Stigma related to labels and symptoms in individuals at clinical high-risk for psychosis

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ABSTRACT

Background: Despite advances that the psychosis "clinical high-risk" (CHR) identification offers, risk of stigma exists. Awareness of and agreement with stereotypes has not yet been evaluated in CHR individuals. Furthermore, the relative stigma associated with symptoms, as opposed to the label of risk, is not known, which is critical because CHR identification may reduce symptom-related stigma.

Methods: Thirty-eight CHR subjects were ascertained using standard measures from the Center of Prevention and Evaluation/New York State Psychiatric Institute/ Columbia University. Labeling-related measures adapted to the CHR group included "stereotype awareness and self-stigma" ("Stereotype awareness", "Stereotype Agreement", "Negative emotions [shame]"), and a parallel measure of "Negative emotions (shame)" for symptoms. These measures were examined in relation to symptoms of anxiety and depression, adjusting for core CHR symptoms (e.g. attenuated psychotic symptoms).

Results: CHR participants endorsed awareness of mental illness stereotypes, but largely did not themselves agree with these stereotypes. Furthermore, CHR participants described more stigma associated with symptoms than they did with the risk-label itself. Shame related to symptoms was associated with depression, while shame related to the risk-label was associated with anxiety.

Conclusion: Both stigma of the risk-label and of symptoms contribute to the experience of CHR individuals. Stereotype awareness was relatively high and labeling-related shame was associated with increased anxiety. Yet limited agreement with stereotypes indicated that labeling-related stigma had not fully permeated self-conceptions. Furthermore, symptom-related stigma appeared more salient overall and was linked with increased depression, suggesting that alleviating symptom-related shame via treating symptoms might provide major benefit.

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1. Introduction

Early intervention for individuals at clinical high-risk (CHR) for psychosis offers the possibility of forestalling the development of threshold psychosis (Fusar-Poli et al., 2012), but simultaneously confers a label of risk with potentially stigmatizing consequences (Carpenter, 2010; Corcoran et al., 2005; Yang et al., 2013). This issue is salient, as the label of risk is conferred upon all participants in a high-risk cohort, irrespective of whether they ever progress to full-blown psychosis (Yang et al., 2010). Capturing complex issues of labeling and stigma in this population is crucial to optimally assist youth at a possibly critical juncture. Our study presents measures of the potentially stigmatizing effects of the label of risk for psychosis, while simultaneously assessing the stigmatization that participants may experience due to symptoms.

1.1. Stigma of psychiatric labeling and CHR

While stigma has myriad manifestations, forms of stigma traditionally linked with "labeling processes" (i.e., when an individual is diagnosed with mental illness via contact with a mental health clinic) have been most studied (Link et al., 1989). One such labeling-related stigma process includes stereotype awareness, or when stigmatized persons become aware of negative stereotypes and subsequently withdraw from others due to anticipated rejection. In the closely-linked concept of "self-stigma" (Corrigan et al., 2006), psychiatrically labeled individuals might internalize and apply stereotypes to themselves in psychologically harmful ways (Ritsher and Phelan, 2004), including agreeing with negative stereotypes and feeling ashamed (Rüsch et al., 2014a). A recent meta-analysis demonstrates that internalized and

self-stigma show a particularly robust relationship with psychiatric symptom severity ($r = .41$, $p < .001$) (Livingston and Boyd, 2010).

Recent cross-sectional (Rüsch et al., 2014a) and longitudinal (Rüsch et al., 2014b) studies of early identified youth at high risk of psychosis, ultra-high risk of psychosis, or risk of bipolar disorder have demonstrated negative effects of stigma and self-labeling on "stigma stress" and psychological well-being. We build on these promising studies, which employed single-item assessment, by characterizing both stigma associated with the label of risk and stigmatizing reactions to symptomatic behaviors; e.g., feeling "different" due to unusual perceptual experiences. Regarding traditionally-defined labeling-related stigma concepts (i.e., when individuals become aware of or internalize societal stereotypes following psychiatric labeling), "stereotype awareness and self-stigma" includes awareness of societal stereotypes ("stereotype awareness"; Link et al., 1989), agreement with such stereotypes ("stereotype agreement"; Corrigan et al., 2006), and experiencing emotions of shame or differentness ("negative emotions [shame]"; Link et al., 2004). Furthermore, stigma associated with a label of risk (e.g., attending a specialized CHR clinic) could also evoke positive feelings (e.g., relief; "positive emotions") coping responses, (e.g., concealment; "secrecy"; Link et al., 1989), unfair community treatment ("experienced discrimination"), and conversely, forms of help ("experienced support").

1.2. Stigma associated with symptoms

Stigma associated with symptoms has particular salience because the CHR label, applied while initiating early identification and treatment of symptoms, may have powerful *positive* effects, by reducing stigma related to these symptoms. Early identification via labeling may provide benefits by offering an explanatory model, validating experiences (Hayne, 2003), and initiating focal treatment (McGorry et al., 2002). Thus, early identification might reduce stigma via treating symptoms which lead to social isolation (a risk factor for psychosis-onset), thereby averting potent effects of a full-blown psychosis label and/or hospitalization (McGorry et al., 2001). Further, individuals identified as CHR likely already experience marked co-morbidity including anxiety and depression (Corcoran et al., 2011), which already evoke stigma. Accordingly, any additional stigma from being identified as CHR may be outweighed by reducing symptoms and any concordant stigma (Corcoran et al., 2005).

We introduce measures assessing stigma of symptoms that are designed specifically for a CHR cohort, so that stigma from varying sources (labeling vs. symptoms) might be distinguished. While labeling-related stigma arises in relation to being psychiatrically labeled (i.e., attending specialized CHR clinic services), 'stigma of symptoms' manifests specifically due to the odd symptoms or behaviors associated with CHR. Complementary to the labeling-related stigma domains, stigma of psychotic-like symptoms might include shame-related emotions (e.g., associated with hallucinatory experiences: "negative emotion (shame)-symptoms"; Lysaker et al., 2008), positive emotions (e.g., feeling hopeful; "positive emotion-symptoms"; Schrank et al., 2014), concealment ("secrecy-symptoms"; Ryder et al., 2000), discrimination ("experienced discrimination-symptoms"; Penn et al., 2000), and support from community others ("experienced support-symptoms"; Wong et al., 2009).

1.3. Aims and hypotheses

This study's aims were threefold. For Aim #1, we characterized as to what extent labeling-related stigma was experienced by CHR individuals. When possible, we descriptively compared stereotype awareness to published data from a sample of adolescents with non-psychotic disorders (Moses, 2009). This adolescent (12 to 18 years old) sample was recruited from a mental health care service for adolescents with severe emotional disturbance and was markedly impaired with ADHD, depression, anxiety or conduct disorder. For Aim #2a, we tested associations among the labeling-related "stereotype awareness" and "self-stigma" constructs, specifically stereotype awareness, stereotype agreement and

negative emotions (shame). For Aim #2b, based upon meta-analysis results (Livingston and Boyd, 2010), we examined the association of anxiety and depression with self-stigma related to the CHR label and with self-stigma related to symptoms, adjusting for core CHR symptoms of negative and attenuated psychotic symptoms. For Aim #3, we compared labeling-related stigma vs. symptom-related stigma. If the label of risk is stigmatizing, we might expect elevated stereotype awareness and agreement (Aim #1), significant associations among labeling-related stigma concepts (Aim #2a), significant associations between labeling-related stigma with anxiety and depression (Aim #2b), and higher label-related stigma (Aim #3). Alternatively, if stigma of symptoms is more prominent, we might expect significant associations between symptom-related stigma with anxiety and depression (Aim #2b) and higher symptom-related stigma (Aim #3).

2. Methods

2.1. Procedure

Assessments were conducted within a longitudinal cohort study of psychosis-risk at the Center of Prevention and Evaluation (COPE) in the New York State Psychiatric Institute (NYSPI)/Columbia University Medical Center. Individuals enrolling at COPE were informed that they met the criteria for being at-risk for psychosis, which was like the experiences and symptoms that they were already experiencing, but more severe, which might further impact functioning. They were also informed that about 65% of participants would not develop psychosis. They were reassured that were they to develop psychosis, they would immediately receive one of several beneficial treatments.

Thirty-eight CHR participants were administered a battery of stigma measures after CHR identification, on average 11.5 (SD = 11.7) months after entering the specialized CHR clinic. Symptom measures took place at baseline and every 3 months thereafter; the most proximal symptom ratings to the stigma assessment were utilized.

2.2. Subjects

CHR individuals were help-seeking and met the criteria for at least one of three psychosis-risk syndromes, as assessed with the Structured Interview for Prodromal Syndromes (SIPS; Miller et al., 2003). Patients were between 12–30 years old and English-speaking. The exclusion criteria included history of psychosis, serious risk of self-harm/violence, major medical/neurological disorders, IQ < 70, and psychotic-like symptoms accounted for by substance abuse or another psychiatric disorder. CHR individuals were referred from a wide network of school administrators and clinicians, or self-referred. Informed written consent was obtained from adult participants and from parents of minors, who themselves provided written assent. This study was approved by the NYSPI/Columbia University Institutional Review Board.

Table 1 summarizes sample characteristics; >85% had been diagnosed with a non-psychotic Axis I disorder, typically anxiety and depression, prior to enrollment. The one individual in Table 1 who had received what was determined to be a prior erroneous diagnosis of "schizophrenia" by community clinicians was referred to COPE within one week of this diagnosis and was found to not have met the full criteria for psychosis or schizophrenia, and instead met the criteria for CHR. In order to preserve the study's naturalistic validity whereby inaccurate diagnoses may result from prior non-standardized clinical assessments and because inclusion of this individual did not change the main results, we retained this individual in all analyses.

2.3. Measures

All stigma measures were adapted from scales developed by Link et al. (1989), with language modified for CHR youth. Unless otherwise specified, stigma items used a 4-point Likert scale (1 = *strongly disagree*