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## Perceived Mental Illness Stigma Among Youth in Psychiatric Outpatient Treatment

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### Abstract

This research explores the experiences of mental illness stigma in 24 youth (58.3% male, 13–24 years, 75% Latino) in psychiatric outpatient treatment. Using Link and Phelan’s (2001) model of stigmatization, we conducted thematic analysis of the interview texts, examining experiences of stigma at individual and structural levels, in addition to the youths’ social-psychological processes. Youth in psychiatric treatment acknowledged that their larger cultural context holds pejorative viewpoints toward those with mental illness and reported experiences of stigma within their families and social networks. Our results also offer insight into the social-psychological processes of stigma, highlighting how labeling may influence their self-concept and the strategies in which youth engage to manage a stigmatized identity. We discuss differences in stigma experiences by gender, age, and diagnosis. Findings provide new information on the stigma experiences of youth in psychiatric treatment and suggest that a multilevel approach to reduce stigma is warranted.

### Keywords

adolescents; young adults; mental illness; stigma; psychiatric disorders

### Introduction

The Surgeon General has identified *stigma* as “the most formidable obstacle to future progress in the arena of mental illness and health” (U.S. Department of Health and Human Services [USDHHS], 1999) and listed the reduction of stigma as an important public health goal. A large body of research has explored the role of stigma in adults with mental illness, yet we still know comparatively little about the experience and effects of stigma among adolescents and emerging adults with mental illness (Moses, 2009a, 2009b).

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Authors’ Note

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## Theoretical Model of Stigma

Stigma has been defined as an attribute or mark that within a given social context is deeply discrediting to the individual, who is in turn perceived as tainted or discounted (Goffman, 1963). Link and Phelan (2001) postulate that stigmatization occurs as a process whereby the stigmatized individual is labeled, set apart, and linked to undesirable characteristics by more powerful individuals, communities, or governments. This labeling and separating process results in a loss of status of the labeled individual who is subsequently devalued and discriminated against. Link and Phelan thus describe discrimination, the actual implementation or behavioral component of the stigma process, at both the *individual level* (overt practices of discrimination against the stigmatized individual) and the *structural level* (institutional practices that work to the disadvantage of the stigmatized group or person). They also include the response of the stigmatized individual as part of the discrimination process. These *social-psychological processes* operate “through the stigmatized person” (Link & Phelan, 2001, p. 373), involving the stigmatized person’s own perceptions and expectations of the negative cultural stereotypes attributed to the undesirable trait and the individual’s subsequent methods of managing their expectations or perceptions. In modified labeling theory, Link and colleagues (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989) further posit that all individuals acknowledge the larger cultural pejorative viewpoint against those with mental illness. However, for those who are subsequently labeled as part of a stigmatized group, the larger cultural viewpoint becomes personally relevant. This may take its toll on the individual who experiences a loss of self-esteem or mastery, who expects or fears others will reject and discriminate against him or her and who then alters his or her behavior accordingly (Link, 1987; Link et al., 1989; Link & Phelan, 2001).

Among adults with serious mental illness (SMI), several studies have shown experiences of stigma are prevalent and result in a devalued sense of self, decreased mastery and quality of life, nonadherence to medication and treatment, impairment in social and leisure functioning, limited employment possibilities, and residence in impoverished neighborhoods with poor accessibility to adequate housing (Link et al., 1989; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001; Perlick et al., 2001; Rosenfield, 1997; Sirey et al., 2001; Wright, Gronfein, & Owens, 2000; Yanos, Rosenfeld, & Horowitz, 2001). Yet despite the significance of its debilitating effects and calls by policy makers to address the stigma associated with childhood mental health problems (USDHHS, 1999), there are few studies that specifically aim to understand and contextualize the experiences of stigma from the perspective of youth with mental illness (Wahl, 2002).

## Stigma and the Developing Identity of Adolescents and Emerging Adults

The effects of stigma may have considerable ramifications for an individual’s developing identity and associated well-being and adjustment (Rappaport & Chubinsky, 2000). One of the central goals of adolescence and emerging adulthood is to develop a coherent and cohesive personal identity (Côté, 2006; Erikson, 1980). This new identity is forged against a backdrop of rapid physical, cognitive, and social change (Feldman & Elliott, 1990; Roisman, Masten, Coatsworth, & Tellegen, 2004), including the increased salience of peers and peer opinions (Crosnoe & McNeely, 2008). The difficulty of this task may be further compounded for youth who receive psychiatric treatment and who have thus been “labeled”

with a diagnosis or as someone with “mental health problems.” Youth with psychiatric difficulties may struggle with aspects of individuation given their need for structured and supportive environments (Côté, 2006) and may be particularly susceptible to the negative evaluation from peers or others in their environment (Donenberg & Pao, 2005). Persistent experiences of stigmatization may result in internalized stigma and a devalued sense of self (Link et al., 1989) as youth engage with the negative evaluations of themselves found within their immediate and broader social context as they age. However, few studies have explored experiences of stigma in both adolescents and emerging adults, and thus our understanding on the effects of stigma during these developmental periods is limited.

### **Mental Illness Stigma and Race/Ethnicity**

For minority ethnic youth, experience of mental illness-related stigma requires still further consideration. First, cultural context can play an important role in shaping an individual’s view of mental illness. There is some evidence to suggest that mental illness-related stigma is more prevalent in minority groups of adults than among whites (Alvidrez, 1999; McKay, Nudelman, McCadam, & Gonzales, 1996). Second, these youth may experience mental illness stigma in tandem with discrimination related to their race or ethnicity and may be particularly susceptible to the negative evaluations of others. Finally, studies of adults have shown that African Americans and Hispanics are reluctant to seek professional assistance regarding their own or a child’s mental health problems compared to their white counterparts (Cabassa & Zayas, 2007; McMiller & Weisz, 1996). This reluctance is in part related to concerns regarding the negative perceptions of others or their own negative attitudes related to mental health treatment (Cabassa & Zayas, 2007) as well as to their mistrust of formal treatment systems based on a history of prior abuses (McMiller & Weisz, 1996).

The few studies of adolescent stigma suggest that stigma cuts across gender and race, but inconsistent findings warrant further research. In a study specifically examining stigma in adolescents, Moses (2009a, 2009b, 2010) determined that adolescents in treatment did not report a great deal of public (i.e., societal or direct experiences of stigma) or internalized stigma and that minority ethnic youth in particular did not self-label as mentally ill (Moses, 2009a). This study, however, did find that some youth experienced stigma across several proximal domains (e.g., family, peers, school) but that females and ethnic minorities reported less peer stigmatization (Moses, 2010). However, Lindsey, Joe, and Nebbitt (2010) found that among African American boys, stigma associated with seeking mental health services was associated with unsupportive and rejecting experiences with peers. Chandra and Minkovitz (2006) found that boys experienced more stigma related to having a mental illness and service use than girls, whereas Moses (2009b) found no differences by gender associated with youth’s likelihood to self-label as mentally ill. These studies of stigma in youth suggest a complex phenomenon and urge further exploration of stigma across multiple domains and the resulting social-psychological processes (e.g., shame, secrecy, withdrawal, and fear of rejection) as youth develop and consolidate their identity.

In sum, adolescence and young adulthood are critical periods for intervention with stigma (Hinshaw, 2005), yet research understanding stigma in adolescents and emerging adults has largely failed to explore the experiences and effects of stigma from the perspective of youth

in psychiatric treatment (Moses, 2009a, 2009b; Pescosolido, 2007). Examining differences by developmental stage (adolescence vs. emerging adulthood), gender, diagnostic group, and the role of the immediate ethnic/racial cultural context can inform developmentally appropriate interventions for youth and emerging adults that promote strategies to minimize the negative effects of stigma on these youth. Such data can also inform community or school-based programming that reduces the stigmatization of mental illness (MacLeod & Austin, 2003). Furthermore, stigma is a significant barrier to seeking mental health treatment (USDHHS, 2001). Many cases of psychiatric disorders in adolescence and young adulthood go untreated, which result in significant impairment to youths' emotional and physical functioning as they age. Gathering data on the experience of stigma among these youth may also contribute to improved treatment seeking and to the prevention and reduction of the long-term effects of stigma that are so profound and deleterious in adulthood (Hinshaw & Cicchetti, 2000; Link, Struening, Rahav, Phelan, & Nuttbrock, 1997; Link & Phelan, 2001).

As a contribution to this literature, the current study sought to understand the experiences of mental illness-related stigma in a sample of adolescents and emerging adults in psychiatric outpatient treatment. We used Link and Phelan's (2001) model to guide our qualitative inquiry in the absence of a model of stigma for youth.

## Method

### Participants and Sampling

Participants were consecutively recruited between October 2007 and May 2008 as part of a study to develop an instrument to measure mental illness stigma and sexual health among youth in psychiatric treatment. Participants were outpatients attending four community mental health clinics in New York City; all sites provide multidisciplinary psychiatric care and support services for youth or young adults with mental illness. All study procedures were approved by the New York State Psychiatric Institute institutional review board. Participants were eligible if they were (a) diagnosed with a *DSM-IV* Axis I disorder, (b) aged between 13 and 24 years, (c) English speaking, (d) capable of providing assent/consent, and (e) receiving psychiatric services at the clinic. Participants were excluded if they (a) had diagnoses of eating disorder, pervasive developmental disorder or Mental Retardation; (b) had a psychiatric disorder due to substance use, withdrawal, or intoxication; or (c) were currently acutely suicidal or psychotic.

We stratified our sample of 24 respondents by gender (14 male, 10 female), age (13–17 years, 18–24 years), and diagnostic group (psychotic, nonpsychotic disorders). A wide age range (13–24 years) was selected to capture different experiences of stigma at varying developmental stages during adolescence and emerging adulthood. Diagnosis was used as a stratifying variable as the adult literature suggests stigma is related to severity of diagnostic symptoms, particularly psychosis (Link, 1987; Link et al., 2001). We divided the sample into two diagnostic “groups”: psychotic disorders (e.g., schizophrenia, bipolar disorder, schizoaffective disorders, psychosis NOS) and nonpsychotic disorders (e.g., major depression without psychosis, generalized anxiety disorder, panic disorder). We did not stratify by race/ethnicity given the geographic location of the clinics where participants were recruited was predominantly Latino (18 Latino, 1 African American, 3 white, and 2 mixed

race/ethnicity). Consequently, we were not able to distinguish differences in the experiences of these youth by race/ethnicity; however, we position our findings in the context of this ethnic/cultural setting.

## Procedures

Participants were informed of the study by clinic providers. Using a purposive sampling method (Patton, 1990), we filled the cells of our sampling framework as recruitment progressed. For participants younger than 18, we obtained written informed assent from the youth and written informed consent for the youth's participation from his or her caregiver. For participants aged 18 to 24, we obtained written consent from the participant only. All those screened for eligibility and selected for the final sample consented to participate. Interviews were conducted in private rooms at the participant's clinic by one of three trained, female interviewers with at least a master's degree in psychology or related field. All interviews were audio recorded to facilitate transcription and took approximately 45 min; all participants received US\$24 for participation.

## Assessments

*Demographic information* was obtained using a nine-item questionnaire that elicited demographic and psychiatric information from the participant including age, gender, current or last grade completed, employment, current residence, treatment modality (type, length, frequency of treatment), current medication, and treatment history.

**The qualitative interview protocol.**—The interview aimed to elicit the subjective experience of stigma based on Link and Phelan's model of stigmatization (2001). The interview began by building rapport, asking participants to describe themselves, their families, friends, and schools/communities. The interviewer asked participants to describe beginning psychiatric treatment for the first time and their current attitude toward treatment (e.g., "What was it like when you first started receiving treatment in this clinic or a clinic like this one?"). The interview then explored specific experiences of stigma at the *individual level*, including experiences of discrimination and rejection by peers, romantic partners, and family members (e.g., "You've just described some of the people in your life. I'm wondering if anyone acted differently toward you, either in a good or bad way, after you began receiving treatment in this clinic?"), and *structural level* such as separation from mainstream groups at school; denial of club or group membership (e.g., "After beginning treatment, some people say they are still allowed to do all the things that they did before, but some people have said this changed. What about you?"). The interview also examined participants' *social-psychological processes* related to stigma, such as self-devaluation, poor self-concept, 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 might they think that? What about you?" "We've talked about experiences where people treated you differently since you began treatment. What do you do to manage these experiences?"). The interview protocol draws from prior research to examine social-psychological processes (Link, 1987; Link et al., 1989; Wright et al., 2000). As prior qualitative work has shown adolescents and adults may struggle with applying the term *mental illness* to themselves (Mowbray & Holter, 2002; Moses, 2009a, 2009b), the interview used terms such as *being in*

*treatment or care.* The interview guide was developed and tested with study team members experienced with this population; we pilot-tested the guide with 2 youth above 18 years of age, 1 male and 1 female, who were in psychiatric outpatient treatment. Medical directors at all study sites reviewed the guide for appropriateness of wording and content.

### **Data Coding and Analysis.**

All transcripts were entered into NVivo, a qualitative data software package. The central research question focused on understanding the experiences of stigma among youth in psychiatric outpatient treatment. We conducted a thematic analysis of the interview texts, employing inductive and deductive approaches. The initial coding scheme focused on the three main domains of stigma in Link and Phelan's (2001) model, which are (a) individual discrimination, (b) structural discrimination, and (c) social-psychological processes of stigma, to help interpret our findings.

The preliminary codebook was developed by three trained coders, including the first author, who selected 3 of the interviews and carried out an open coding phase together in which narratives pertaining to the above three domains were examined and primary codes applied. In the next phase, another 3 interviews were coded in order to expand primary codes and define secondary codes. As themes were identified, the transcripts were recoded by each rater working independently to document evidence that supported or refined the themes, to examine other mentions of these themes, or to identify other themes. Specific quotations within each category were then analyzed to identify similarities or differences to determine trends that might tie them together. After this initial coding, the three raters clarified and reached consensus about the coding scheme. The coders then independently applied this final code list to the remaining transcripts and compared codes for all interviews in order to achieve consensus. In cases where there was disagreement among the raters, only themes about which two or more coders agreed were included in the final analysis. Decision trails were documented to assure that interpretations were supported by the data. From this point forward, the coding schema were expanded only to capture novel responses or to refine secondary codes. This coding process is standard in qualitative methods and known as focused and intensive coding for primary and secondary themes (Lofland & Lofland, 1995; Straus & Corbin, 1998). We then compared and contrasted the major themes by subgroups comprised of gender, age (13–17 years vs. 18–24 years), and diagnostic group (psychotic vs. nonpsychotic disorders) in a process known as *descriptive cross-case analysis* or *analytic cross-case analysis* (Miles & Huberman, 1994). In order to achieve a deeper understanding of how stigma is experienced in different demographic or clinical contexts or conditions, we examined within subgroup differences or similarities in the major themes, for example, comparing differences in individual experiences of stigma (i.e., rejection by others, changes in relationships) between males and females or between older and younger youth.

## **Results**

### **Sample Characteristics**

Overall, 58% of the sample was male, 75% was Hispanic, 8.3% was white, 4.2% was African American, and 12.5% was mixed race/ethnicity (Hispanic and white). The mean age



was 18.1 years ( $SD = 3.3$  years), with 46% aged between 13 and 17 years. The majority of youth were in school (79.2%), 4.2% had dropped out of school, 16.8% had graduated high school and 8.4% had completed some college<sup>1</sup>; two participants stated they were currently employed. Almost all youth (95.8%) resided with family members and one youth reported living with his partner. Most youth (70.8%) reported initiating services at the clinic within the past year, 8.3% began treatment at their clinic within the past 5 years and 20.8% within the past 10 years; 62.5% reported taking psychiatric medication. Approximately 29% of the sample was diagnosed with a psychotic disorder: 4.2% had schizophrenia, 12.5% had bipolar disorder, type I, 8.3% had schizoaffective disorder, and 4.2% had psychosis NOS. Nonpsychotic disorders were major depressive disorder (without psychosis) or dysthymia—50.1%; generalized anxiety disorder—4.2%; ADHD—4.2%; panic disorder—4.2%; adjustment disorder—4.2%; and mood disorder NOS (without psychosis)—4.2%.

### The Experience of Stigma

Our analyses revealed eight main themes. We examined differences in major themes by age (younger [age 13–17] vs. older [age 18–24]), gender (male vs. female), and diagnostic group (psychotic disorder vs. nonpsychotic disorder). All youth are described by an alias in addition to their age, gender and diagnostic group.

### Perceptions of Stigma: Us and Them

In almost all transcripts we analyzed (23 interviews), youth articulated a general understanding that the larger society perceived and labeled those with mental illness as different. It was both tacitly and explicitly acknowledged that this social distinction was not a positive one. For example, one youth noted that the nonmentally ill “see you as, not necessarily a mental case, but they see you different ... you’re like outcasted” (Julie, female, age 20, white, psychotic disorder). Other youth noted the idea of mental illness as being contagious, “people think they can almost catch it” (Joseph, male, age 21, Other race/ethnicity, psychotic disorder). Finally, several youth articulated specifically how they believed people with mental illness were seen as different and set apart from the larger group. In particular, many youth believed that people without mental illness perceived individuals diagnosed with a mental illness as violent and dangerous, “They think you’re a murderer” (Augusto, male, age 23, Hispanic, psychotic disorder) or in some way unpredictable or unstable, “Some people might say, ‘I don’t want to be by you, because you may just wild out on me for no reason’” (Dameka, female, age 16, African American, nonpsychotic disorder). Although the origins of these messages were not discussed by many youth, one youth mentioned popular media as a powerful influence.

I think it’s because, usually when you see images of a mental institution on TV, it’s perceived as a place where dangerous and violent people are kept.... So they’d see me as some violent person who is going to therapy for some random violent reason.

(Richard, male, age 16, white, nonpsychotic disorder)

<sup>1</sup>Data on economic indicators were not collected but the average adjusted gross income in the community where the clinics were situated was US\$27,909, with approximately 26% of residents living below the poverty line (<US\$25k for NYC). See <http://www.city-data.com/zips/10040.html>

Some youth also acknowledged that not all people held stigmatizing beliefs about those with mental illness and that in many cases “it depended on the person” (Carlos, male, age 16, Hispanic, nonpsychotic disorder). Youth noted that although most people, teenagers especially, are “judgmental,” people who were “open-minded” were more likely to be accepting of the youth’s mental illness and to see them as “a human being, ... just going through a hard time” (Estrella, female, age 20, Hispanic, nonpsychotic).

We next explored how youth experienced stigma via individual and structural discrimination and also explored the social-psychological processes that operate through stigmatized individuals. All stigma-related experiences were described at the individual level and the youths’ social-psychological responses to these experiences.

### Individual Experiences of Stigma

**Rejection by Others.**—A key theme discussed by many youth (13) was experiences of rejection by others which typically occurred following the youths’ disclosure of their diagnosis or participation in therapy. Some youth believed this was because the other person considered their illness scary: “People were just afraid of my mental illness” (Joseph, male, age 21, Other race/ethnicity, psychotic disorder). Other youth indicated that people rejected them because their illness was difficult to manage or be around: “I have days when I’m just real serious [depressed]. And when she [a friend] sees that, she stays away from me” (Fernando, male, age 15, Hispanic, nonpsychotic disorder). The youth noted that he felt this friend gave him “attitude” when he was depressed and perceived her response to distance herself from him during these times as “childish.” Some youth reported a more subtle rejection by others. For example, one youth described the response of his teacher after he disclosed that he was in psychotherapy: “he just raised his eyebrows at me, but he didn’t say anything.... It was like a quick, sudden thing, and then we just moved on with the conversation” (Felipo, male, age 15, Hispanic, nonpsychotic disorder). This youth was “surprised” by his teacher’s response, and he felt ashamed as evidenced by his observation that he subsequently became more guarded about who he told “like I trust, but like I trust to a certain limit.... I’ll tell you certain things but then I stop telling about [being in psychotherapy].”

More prominent or salient experiences of rejection described by youth by family members who rejected the youths’ diagnosis and dissuaded the youth from seeking treatment. One youth with bipolar disorder described a visit from her grandmother following her first hospitalization: “She’s like ‘you tell your mom to leave you alone, and you don’t need to be taking no pills, ‘cause you’re not sick’” (Pilar, female, age 24, Hispanic, psychotic disorder). In some instances, rejection was due to the possible shame it would bring to the family to discuss one’s problems with nonfamily members: “My dad asks ‘Why do I have to talk to a stranger about my problems?’” (Leticia, female, age 17, Hispanic, nonpsychotic disorder). For some family members, their rejection of the youth’s diagnosis or need for treatment was perceived by the youth as a result of the family member’s own experience with mental illness or shame around how the youth’s diagnosis reflected upon them. “But she [mother] still has problems accepting that I have bipolar ... I think it reflects on her. When people say



‘oh your son’s bipolar’ and they start thinking ‘well you’re kind of crazy yourself’” (Joseph, male, age 21, Other race/ethnicity, psychotic disorder).

Of note, many (15) youth who reported experiences of stigma and rejection also reported experiences of support and acceptance by others. Youth reported that, despite their expectations of rejection, friends and family members to whom they disclosed supported their choice to get treatment: “They were like ... ‘yeah, you have to take medications, so take them’ ... and you know like they really like encouraged me to keep on coming [to therapy]” (Estrella, female, age 20, Hispanic, nonpsychotic). It is likely that these conflicting experiences contributed to the beliefs described earlier by youth that stigmatization of the mentally ill largely depends on the individual.

**Changes in Relationships.**—Although not completely rejected by friends and family members, several youth (10/24) reported negative changes in their interpersonal relationships following their diagnosis, hospitalization, or disclosure about treatment. Youth frequently reported that friends and family members communicated messages that suggested they were now different and not to be given independence or trusted: “they don’t treat you the same as you were before” (Rocio, female, age 23, Hispanic, psychotic disorder). One youth frustratingly described changes in her relationship with her mother following her diagnosis with bipolar disorder and release from hospital: “It’s since I came out of the hospital. She doesn’t trust me at all now” (Pilar, female, age 24, Hispanic, psychotic disorder). Youth also complained that too often they were seen by their family or friends as only their diagnosis and that much of their behavior was attributed to their illness.

Similar to positive or supportive experiences upon disclosure, many youth (13) also reported that some relationships in their lives changed for the better. In particular, several youth commented on improvements in their relationships with their parents, noting that their parents seemed “to understand” them more, “to back off” and in some cases “to be more open” with the youth once treatment had begun.

Some, youth described both positive and negative changes in relationships after being diagnosed with a mental illness and revealing this to friends or family members. The underlying message that these positive or negative changes conveyed was that they now required different treatment compared with those without mental illness because there was something “wrong with them.” This sentiment is captured by a youth following his hospitalization and subsequent diagnosis with bipolar disorder:

I: Did anybody else treat you differently.... ?

R: I guess everybody did. It was either people tried to treat me better, like I have some disability, and I had some people treat me worse, like I had some disability.

I: And why do you think people treated you better?

R: Because they thought something was wrong with me.

I: And why do you think people treated you worse?

R: Because they don't like people that have something wrong with them. (Oswaldo, male, age 13, Hispanic, psychotic disorder)

### Structural Experiences of Stigma

Contrary to expectation based on Link and Phelan's model, we found no themes in the data to suggest, even when asked, that youth were aware of or experienced structural discrimination, such as separation from mainstream groups at school, denial of membership to clubs, and so on. Rather, government institutions appeared to protect youth. For example, medical privacy laws allowed youth to provide minimal information (e.g., "doctors visit") to school staff about psychotherapy or psychiatric appointments. Similarly, weekly psychotherapy appointments were available before or after school hours which minimized disruption of education and other school activities.

### Social-Psychological Processes

Acknowledgment of societal stigma and individual-level experiences of stigmatization and discrimination appeared to take their toll on youth as they explicitly described internalized stigma and shame. Many youth also reported using coping mechanisms with which they attempted to manage and minimize the possible stigmatization and rejection by others.

**Internalized Stigma.**—Almost all youth (17) articulated beliefs about themselves as a person with mental illness that suggested that these youth had engaged with and internalized stigmatizing messages about mental illness. Shame permeated several narratives as youth described how having a mental illness made them different to everyone else, considering it a "vulnerability" or a "flaw" in who they were. In general, the theme of shame and believing themselves as "less than" due to having a mental illness was prominent among the narratives of youth with psychotic disorders. Some youth also reported a loss of self-worth following being diagnosed or when suffering from symptoms. One youth described how she "went from like being an independent person to just being home, being scared all the time" (Marisela, female, age 21, Hispanic, nonpsychotic disorder).

**Managing a Stigmatized Identity: Coping Strategies.**—Irrespective of whether youth internalized the belief that they were "less than" because of their mental illness, almost all youth (22) reported using coping mechanisms to manage a stigmatized or spoiled identity (Goffman, 1963) and to avoid potential rejection and discrimination by others: (a) distancing from the labeled group and (b) silence and withdrawal. Use of these coping mechanisms was possibly driven by the youth's general awareness of the negative views about those with mental illness.

**Distancing from the label group.:** Some responses indicated a subtle hierarchy of stigmatization as youth used language that distanced themselves from those they considered "crazier." For example, one youth commented on other patients she had seen at the clinic she attended: "I've seen crazy people here ... Like they talk to themselves and stuff ... It makes me feel a little better, because I'm not crazy" (Lupe, female, age 18, Hispanic, nonpsychotic disorder). When asked about themselves in comparison to this "crazy" other, youth noted that they were simply seeking help for problems and needed to "talk things through" with

someone who was trained to listen. By redefining the stigmatized group so that it did not include them, youth were able to acknowledge and agree with the larger cultural viewpoint about those with a mental illness as being devalued without it having direct meaning to them: “You remember that guy from the Virginia Tech thingy? Yeah, that’s a crazy person. I’m not that” (Milena, female, age 18, Hispanic, nonpsychotic disorder).

In tandem with moving themselves away from “crazy,” youth moved themselves closer to “normal” by describing themselves as “just like everyone else” or their illness in generic terms (e.g., “like diabetes”). Some youth normalized or de-exceptionalized their status as someone with mental illness by noting how common or prevalent mental illness is: “everybody has something wrong with them” (Rafael, male, age 17, Hispanic, nonpsychotic disorder), whereas others articulated that “everyone should go to therapy” (Roberto, male, 18 years old, Hispanic, nonpsychotic disorder), because “people always need somebody to talk to” (Alejandro, male, 18 years, Hispanic, nonpsychotic disorder).

**Silence and withdrawal: To disclose or not to disclose.:** Many youth struggled with disclosing their mental illness to others, fearing rejection or other forms of discrimination. Some youth noted that disclosing their mental illness to someone, particularly if that person was not well known to the youth, would “scare people away” and “create a barrier” (Julie, female, age 20, white, psychotic disorder), making it difficult to develop friendships. In general, youth chose silence or secrecy, “just don’t tell anybody you have schizophrenia” (Rocio, female, age 23, Hispanic, psychotic disorder), rather than disclose their status as someone with mental illness and risk rejection. One youth noted lying about the reason for his hospitalization to friends, telling them he “had pneumonia” because “they would probably say something ... or they’d just tell other people” (Oswaldo, male, age 13, Hispanic, psychotic disorder). This choice of coping strategy predominated in narratives irrespective of diagnostic group.

For some youth, disclosure of one’s mental illness occurred only when the other was someone they were “really close with,” and could “trust,” or was someone who had a mental illness or held nonjudgmental views on mental illness. The Internet also emerged as a place where youth could anonymously disclose their illness and discuss their experiences with virtual friends who understood.

**Denial of Stigma.**—Finally, the issue of stigma was also something some youth struggled to acknowledge or describe as relevant to their experience (7). However, despite their denial of being or feeling stigmatized, these youth used many of the coping strategies described by other youth (e.g., silence, withdrawal). For example, one youth when questioned about why he had told his friends he had Lupus but did not reveal that he was in treatment for depression and was unable to articulate a reason: “It’s different because—I don’t know.... I know why you ask me that, because in a way it’s like, why? They know I have Lupus, so it’s like why can’t they know I see a psychologist? I don’t really know” (Luis, male, age 19, Hispanic, nonpsychotic disorder).

For some, rather than attribute difficulties with disclosure to a fear of rejection by others, youth explained that their choice not to disclose was simply because it was “none of their

business” or that there was no point: “It’s not that I’m ashamed, it’s just—what good would it do?” (Carlos, male, age 16, Hispanic, nonpsychotic disorder). Although some youth did not anticipate any negative reactions from peers or family members if they were to disclose, they still had not done so but were unable to describe why: “I think it wouldn’t be a problem, but I don’t feel like it’s necessary for me to tell them” (Miguel, male, age 16, Hispanic, nonpsychotic disorder).

**Refusing to Hide: Rejection of the Negative Attributes of Mental Illness.**—Not all narratives reflected internalized stigma or recognition of being part of a discounted group. Several youth rejected the “label” of having a mental illness stating that they see no reason to hide their diagnosis or the fact that they are in treatment: “Like I don’t really care. [My friend] was like ‘hey, where are you going?’ ‘I’m going to therapy, dude!’” (Rafael, male, age 17, Hispanic, nonpsychotic disorder). Similarly, another youth questioned the need to hide and be secretive: “Why should you hide, just because you have to talk to a psychiatrist? I don’t mind telling anybody I have a psychiatrist” (Richard, male, age 16, white, nonpsychotic disorder). Other youth believed that rather than decreasing their worth, having a mental illness produced strength. This belief was held by several youth who had suffered through difficult periods with their illness or had experienced severe and often debilitating symptoms. This sentiment was captured by a woman who noted: “. . . it’s such a big thing to say, ‘but I was able to get through it.’ So I sort of felt that I accomplished something” (Milena, female, age 18, Hispanic, nonpsychotic disorder).

### Differences in Stigma by Clinical and Demographic Factors

When examining variations in the main themes by demographic and clinical characteristics, we found differences based on diagnostic group (psychotic vs. nonpsychotic disorder), age group (13–17 vs. 18–24), and gender. Although the distribution of the sample precluded our examining differences by youth’s race/ethnicity, there were no instances during the interviews where youth explicitly linked their experiences to their race/ethnicity or to cultural norms.

**Perceptions of Stigma: Us and Them.**—While general recognition of the larger cultural negative view of mental illness did not differ by age, gender, or diagnostic group, only youth with nonpsychotic disorders noted that some people, but not all, held pejorative or negative beliefs about those with mental illness. In contrast, no youth with psychotic disorders voiced the belief that not everyone stigmatized against the mentally ill. There were also gender differences in youths’ perceptions of how those with mental illness were treated by nonmentally ill others. Males tended to note that the nonmentally ill considered those with mental illness as violent, whereas females reported that the nonmentally ill perceived those with mental illness as fragile or incapable.

**Individual Experiences of Stigma: Rejection by Others.**—We found that there were differences in experiences of rejection by others for youth with psychotic versus nonpsychotic disorders. The experience of supportive or nonjudgmental responses from others was clearly defined along diagnostic lines with few, if any, youth with psychotic disorders reporting supportive experiences upon disclosure of their diagnosis or status as a

psychiatric patient. Also, youth with psychotic disorders generally reported rejection by family members and described experiences that were more confrontational, severe, and in which they were blamed for their illness or current situation: “Get your shit together.” In contrast, youth with nonpsychotic disorders reported more subtle experiences of rejection such as a raised eyebrow or a momentary “pause in the conversation.” Irrespective of age, youth reported experiences of rejection by peers and family members. However, unlike older youth, younger youth (aged between 13 and 17) described experiences where their families denied or rejected their illness or need for treatment. As younger youth had more recently entered treatment compared with older youth in the current sample, these differences in family responses may reflect the process of accepting the child’s more recent diagnosis of mental illness. Similarly, although both males and females experienced rejection by others, females characterized their rejection experiences in terms of change in quality or ending of relationships with friends or family members, whereas males described singular or direct experiences of rejection, such as being made fun of for taking medications or being described as “lazy.”

**Individual Experiences of Stigma: Changes in Relationships.**—Negative changes in relationships were typically described by youth with psychotic disorders. In contrast, it was only youth with nonpsychotic disorders who described improvements in their relationships with their friends and family members following the disclosure of their diagnosis; we found few differences by age or gender.

**Internalized Stigma.**—Youth who were older and who had been diagnosed at an older age commented on their struggle to understand their new identity in the context of having a mental illness and described a need to “find their ‘real self’” following diagnosis or to “adapt to their new self.” Males and females differed in the source of their internalized shame. Females tended to report feeling less-than because *others* would think less of them for having a mental illness or being in treatment. In contrast, males noted feeling different or less-than compared to others because *they* had a mental illness or were in treatment. Youth with nonpsychotic disorders spoke of their illness in terms of being “normal,” or that they “just need a little help” and “treatment is for everyone,” thereby separating themselves from the more “crazy” group. In contrast, most youth with psychotic disorders did not distance themselves from those who are sicker; this was possibly due to the youth being less able to “hide” the mental illness symptoms. Youth with nonpsychotic disorders also reported more difficulty with disclosure and tended to deny stigma, despite engaging in various coping strategies to manage a stigmatized identity.

**Rejecting Stigma.**—Examining differences by age, we found that older youth or youth who had been in treatment/diagnosed for a longer period of time reported an early period of shame regarding their mental illness but described how they no longer felt this way about themselves, that they had outgrown feeling stigmatized. “I grew out of that stage of, ‘Oh my God, I’m crazy! And I can’t tell nobody that I go to a doctor and a therapist,’ ... whatever!” (Milena, female, age 18, Hispanic, nonpsychotic disorder).

As youth age, they may be better equipped to deal with the negative stereotypes associated with having a mental illness. However, this may be a function of diagnosis. Youth with a

psychotic disorder did not articulate rejecting the “label” and freely disclosing their diagnosis to others.

## Discussion

The current study extends the growing literature of mental illness-related stigma by examining the experiences of stigma in both adolescents and emerging adults receiving psychiatric outpatient treatment. The results show that stigma is prominent in the lives of youth with mental illness who are aware that they exist within a larger cultural context that holds pejorative viewpoints toward those with mental illness. Findings suggest that youth in the current study experience stigma in the form of individual discrimination and rejection within their families and social networks and through several internalized stigma messages from the larger society as well as from family and peer systems. Several of the themes identified are similar to those described in the adult and youth literature. Our results offer additional insight into the social-psychological processes of stigma by highlighting how labeling may influence the self-concept of youth with mental illness and the strategies in which they engage in order to manage these identities, including differences by age, gender, and diagnostic group. We first discuss findings in context of the extant literature and then provide recommendations for intervention.

Irrespective of diagnosis, age, gender, or individual experiences of discrimination, all but one participant in the current sample acknowledged that society held pejorative views of and engaged in rejecting behaviors toward those with mental illness. Their recognition of this broader cultural viewpoint is in contrast to Moses (2009b) who found that youth in general believed the larger community held benign views toward those with mental illness. These differences, however, may be attributable to sample characteristics. Youth in the current study were, on average, older, were older at first diagnosis, and had a greater number of psychotic disorders. In addition, the majority was Latino and resided in a large urban city, whereas Moses' (2009b) sample was predominantly white and resided in a smaller Midwestern city. This racial/ethnic difference in sample composition is particularly meaningful as studies of adults have suggested that stigma may be more prominent in the Latino cultural context (Alvidrez, 1999; Gonzalez, 1997), although we did not recruit a non-Latino comparison group in the current study that would allow us to specify how this appears in youth. Our findings are, however, consistent with studies of adults with SMI and with other stigmatized statuses in which acknowledgement of the larger negative cultural viewpoint was found (Earnshaw & Chaudoir, 2009; Link et al., 1997).

Stigmatizing messages also came from within the family. Consistent with Moses (2010), parents and family members communicated messages that mental illness was a negative trait via rejection or denial of the youth's illness/need for treatment; change in how they related to, treated, and perceived the youth; failure to acknowledge the youth's illness; or expressed preference for the youth to not discuss mental health difficulties outside of the family. Such behavior may be a result of the shame, blame, or fear of “catching” the youth's illness that family members experience (Corrigan & Miller, 2004).



Given the Latino cultural context of a large majority of the sample, family members' views about mental illness and acceptable ways of healing are also likely culturally and historically grounded. In the context of heightened stigma around mental illness, Latinos tend to perceive physical illness as more serious than mental illness and may struggle to acknowledge their child's difficulties in terms of a psychiatric illness (Gonzalez, 1997; Wells, Hough, Golding, Burman, & Karno, 1987). Furthermore, the concept of familism—the individual's strong attachment and loyalty to the family (Sabogal, Marín, Otero-Sabogal, Marín, & Perez-Stable, 1987)—is associated with Latinos' preference to seek assistance and support from within the family, and to value privacy, and is likely associated with family members' requests to not discuss problems with a professional. Given the importance of the family in youth healthy development, particularly in the Latino culture, the impact of stigmatizing messages and discrimination within the family likely has long-term consequences for these youth. Longitudinal research is needed that examines the effects of stigma and discrimination experienced within the family as the youth incorporates family values, attitudes, and beliefs into his or her own identity and self-concept throughout adolescence and emerging adulthood.

As in other studies of youth and adults (Lindsey et al., 2010; Link & Phelan, 2001; Moses, 2010), we identified challenges in the social-psychological domain that often accompany the label of mental illness, such as shame, lower self-worth, and anticipation or fear of rejection. We found that several adolescents and emerging adults expressed difficulty integrating or adapting to their new identities as someone with mental illness. This was particularly true of youth who were diagnosed at an older age and who likely had a more developed or integrated identity, into which a mental illness diagnosis was hard to incorporate. The result was a loss of self-confidence or uncertainty of their own functioning. Interestingly, only older youth who had been diagnosed with a nonpsychotic illness when younger acknowledged “growing out” of feeling ashamed about their mental illness. These findings suggest that some youth may develop resilience to stigma and its associated social-psychological effects as they age.

Similar to other studies of adults and adolescents with mental illness (Link et al., 1997; Moses, 2009b), youth in the current sample reported engaging in multiple methods of coping with stigma, such as silence and withdrawal. In some instances, youth moved away or separated themselves from the labeled group and denied the impact of stigma or its relevance to their lives. This demonstrates that there is wide variability in the stigmatization of mental disorders and the extent to which youth respond to the label of *mentally ill* as a result. Refusing to self-label or distancing oneself from the labeled group is consistent with Moses' study in which only 20% of youth applied a diagnostic label to themselves (Moses, 2009a). In the current study, this strategy was used primarily by older youth with nonpsychotic disorders, the majority of whom had an internalizing disorder (e.g., anxiety or depression). As the name suggests, internalizing disorders are those with less overt symptoms which may be more easily hidden.

Issues around disclosure—when to tell, whom to tell—were prominent for almost all youth, regardless of gender, race/ethnicity, age, diagnosis, or direct experiences of stigma. Given the developmental stages of adolescence and emerging adulthood, during which youth are

consolidating their social conceptualization and worldview while simultaneously seeking acceptance and belonging (Erikson, 1980), their awareness of the negative perceptions and potential rejection by others is likely acute and the impact of stigma profound. Youths' narratives suggest that awareness of the larger cultural viewpoint subsequently affected their self-concept and social behavior. Yet research on the effects of stigma on a wide array of youth behavior is limited. Further research is warranted that examines the association between youths' experiences of mental illness stigma, social psychological processes, and behaviors.

This study finds some support for the application of Link and Phelan's (2001) theoretical model of stigma to adolescents. Of the three central stigma processes—individual discrimination, structural discrimination, and the internal social-psychological processes—we failed to find evidence of structural discrimination in our sample. Instead, we observed that structural factors were “protective” and potentially limited opportunities for stigmatization. The absence of structural discrimination may be a function of the youths' age as their constricted social experiences may have limited their opportunities for more structurally determined forms of discrimination. We did find, however, evidence to suggest that the effects of modified labeling theory, as proposed by Link et al. (1989), were already present in youth as young as 13 years old. We also identified social-psychological processes of stigma that are perhaps unique to youth and emerging adults such as struggling to incorporate stigma into their identity or the experience of “growing out” of internalized stigma.

We did not find any explicit recognition of the role of race/ethnicity or cultural context on the stigma experiences described by the youth. This may be a function of the lack of exposure to other race/ethnic groups in this largely Latino sample. All youth in the current study resided and worked in a Latino neighborhood in New York City, attending high schools comprising predominately Latino youth. Research suggests that such youth often do not examine ethnic issues and that ethnic identity formation continues well after adolescence as youth have more experiences that highlight their minority status within the larger culture (Phinney, 2006). Additional studies with larger and more ethnically diverse samples should be conducted to more clearly examine the role of race/ethnicity in the stigma experiences of youth and emerging adults.

## Limitations

This study has a number of important 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 socioeconomic statuses (SESs), other types of psychiatric treatment, or other parts of the country. Findings from this self-selected, voluntary 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 of mental illness. Second, 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 seeking treatment may

not generalize to other ethnic communities. The effects of mental illness stigma also may have been confounded by experiences of racial discrimination experienced by these youth. Moreover, studies of Latino and African American families have shown reluctance to seek mental health treatment from professionals or institutions (USDHHS, 2001). However, the presence of these youth in treatment may indicate that these youth and families hold differing ideas about mental illness and psychiatric treatment than others in their community. Third, we did not capture data on youth's SES, differences in which may have also affected perceptions or experiences of stigma (Bird & Bogart, 2001; Moses, 2009a). However, all youth in the sample resided in the same economically depressed area of New York City, and it is likely that a vast majority of the youth were from the same socioeconomic class. When given the opportunity to describe other experiences of stigma and discrimination related to their race/ethnicity or SES, no youth volunteered these experiences. 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. 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; Moses, 2009a).

### Practical Implications

These limitations notwithstanding, this study offers several prevention implications for both clinical and nonclinical settings. Many interventions for mental illness stigma have been focused at structural or community levels (Corrigan, Kerr, & Knudsen, 2005), yet in other stigmatized identities (e.g. HIV/AIDS), the impact of interventions at this level have not always translated into improved individual-level outcomes (Earnshaw & Chaudoir, 2009). Data from the current study suggest a multilevel approach to combat stigma is needed, one that addresses risk at individual, family, and community levels.

**Individual.**—Mental health treatment providers are well positioned to address internalized stigma through discussion of the effects of stigma and by building mastery and self-esteem for these youth. Providing evidence-based tools to practitioners for helping youth to overcome effects of stigma would be consistent with the growing emphasis on recovery (Sullivan, 1997). Group-based prevention interventions that provide support for youth and promote the development of healthy identities and coping responses to stigmatizing experiences are needed. Providers should also be particularly sensitive to issues around identity development and stigma in minority ethnic youth. As these youth begin to formulate their ethnic identity, which begins as they develop an awareness of characteristics that differentiate them from certain people (Côté, 2006), they may simultaneously become aware of additional characteristics related to their identity as a person with mental illness that differentiate them from their own ethnic/racial group as well as the dominant racial/ethnic group. Interventions for ethnic youth must address issues related to stigma within the youth's dominant and proximal cultures.

**Family.**—Family-based antistigma prevention programs that address stigma within families, provide positive messages around mental illness, and promote active, frank discussion as opposed to silence and denial of the youth's illness may promote the development of youths' positive self-concept. These interventions must be attuned to the cultural context to which

the families belong, acknowledging learned values and norms around mental illness and treatment seeking while addressing stigma. Furthermore, not all family members in this study conveyed stigmatizing messages but instead were supportive of the youth, suggesting that multiple family groups may serve to reduce the effects of stigma felt within and by families (Lindsey et al., 2010). “Psychiatric socialization” within the family may be a potentially robust protective factor against the impact of stigma among adolescents given the greater daily proximity to their parents.

**Community.**—Data from the current study suggest that school, community, and media-based intervention programs that dispel myths associated with mental illness, promote understanding about the etiology of mental illness, and “de-exceptionalize” mental illness are still needed. The National Comorbidity Study found that approximately one out of two people in the United States will experience a mental *disorder* in their lifetime (Kessler et al., 2005), suggesting that psychiatric illness is neither unusual nor restricted to a troubled few.

## Conclusions

The current study reveals that stigma associated with mental illness is prominent in several domains in the lives of adolescents and emerging adults with mental illness, for whom the possible lifetime management of a mental disorder has only just begun. Some youth had already internalized the pejorative messages about those with mental illness, which were received from their families, social networks, and the larger sociocultural context in which they live. Multiple efforts to reduce the stigmatization of these youth are likely required in order to combat the negative effects of stigma in youth, and programs aimed at assisting youth with managing stigma should perhaps begin in tandem with the initiation of treatment.

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