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Impact of "Psychosis Risk" Identification: Examining Predictors of How Youth View Themselves

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Contributors

LHY, LS, WM, CC and BGL designed the study.
KW, DS, DD, and RG coordinated the study.
CB, DD, GB, and FMC collected the data.
DH and LHY analyzed the data, and LHY, KW, BGL, CC, LS, and WM interpreted the data. FMC conducted the literature search.
LHY and KW wrote the first draft, and BGL, CC, LS and WM commented on and edited the manuscript for intellectual content.
All authors reviewed the manuscript for important intellectual content and approved the manuscript for publication.

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Abstract

Background: Identifying young people as at clinical high-risk (CHR) for psychosis affords opportunities for intervention to possibly prevent psychosis onset. Yet such CHR identification could plausibly increase stigma. We do not know whether these youth already perceive themselves to be at psychosis-risk (PR) or how their being told they are at PR might impact how they think about themselves.

Methods: 148 CHR youth were asked about labels they had been given by others (labeling by others) or with which they personally identified (self-labeling). They were then asked which had the greatest impact on how they thought about themselves. We evaluated whether being told vs. thinking they were at PR had stronger effects.

Findings: The majority identified nonpsychotic disorders rather than PR labels as having the greatest impact on sense of self (67.6% vs. 27.7%). However, participants who identified themselves as at PR had an 8.8 (95% CI=2.0-39.1) increase in the odds of the PR label having the greatest impact ($p<0.01$). Additionally, having been told by others that they were at PR was associated with a 4.0 increase in odds (95% CI=1.1-15.0) that the PR label had the most impact ($p<0.05$).

Interpretation: Nonpsychotic disorder labels appear to have a greater impact on CHR youth than psychosis-risk labels. However, thinking they are at PR, and, secondarily, being told they are at PR, appears to increase the relative impact of the PR label. Understanding self- and other-labeling may be important to how young people think of themselves, and may inform early intervention strategies.

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Keywords

Clinical high risk state for psychosis; psychosis risk; early intervention; identity; stigma

1. Introduction

Despite emerging evidence that early treatment of mental illness may positively impact illness course and recovery (Fusar-Poli et al., 2013; McFarlane et al., 2015), stigma can prevent those experiencing early signs of mental illness from accessing treatment, cause psychological distress, and disrupt capacity for full recovery (Yang et al, 2010, Corcoran et al., 2005). A vanguard movement is now identifying youth at clinical high-risk (CHR) for psychosis with the aim of altering the course of illness and potentially preventing the onset of an initial episode of psychosis (Yung et al, 2003, Fusar-Poli et al., 2013). Yet identification of CHR youth, and conveying of psychosis-risk (PR) status, has raised questions about what effects communicating this high-risk status may have upon identified

youths' views of themselves. To advance strong preventive measures, public mental health efforts must confront these issues to maximize benefit and minimize harm.

Youth identified as at CHR (henceforth: "CHR youth") are identified via interview (e.g., for this study, the Structured Interview for Psychosis-Risk Syndromes [SIPS]; Miller et al., 2003) predominantly by the presence of new or worsening attenuated psychotic symptoms (e.g., unusual and unfounded concern about being watched) accompanied by distress or impairment (Woodberry et al., 2016). We use "CHR" to refer to the syndrome itself and youth identified by internationally-recognized risk criteria (via the SIPS). It is thus a technical term. We use "psychosis-risk (PR)" to refer to the broad concept of elevated risk for developing psychosis as it might be conveyed or understood by non-researchers.

CHR programs may alleviate stigma through careful clinical practice. This often includes taking a proactive mental health care perspective centered on an individual's or family's specific experiences, values, and understanding of mental health and illness (Friedman-Yakoobian, in press). Conveying PR to youth may bring relief and encourage health-promoting behaviors (Yang et al., 2015). Conversely, conveying PR to youth may activate stigma via an additional psychiatric "label" of PR (Yang et al., 2015; Tsuang et al., 2013), thus eliciting distressing negative stereotypes associated with psychosis (Uttinger et al., 2015). Approximately 30-35% of CHR youth may develop threshold psychosis within 2-2½ years of identification, meaning that a majority thus identified could be exposed to potential stigma for a condition that in some cases will never develop (Fusar-Poli et al., 2012).

Understanding stigma related to CHR identification is complicated by high rates of comorbid, pre-existing diagnoses and prior labeling. The majority (~82%) of identified individuals have had treatment (and thus encountered labeling) for nonpsychotic disorders (e.g., depression or anxiety; Woodberry et al., 2016, McFarlane, et al, 2015). CHR youth are distressed by affective or cognitive symptoms that may themselves elicit burden or exclusion (Cavelti et al., 2014) and are identified with heterogeneous diagnoses (e.g., depression or anxiety, and/or CHR), any of which could have differential ramifications for the future development of distress, stigma, help-seeking or treatment engagement (Moses 2009a, 2009b, Yang et al, 2013). It thus remains unknown to what extent CHR youth identify with pre-existing nonpsychotic conditions, compared with a newly-developing PR status.

1.1 'Labeling by Others ' and 'Self-Labeling ' Processes

Dual processes of being told that one is at PR (labeling by others) and thinking oneself to be at PR (self-labeling) may be associated with increased sense of stigma and poorer psychological well-being (e.g., among youth with nonpsychotic disorders who think of themselves as "mentally ill"; Moses, 2009a, Moses 2009b). Psychiatric "labeling" by socially-relevant others (Link et al., 1989), including via formal diagnosis by mental health clinicians, may alter youths' views of themselves. Given that PR may be conveyed to youth whose self-views are still developing (Nieman & McGorry, 2015), the impact of being labeled as at PR by others (including mental health professionals, school officials, and relatives; Wisdom & Green, 2004) may have long-lasting effects.

However, youths' identities are not entirely dependent on others telling them they are at PR (see Figure 1). CHR youth may also be affected by their own "self-labeling", or what they have come to believe about themselves through experience or their own meaning-making (Thoits, 1985). Self-labeling with PR may begin when an individual observes and classifies his/her symptomatic experiences as indicators that something is seriously wrong, and that they may be experiencing a form of nascent psychosis. This self-labeling might then lead to a heightened awareness and agreement with societal stereotypes of psychosis (Corrigan et al, 2011). Having a family history of psychosis may further facilitate this (Kim et al, 2017). Private 'self-labeling' of PR status could thus initiate changes in how CHR youth see themselves. No prior research has examined *if, and what, CHR youth label themselves at-risk for*. Further, we do not know the relative impact of self-labeling and other-labeling on a youth's sense of self.

Being told that one is at PR may introduce or reinforce self-labeling as being at PR. Self-labeling may thus partially account for some effects of being labeled by others. Alternatively, being told one is at-risk for PR may impact how one thinks about oneself independent of self-labeling processes. Understanding how these processes impact CHR youth' self-identification is key because changes in sense of self have been linked with stigma, psychological well-being, and mental health service utilization in youth with nonpsychotic illnesses (Moses, 2009a; Moses, 2009b).

Self-labeling and labeling by others also take place within the context of "individualized feedback" by specialized CHR programs, or when the PR status is communicated by specialized CHR clinicians to identified youth (which also might be considered a specialized form of being "labeled by others"). Yet the content and timing of individualized feedback regarding PR status varies across CHR programs by context, clinician, youth, and family (Friedman-Yakoobian et al., in press). Further, there currently is no consensus on a standardized feedback procedure for all participants in CHR programs. Specialized CHR program clinicians are typically trained to give individualized feedback based on a wide range of factors, including the individual and family's concerns and treatment engagement, cultural background, and estimated risk within the CHR classification. For example, PR feedback might be adapted according to relatively low level symptoms or the presence of factors associated with reduced risk (e.g., intact cognition, being of older age, having high social functioning, etc.; Cannon et al., 2016). Better understanding of how self-labeling and labeling by others contribute to how CHR youth see themselves could help guide the process of how PR status is conveyed to youth across specialized CHR programs.

1.2 Hypothesis:

We first provide descriptive data by assessing the extent to which CHR youth self-identified as at PR, vs. other non-psychotic labels. Following, given prior literature showing respective effects of both labeling by others and self-labeling, we hypothesized that being told one is at PR, and thinking one is at PR, would each have independent effects on how CHR youth view themselves.

2. Methods

2.1 Procedures

Data are from 148 CHR participants in a study conducted between November 2012 and December 2015 at Beth Israel Deaconess Medical Center/Harvard Medical School (Boston, MA), Maine Medical Center (Portland, ME), and New York State Psychiatric Institute (New York, NY). In conveying PR status, while site clinicians were not trained or instructed to provide uniform PR feedback (following standard practice as described above), PR feedback addressed the risk that the individuals' attenuated psychotic symptoms might worsen, that they were at higher risk of developing a psychotic disorder than their peers, and that being 'at risk' is different than actually 'having developed' a psychotic disorder. The specific language used, timing and spacing (one session or multiple), and nature (oral and/or written) of feedback varied according to clinical judgment and individual factors such as presenting concerns and questions, language capacity, symptom severity, insight, and family cultural values and norms. These variations are common to many CHR clinics and research settings around the world. Thus, in lieu of mandating provision of the exact same information at every site at precisely the same time, we recorded who had been formally told by specialized CHR program staff that they were at PR prior to administration of measures and controlled for it statistically (see "Analyses"). This method reflects what happens naturalistically across sites, across the country, and internationally.

2.2 Subjects and CHR identification procedures

CHR individuals 12-35 years old were recruited from outreach efforts or self-referred in response to media, public transportation, and online advertisements. Some were recruited from specialized clinics or other CHR studies. Participants met criteria for ≥1 of three CHR syndromes assessed by the SIPS (Version 5.0; Miller et al., 2003). Per SIPS guidelines, the syndromes could not be better accounted for by another psychiatric disorder, including substance use and medical disorders, per careful assessment of symptoms, timelines and syndrome/disorder overlap. Current and lifetime (comorbid) mental disorders were diagnosed according to the Structured Clinical Interview for Diagnostic and Statistical Manual of Mental Disorders, Version IV (SCID-I/P, First et al. 2002). Exclusion criteria included history of psychotic disorder, imminent risk of self-harm/violence, major medical/neurological disorder, or IQ<70. SIPS assessors were masters and doctoral-level clinicians and trainees rigorously-trained by clinicians trained and certified by the official Yale SIPS trainers. Further, SIPS ratings and final CHR classification were confirmed by consensus during conference calls attended by all clinicians across sites.

Written informed consent was obtained from adult participants; minors provided written assent and their parents/guardians provided written informed consent. Consent forms described the study purpose in accordance with IRB requirements and pre-existing standards with this population at each site. All sites' consent forms described possible CHR symptoms (e.g., feeling suspicious of others), with the New York site indicating that participants were at "a somewhat increased risk of psychosis". This study was approved by the Beth Israel Deaconess Medical Center, Maine Medical Center, and New York State Psychiatric Institute

Institutional Review Boards. All participants were referred to mental health treatment if not already receiving it.

2.3 Measures

CHR symptoms and functioning were assessed by clinician interview; all other responses were assessed via self-report by questionnaire or by interview with a BA-level research assistant who had received extensive training in administering the measures.

2.3.1 At-Risk Labeling Module: We queried perceptions of being 'at-risk' for five conditions: "depression", "anxiety", "bipolar", "psychosis", and "schizophrenia." Figure 2 outlines our three main variables: 1) *Told* ("Has anyone *told* you that you were 'at-risk for' or 'developing' [condition]?"); 2) *Think* ("Do you *think* you are 'at-risk for' or 'developing' [condition]?"); 3) *Most impact* ("What [single condition] had the *biggest impact* on how you think of yourself?"). For the *told* variable, the recalled source of labeling was recorded (clinician, school personnel, relative, or friend) when possible; individualized PR feedback delivered by CHR clinicians was tracked separately. Participants responded "Yes/No" to *Told* and *Think* questions for each at-risk condition. For the *most impact* question, respondents identified one at-risk condition only.

2.3.2 CHR Symptoms—The SIPS was used to evaluate positive (five items), negative (six items), disorganized (four items), and general (four items) symptoms (rated 0 [absent] to 6 [severe and psychotic]) (Miller et al., 2003).

2.3.3 Social Functioning—To further characterize the sample, involvement with peers, intimate partners, and relatives was measured by the Global Functioning: Social Scale, and performance in school or work was measured by the Global Functioning: Role Scale (1-10 rating; Cornblatt, et al., 2007).

2.4 Analysis

We calculated frequencies of yes/no responses for the *told* (labeling by others), *think* (self-labeling), and *most impacted* questions for each of the five at-risk categories. Further, responses to being at-risk for "psychosis" or "schizophrenia" were combined into a single "Psychosis Risk" (PR) category, and responses to being at-risk for "depression", "anxiety" or "bipolar" were combined into a single "Non-Psychotic Disorder" category; McNemar's test was used to test whether endorsement of PR or Non-psychotic disorders across variables differed significantly. Bivariate associations were examined between: a) "labeling by others" (*told*), b) "self-labeling" (*think*); and c) being *most impacted* by PR (our main outcome, defined as "yes/no"). Second, bivariate associations between receiving individualized PR feedback and having been *told, thinking*, and having been *most impacted* by PR were examined. These analyses were repeated stratifying for those who had received "prior individualized PR feedback" and those who had not. Third, to test the association of *told* and *think* responses with PR having the *most impact*, we conducted a series of logistic regressions. In the first model, we entered *told* as a predictor of being "*most impacted*" by PR. To account for whether individuals had been given individualized PR feedback prior to administration of measures, this binary variable was included in the model. In the second

model, family history of psychosis, sociodemographic variables, and CHR symptoms were added. In a third model, *think* was added as a predictor to examine this variable's effect, and to examine whether the effect of *told* was attenuated by the effect of *think*. Finally, to account for site effects, we replaced individualized PR feedback (which covaried highly) with site in a separate set of regressions (Supplementary Table 2). Statistical significance was set at $p<0.05$ (two-sided).

3. Results

Sociodemographic and Clinical Characteristics

Our sample was comprised of a late adolescent, primarily student, cohort which was approximately 2/3 male and >60% white (Table 1). The majority (>70.3%) met criteria for ≥1 comorbid disorder, most commonly depressive (50.7%) and anxiety (43.2%) disorders. Of participants, 30.4% had received individualized PR feedback prior to administration of measures, 68.9% of whom were from the New York site. The differing timing of having received individualized PR feedback was due to differences across sites in whether participants could be recruited and assessed *prior to* PR feedback (n=103; 88% of participants from the Boston and Maine sites [103/117 total]) or only *after* PR feedback (n=45; remaining Boston and Maine participants and all of New York participants; New York participants n= 31, M=10.2, SD=9.3 weeks).

3.1 Descriptive Statistics: Labeling by others (told), self-labeling (think), and "most impacted" variables

When examining descriptive statistics, consistently across all labeling and most impacted queries, participants appeared to endorse being "at risk for" or "developing" 'depression' and 'anxiety' at higher frequencies than 'psychosis' and 'schizophrenia' and 'bipolar' (Table 2A). Statistical comparisons indicated that endorsement of psychosis-risk (i.e., psychosis and schizophrenia) was higher for *told*, *think*, and *most impacted*, when compared with non-psychotic (i.e., depression, anxiety and bipolar) conditions (Table 2B). Only 27.7% identified PR labels as having *most impacted* them.

3.2 Bivariate Associations: Other- and self-labeling and being "most impacted'' by PR

When examining bivariate associations, being *told, thinking*, and being *most impacted* by PR were all significantly associated with each other (Tables 3 A-B). To check whether these results held for those who had received "prior individualized PR feedback" (n=45) and those who had not (n=103), Chi-square tests were conducted to probe whether the effect of being *told* or *thinking* one was at PR was significantly associated with being *most impacted* by PR in each subgroup. For both subgroups, Chi-Square tests showed significant effects in the expected direction for both *told* and *think*; i.e., CHR youth who were *told* or *think* they were at PR showed higher proportions of being *most impacted* by PR (all Fisher's Exact Tests p<05; see Supplementary Table 1). As expected, having received "individualized PR feedback" prior to administration of measures was also associated with higher proportions of being *told* and *thinking* one was at PR. However, it was not associated with being *most impacted* by PR (Table 3C).

3.3 Logistic Regression: Is labeling by others us. self-labeling more strongly related with being “most impacted” by PR?

In an initial logistic regression (Table 4; Model 1), having been *told* was associated with an 8.7 increase in odds of being *most impacted* by PR (95% CI=3.1-24.8), with individualized PR *feedback* entered into the regression model. Results for being *told* remained consistent (OR=10.6 [95% CI 3.3-33.9]) after adding family history of psychosis, sociodemographic variables, and CHR symptoms into the model (Model 2). When *think* was added into the model (Model 3), the effect of being *told* was diminished by 68.8% to a 4.0 increase in odds of being *most impacted* by PR (95% CI=1.1-15.0). In that analysis, as expected, *think* was independently associated with an 8.8 increased odds of being *most impacted* by PR (95% CI=2.0-39.1). Finally, results for *think* and *told* remained significant when substituting site for individualized PR feedback (Supplementary Table 2).

4. Discussion

These findings provide new insights into how CHR youth self-identify and the relative impact of the PR label on how they think about themselves shortly after entry into a specialized CHR program. On one hand, only a minority (27.7%) identified the PR label as having more impact than non-psychotic labels (particularly depression and anxiety). Yet we also identified that youth considering themselves to be at PR mattered more than having been *told* they were at PR in the PR label having the most impact. Yet having been *told* one was at PR (e.g., by CHR program or community clinicians, school personnel, or relatives) remained independently associated with a four-fold increased odds of PR having the *most impact*, even after considering the impacts of *thinking* and individualized PR feedback.

Our results help to illuminate findings from another key labeling study of Ultra High-Risk youth (Rüsch et al., 2014a). This study demonstrated that the extent to which individuals self-labeled as “severely mentally ill” was relatively high on average (mean=5.1 [SD=1.8]; 9-point rating scale) following UHR identification, and that self-labeling was significantly associated with appraisal of stigma as harmful. Our results suggest that these youth may identify as "severely mentally ill" based on *nonpsychotic* labels or symptoms (whereby >70% of our participants were co-morbid for ≥1 non-psychotic disorder) rather than or in addition to psychotic labels or symptoms. Accordingly, nonpsychotic labels (or symptoms) in our study were experienced as conferring more impact than intermittent psychotic-like labels (or symptoms) for over 2/3 (67.6%) of participants at initial CHR identification.

Although additional data, particularly qualitative, are needed to explore why PR appears to be less influential to sense of self at initial PR identification, a number of explanations exist. First, labeling may occur in fairly benign ways, e.g., in a school counselor's office where a student's concerns are heard, and hope is instilled regarding available treatments. Second, the majority of participants were voluntarily help-seeking, and this agency may reduce the salience of psychosis-risk stereotypes. Third, the PR label may be less influential due to the optimism common to adolescence (Elkind, 1967, Moses, 2009a). Fourth, the vast majority (>90%) of CHR youth in preventive clinical trials indeed do not develop a psychotic disorder (Fusar-Poli, et al., 2012; McFarlane, et al., 2015). The impact of the PR label may be attenuated to the degree that these youth intuit this or have this explained to them, as is

standard practice in many CHR programs. Finally, a less influential impact of the PR label could be attributed to heightened stigma towards the PR label (Yang et al, 2013), which could lead CHR youth to endorse it less.

Our findings begin to elucidate how labeling processes—via others' actions (i.e., being *told*) and one's own interpretation of symptomatic experiences (i.e., what one *thinks*)— shape the impact of the PR label. First, because *thinking* oneself to be at PR reduced the effect of being *told*, individuals' self-labeling appears to account in part for the effect of being *told*. However, among those who had not been *told* by others of their PR status (n=62 total), 21% (13/62; see bottom left hand cell, Table 3A) still reported *thinking* they were at PR, thus illustrating how interpretations of one's symptoms remains vital (Ben-David et al., 2014). Second, being *told* about PR remained an independent correlate with one's sense of self after adding *think*, thus indicating that being informed about one's PR status had distinct, albeit smaller, effects. This highlights the need to further understand the relative impact of different aspects of PR labeling, including *who* does the labeling, *what* is actually said, and *how* it is done (e.g., being *told* that one is PR in a derogatory fashion by a peer may have diametrically opposite impacts than being told by a specialized CHR program). Providing accurate education regarding PR has been shown to reduce stigma in community respondents (Yang et al., 2013). Unfortunately, these data cannot speak to the effects of being *told* by a specific source (school personnel, relative, friend, or clinician).

4.1 Limitations and Future Research

Limitations include sampling of voluntary participants who, for the most part, were in or seeking treatment, and who thus may have been less concerned about stigma than nonparticipant CHR youth. Nonetheless, study inclusion was less restrictive (i.e., it did not have typical restrictions for MRI and other biomarker studies) and less burdensome than other CHR studies at these three sites, such that the sampling and descriptive data is likely to be more representative of the true help-seeking CHR population. Further, our assessment of which label had the most impact came from a single-item, precluding assessment of reliability. However, it was an important initial probe of relative impact on sense of self that could elicit follow-up studies examining construct validity with other outcomes (e.g., stigma, help-seeking) in PR youth. Further, because some participants might have thought about how their symptom experience, rather than the label, impacted them in response to being asked what at-risk status had the biggest impact on sense of self, it is important for future research to more clearly separate impact of labels from that of symptoms on how PR youth view themselves. Another limitation is that for participants assessed prior to PR feedback, prior diagnoses of nonpsychotic disorders may have had more impact simply because they were the most salient or only known diagnoses, particularly for individuals who were administered measures before feedback. Due to the cross-sectional design, we cannot determine causality; being '*most impacted*' by PR may shape how individuals recall being *told* of, vs. *thinking* they were at-risk for, this status. We could not ascertain exactly when participants were first *told*, and this variable could be influenced by recall and social desirability bias. The impact of being *told* is likely influenced over time by the subsequent course of symptoms, including natural fluctuations as well as the effects of treatment. Thus, participants who had been *told*, even 1-2 months prior, may find the PR label to have less

impact if their symptoms have not progressed, or even improved. While individualized PR feedback was not associated with PR having the *most impact*, we cannot conclusively determine this effect due to this study's cross-sectional design. Most participants who had received individualized PR feedback were assessed on average 10.2 weeks after receiving PR feedback at the New York site, confounding effects of time, site, treatment and possible symptom change. Further, the New York site recruited into the study only participants who had already been recruited into the COPE clinic (and hence, previously identified as at PR) and thus their consent forms stated that participants were at a somewhat increased risk for psychosis. It is not clear whether this may have had any additional impact given that participants had already received PR feedback. As noted, no uniform mode or timing of informing youth of PR status exists across programs, and we intend for future reports from this dataset to empirically inform the future development of such approaches. We plan to systematically examine the effects of individualized PR program in a forthcoming study that will utilize a longitudinal, 'pre-feedback' vs. 'post-feedback' design. It will be particularly interesting to examine why some CHR youth (8/45; 17.8%, see Table 3C results for *told*) who had received PR program feedback did not recall being *told* that they were at PR. Finally, it is possible that degree of illness severity is inversely associated with being most *impact*ed by PR (e.g., CHR youth who show most negative symptoms or least insight may be less likely to describe themselves as most *impacted* by PR). However, symptom severity was not a significant predictor (Table 4).

We focused upon what CHR youth thought about themselves because this has shown robust associations with stigma, distress, negative psychological outcomes, and mental health service use in other adolescent studies (Moses, 2009a, Moses, 2009b). Yet future studies should elucidate the relative impact of PR labeling on stigma, especially since stigma in UHR youth has been linked with harmful psychological effects (Rüsch et al., 2014a; Rüsch et al., 2014b, Rüsch et al., 2015). Longitudinal investigations of sense of self in relation to internalized stigma and other outcomes are particularly needed. It will be equally important to examine any beneficial effects of PR labeling, including activating health-promoting behaviors and treatment engagement (Fusar-Poli et al., 2013). Our initial qualitative study investigating the meaning of PR labeling suggests both positive and negative effects on self-views (Yang, et al., in progress).

Our findings have important clinical implications. First, because most CHR youth identified being most impacted by non-psychotic disorders, specialized CHR programs should be careful to avoid a singular focus on PR and make it a point to attend to what is most distressing to each individual. Nonpsychotic disorders also can have enduring impacts on self-concept for adolescents, resulting in significant stigma (Moses, 2009a; Moses 2009b). Second, as a majority (58.9%) of CHR youth thought they were at PR, clinicians would do well to help these youth see this insight as a strength and protective factor, enabling them to effectively engage in treatments that can reduce their risk and improve their lives. Indeed, this self-labeling reflects the very insight into illness that makes the prodromal period a critical window for early intervention. Finally, CHR programs must also recognize that this self-labeling, however important to engagement, may have adverse effects on individuals' sense of self and possible self-stigma (Rüsch et al., 2014b; Rüsch et al., 2015), and do whatever they can to minimize this risk. For example, the psychoeducational multifamily

group fosters cross-family, non-stigmatizing illness definitions to address stigma (McFarlane et al., 2012), and we are adapting empirically-based stigma interventions (Lucksted et al., 2016) for use at time of conveying of PR status. By informing efforts with our data, we highlight greater attention to perceptions of self and labeling experiences across both PR and non-psychotic diagnoses in the delivery of services.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Conflict of Interest

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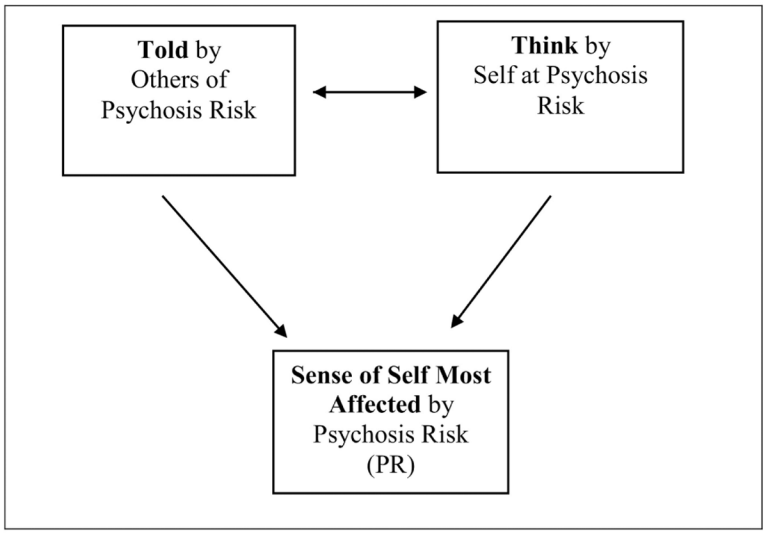

Figure 1.

Conceptual Model of Hypothesis: Labeling by Others (*Told*) and Self-labeling (*Think*) Processes and Associations with Sense of Self Being Most Affected

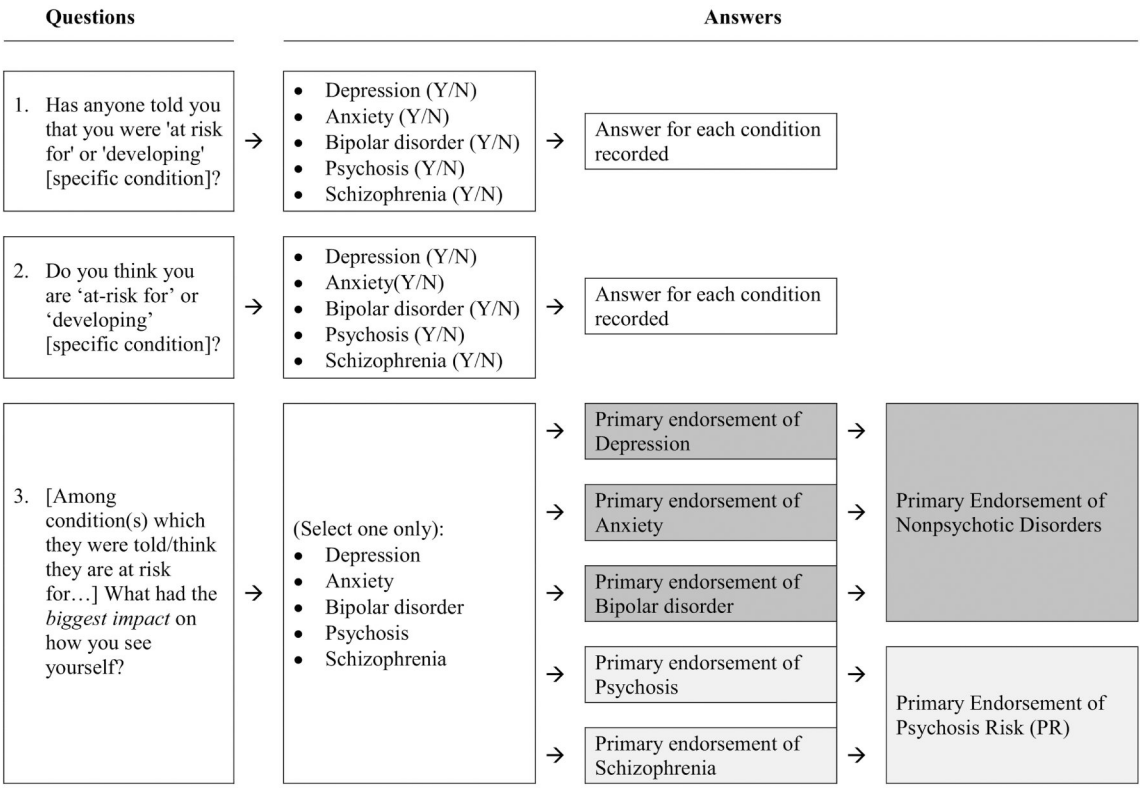

Figure 2.
Flowchart of the At-Risk Labeling Module

Table 1.

Sample Characteristics[a]

	Participants (n=148)	
	N (%)	**Mean (SD)**
Age (in Years)		18.6 (4.2)
Sex- Male	97 (65.6%)	
Site		
Massachusetts	70 (47.3%)	
Maine	47 (31.8%)	
New York	31 (20.9%)	
Received PR Feedback Prior to Stigma Assessment	45 (30.4%)	
Years of education		11.7 (3.1)
Born in US	136 (91.9%)	
Preferred Language-English	138 (93.2%)	
Household Income (dollars/ year)		
Less than $19,999	20 (13.5%)	
$20,000-$39,999	19 (12.8%)	
$40,000-$59,999	8 (5.4%)	
$60,000-$99,999	19 (12.8%)	
$100,000 and above	24 (16.2%)	
Don’t know, Refused or Missing	58 (39.2%)	
Marital Status-Not married	140 (94.6%)	
Currently Employed (full-time or part time)	43 (29.1%)	
Enrolled as a Student	113 (76.4%)	
Race/Ethnicity		
White	91 (61.5%)	
Black	19 (12.8%)	
Hispanic	20 (13.5%)	
First Nations	3 (2.0%)	
Other[b]	15 (10.2%)	
Family History of Psychosis or Schizophrenia	42 (28.4%)	
Axis-1 Disorders		
≥1 Axis 1 Disorder	104 (70.3%)	
Depression/MDD	75 (50.7%)	
Anxiety Disorders	64 (43.2%)	
Post-traumatic Stress Disorder	7 (4.7%)	
Attention Deficit/Hyperactivity Disorder	19 (12.8%)	
Bipolar Disorder	17 (11.5%)	
Personality Disorders	1 (0.7%)	
Developmental Disorders	2 (1.4%)	
Substance Abuse Disorder	11 (7.4%)	

	Participants (n=148)	
	N (%)	Mean (SD)
Symptoms		
Total positive		13.6 (4.1)
Total negative		15.0 (6.5)
Total disorganized		7.0 (3.7)
Total general		11.2 (4.1)
Current Social Scale		5.7 (2.1)
Current Role Scale		5.9 (1.5)

Note: Social Scale assessed quantity and quality of age appropriate relationships, and scores ranged from 1 (poor functioning) to 10 (superior functioning). Role scale assessed performance in school, work, or as a homemaker, and scores ranged from 1 (poor functioning) to 10 (superior functioning).

[a]CHR symptoms and functioning were assessed by clinician interview; all other responses were assessed via self-report or by interview with a non-clinician.

[b,]Other' Racial breakdown: Missing 1.4%, East Asian 0.7%, South Asian 1.4%, West/ Central Asia and Middle East 2.0%, Interracial 4.7%.

Table 2A.

Descriptive Statistics for Endorsement of Specific Condition

Variables[a]	**Depression**	**Anxiety**	**Bipolar**	**Psychosis**	**Schizophrenia**
Has anyone **TOLD**[b] you that you were at-risk for [condition]? –Yes	71.6% (106/148)	60.8% (90/148)	28.4% (42/148)	49.3% (73/148)	31.1% (46/148)
Do you **THINK**[b] you are at-risk for [condition] ? -Yes	76.4% (113/148)	78.4% (116/148)	34.5% (51/148)	50.7% (75/148)	39.9% (59/148)
What had the biggest **IMPACT**[c] on how you see yourself-[condition]? -Yes	35.8% (53/148)	25.7% (38/148)	6.1% (9/148)	16.9% (25/148)	10.8% (16/148)

[a]Note: The total “n” for each condition reflects missing values. The “Impact” variable has n<148 because some respondents were not able to identify a single condition which had the greatest impact on their sense of self (n=7).

[b]Note: Percentage of endorsed conditions does not add up to 100% because respondents could endorse one or more at-risk condition

[c]Note: Percentage of endorsed conditions could add up to 100% because respondents could only endorse one at-risk condition that *most impacted* them (seven participants did not endorse any disorder).

Table 2B:

Descriptive Statistics for Endorsement of Psychosis-Risk Condition

Variables	Frequency Yes to Non-Psychotic Risk[a] (n/N)	Frequency Yes to Psychosis-Risk[b] (n/ N)	p-value[e]
Has anyone **TOLD**[c] you that you were at-risk for…?	85.1% (126/148)	58.1% (86/148)	<0.001
Do you **THINK**[c] you are at-risk for…?	91.9% (136/148)	58.9% (87/148)	<0.001
What had the biggest **IMPACT**[d] on how you see yourself?	67.6% (100/148)	27.7% (41/148)	0.008

[a] Includes those who endorsed being at risk for “depression”, “anxiety” or “bipolar”.

[b] Includes those who endorsed being at risk for “psychosis” or “schizophrenia”.

[c] Note: Percentage of endorsed conditions does not add up to 100% because respondents could endorse one or more at-risk condition

[d] Note: Percentage of endorsed conditions could add up to 100% because respondents could only endorse one at-risk condition that *most impacted* them (seven participants did not endorse any disorder).

[e] McNemar’s Test

Table 3A:

Categorical Analyses between ‘Psychosis-Risk’ Variables

	THINK you were at psychosis-risk			
	YES	**NO**	**Chi-Square (χ^2)**	**p-value**
***TOLD** you are at psychosis-risk-*				
YES	86.0% (74/86)	14.0% (12/86)	63.0	<.001
NO	21.0% (13/62)	79.0% (49/62)		

Table 3B.

Categorical analyses between 'told', 'think' and 'most impacted' variables.

	Psychosis-risk had the biggest IMPACT on how you see yourself			
	YES	**NO**	**Chi-Square (χ^2;)**	**p-value**
TOLD YOU WERE AT PSYCHOSIS-RISK				
YES	41.9% (36/86)	58.1% (50/86)	20.5	<0.001
NO	8.06% (5/62)	91.9% (57/62)		
THINK YOU ARE AT PSYCHOSIS-RISK				
YES	43.7% (38/87)	56.3% (49/87)	26.9	<0.001
NO	4.9% (3/61)	95.1% (58/61)		

Table 3C.

Categorical analyses between 'PR program feedback' and 'told', 'think' and 'most impacted' variables.

PR Program Feedback	TOLD you are at psychosis-risk (Y/N)			THINK you are at psychosis-risk (Y/N)			Psychosis or schizophrenia risk had the biggest IMPACT on how you see yourself (Y/N)		
	Yes	No	p-value[a]	Yes	No	p-value[a]	Yes	No	p-value[a]
Yes	82.2% (37/45)	17.8% (8/45)	<0.001	80.0% (36/45)	20.0% (9/45)	<0.001	33.3% (15/45)	66.7% (30/45)	0.312
No	47.6% (49/103)	52.4% (54/103)		49.5% (51/103)	50.5% (52/103)		25.2% (26/103)	74.5% (77/103)	

[a] Chi-square test

Table 4.

Logistic Regression Showing Predictors of Being '*Most Impacted* by Psychosis Risk'

	Model 1 N=148 AOR (95% CI)	**Model 2** N=137[d] AOR (95% CI)	**Model 3** N=137[d] AOR (95% CI)
Told at Psychosis Risk			
No	*Ref*	*Ref*	*Ref*
Yes	**8.7 (3.1, 24.8)**[c]	**10.6 (3.3, 33.9)**[c]	**4.0 (1.1, 15.0)**[a]
Think at Psychosis Risk			
No	--	--	Ref
Yes			**8.8 (2.0, 39.1)**[b]
Received PR Feedback[e]			
No	*Ref*	*Ref*	*Ref*
Yes	0.8 (0.4, 1.9)	1.1 (0.3, 3.6)	0.8 (0.2, 2.7)
Family History of Psychosis/Schizophrenia			
No	--	*Ref*	*Ref*
Yes		0.6 (0.2, 1.7)	0.6 (0.2, 1.8)
Age (Years)	--	1.0 (0.9, 1.1)	1.0 (0.8, 1.1)
Sex			
Female	--	*Ref*	*Ref*
Male		2.5 (0.9, 6.7)	2.6 (0.9, 7.4)
Race/Ethnicity			
Non-White	--	*Ref*	*Ref*
White		1.0 (0.4, 2.6)	0.7 (0.2, 2.0)
SIPS Symptoms			
Positive		1.1 (1.0, 1.3)	1.1 (0.9, 1.3)
Negative		1.0 (0.9, 1.1)	1.0 (0.9, 1.1)
Disorganized		0.9 (0.7, 1.0)	0.9 (0.7, 1.0)
General		1.0 (0.8, 1.1)	0.9 (0.8, 1.1)

Note. OR=Crude Odds Ratio; AOR=Adjusted Odds Ratio; CI=Confidence Interval; Ref=Reference Group; White=non-Hispanic White

Statistically significant at

[a] p<0.05,

[b] p<0.01,

[c] p<0.0001

[d] 11 participants were excluded from Models 2 and 3 due to missing information on family history of psychosis (n=5), racial/ethnicity information (n=2) and SIPS data (n=4).

[e] Mean time since PR program feedback for NY site participants= 10.2 weeks (*SD*= 9.3 weeks)