships (e.g. passivity) may have also been attributable to illness related effects, such as depressed mood or other illness related effects.

Despite these limitations, findings from the current study have several important implications for clinicians and for HIV/STI and MI stigma prevention interventions. First, providers are well-positioned to identify and address experiences of stigma among all youth in treatment regardless of the youth's direct discussion of these concerns. In the current study we found some youth engaged in compensatory stigma-management behaviors while not reporting experiences of stigma or beliefs suggestive of internalized stigma. Although these youth may not articulate experiences with stigma, their behaviors suggest that they had internalized their "lower" sexual-romantic status, and a poor sexual or romantic self-concept was likely part of their experience. Clinicians must not only address or inquire about direct experiences of stigma and rejection but also explore various behaviors with the youth, including those that may indicate youth are not equal in status, power, or sexual decision-making to their intimate partners, and other factors that could increase their risk of HIV/STIs. In addition, youth in the current study reported that they received information and



support to practice safe sex behaviors from their clinicians and that this clinician effort was viewed positively by youth. Clinicians should be prepared to discuss romantic and sexual relationship issues and safe sex behaviors with youth in their care, which may also include providing condoms.

Finally, youths' negative sexual and romantic self-concepts, in addition to other "spoiled" social identities, and associated negative stigma management strategies should be addressed as a part of both MI stigma-reduction programming and HIV/STI prevention programming. Youth are still shaping their identities and may be particularly amenable to intervention within this domain. By targeting internalized MI stigma within the context of youth's main or primary relationships, clinicians can promote condom negotiation skills and otherwise help youth to eliminate risky sexual behaviors.

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## Biographies

**Katherine S. Elkington, Ph.D.** is an Assistant Professor of Clinical Psychology at the HIV Center for Clinical and Behavioral Studies in the Department of Psychiatry at the New York Psychiatric Institute and Columbia University. Her research focuses on examining individual (e.g. psychiatric disorders, substance abuse), and contextual (family, peer) correlates of HIV and other risk behaviors among high-risk adolescents. Additionally, her work is focused on the development and efficacy testing of HIV prevention interventions for high risk youth.

**Dusty Hackler, M.A.** is a Program Coordinator for the Columbia University HIV Mental Health Training Project at the New York State Psychiatric Institute. She is currently a graduate student of School Psychology at Teachers College, Columbia University, New York. Her current research interests include the intersection of HIV and mental health and understanding outcomes of PTSD in youth and adults.

**Jessica A. Latack, M.S.** is a doctoral student in Clinical Psychology at the State University of New York at Stony Brook. Her research focuses on the ways in which childhood sexual abuse and later sexual trauma may affect individuals' behavior in adult romantic relationships. Specifically, she is interested in examining the mechanisms that operate between one's experience of sexual trauma and their later relationship functioning.

**Tracy A. Walsh, B.A.** is a Research Assistant at the HIV Center for Clinical and Behavioral Studies and a Masters of Public Health student at Columbia University's Mailman School of Public Health. Her research interests include intervention design and evaluation, sexually transmitted disease, and adolescent health, particularly among youth involved in the juvenile justice system.

**Karen McKinnon, M.A.** is a Research Scientist in the Department of Psychiatry at the New York Psychiatric Institute and Columbia University who conducted the first HIV seroprevalence and risk behavior studies among people with severe mental illness beginning in the late 1980s. Her research focus includes Community Based Participatory methods, development, piloting and efficacy-testing of HIV prevention intervention studies for psychiatric patients in multiple cities in the U.S. and in Brazil. Additional interests include developing capacity-building and training programs to providers who work with clients with HIV and mental health issues, both in the US and internationally.

**Cristiane Borges, M.D.** is a Research Project Manager at the New York State Psychiatric Institute and Columbia University. Her research and clinical work has focused on working with minority populations at the National Family Health Program in Brazil; and in the design and development of HIV prevention interventions for adults and adolescents with mental health problems.

**Eric R. Wright, Ph.D.** is Associate Dean, School of Public and Environmental Affairs, Director, Center for Health Policy, and Professor of Health Administration and Policy, School of Public and Environmental Affairs, Indiana University-Purdue University. His research interests center on stigma and other social responses to mental health and health problems and the social organization and effectiveness of mental health and healthcare services and public health programs.

**Milton L. Wainberg, M.D.** is an Associate Clinical Professor of Psychiatry at Columbia University, the Medical Director of the Columbia University HIV Mental Health Training Project. His research focus includes understanding correlates of HIV risk behaviors, such as substance use, in high risk populations, including adults with mental illness and MSM; Community Based Participatory methods; and HIV intervention adaptation, development, and efficacy-testing. Additional interests include capacity-building and training both providers and researchers in interdisciplinary teams.

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**Table 1**

## Interview vignettes with follow-up questions/probes

Vignettes	<p>There's a girl Maria who sees a therapist and a psychiatrist. She likes this one guy on her block but doesn't want to tell him.          Why do you think this might be?          Can you tell me about an experience like that that you may have had?</p>
	<p>Sarah is a girl who, because she's receiving care in a clinic like this one, thinks that guys don't like her. She has a boyfriend but she's not totally down with him. She goes out with him anyway.          Why do you think Sarah goes out with someone she doesn't like?          What do you think are the pluses and minuses of her having a boyfriend/girlfriend?          Can you tell me how important it is for you to have a boyfriend/girlfriend?</p>
	<p>Juan has been in treatment at a clinic like this for a few months. He always does what his girlfriend tells him to do. He never gets to decide what kinds of things they do together, or who they hang out with – she makes a lot of the decisions.          Why might he let her make a lot of the decisions?          What about you? Who makes decisions in your relationships? Why?</p>
	<p>There's another boy, Michael. He has been struggling with his mood for about 2 years. His new girlfriend wants to have sex, he's not sure he wants to yet but he's afraid to say no. Why?          What might he be afraid of?          What might happen if he says no? Why?          Can you tell me about a situation like that that you've been in?</p>