https://doi.org/10.1037/abn0000679

HHS Public Access
Author manuscript
J Abnorm Psychol. Author manuscript; available in PMC 2022 August 01.

Published in final edited form as:
J Abnorm Psychol. 2021 August ; 130(6): 587–593. doi:10.1037/abn0000679.

Predictors of internalized mental health stigma in a help-seeking sample of youth: The roles of psychosis-spectrum symptoms and family functioning

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Abstract

Background: Experiencing psychosis-spectrum symptoms is challenging to youth. Among many difficulties, internalized mental health stigma—the internalization of negative stereotypes—can lead to shame and withdrawal. The objective of this study was to better understand the correlates of internalized stigma among a clinical sample of youth with psychosis-spectrum symptoms.

Method: Participants (n=66; 12-25-years-old) were referred by community providers in Maryland, United States. Psychosis-spectrum symptoms were measured via the *Structured Interview for Psychosis-Risk Syndromes* (SIPS); family-functioning was measured via the *Family Assessment Device.* Interviewers rated participants' social/role functioning via the *Global Functioning: Social and Role Scales.* Internalized stigma was measured using the *Internalized Stigma of Mental Illness (ISMI)* total scale and subscales.

Results: The sample included 34 individuals at clinical high risk for psychosis, 16 experiencing early psychosis, and 16 help-seeking controls. Regression analyses indicated that unusual beliefs,

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Some of the ideas and results presented in this Brief Report were shared at the annual meeting of the International Conference on Stigma at Howard University in Washington, D.C., in November 2019.

Ethical Approval Information:
Granting Body: University of Maryland Baltimore, Protocol Number: HP-00057603, Protocol Title: Maryland Early Intervention Program
Granting Body: University of Maryland Baltimore County, Protocol Number: Y15JS20043, Protocol Title: Maryland Early Intervention Program

avolition, role functioning, and lower family-functioning (caregiver-reported) were significantly associated with higher aspects of internalized stigma, controlling for other symptoms and sociodemographics. These models explained 27% of the variance (adjusted R^2) in the total ISMI scale and between 15%-49% of the variance in ISMI-subscales.

Conclusions: Among this help-seeking sample, unusual beliefs, avolition, higher role functioning, and lower family-functioning (caregiver-reported) were associated with more internalized stigma. Pending future research with larger samples, therapeutic interventions focused on these factors and their correlates may benefit youth. Future research is needed to determine temporal precedence of these associations.

General Scientific Summary:

Endorsement of unusual thought content and avolition, as well as poor role functioning and lower caregiver-reported family functioning, were associated with increased self-reported internalized mental health stigma. This study supports the notion that specific clinical variables are related to internalized stigma. Pending future research, individual, group, and/or family-based interventions may be developed and adapted to specifically target these areas and to reduce internalized stigma across help-seeking youth.

Keywords

clinical high risk for psychosis; early psychosis spectrum; internalized stigma; family cohesion; adolescents

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Stigma involves labeling and stereotyping that can lead to discrimination (Link & Phelan, 2001). *Internalized mental health stigma* (or “self-stigma”) is a process of incorporating negative stereotypes into one’s sense of self (Ritsher et al., 2003). Adults who internalize stigma can experience shame and hopelessness leading to negative outcomes and impeding mental health recovery (Livingston & Boyd, 2010). Less is known about the impact of internalized stigma on youth, and most research in this area has been with non-help-seeking samples (Hartman et al., 2013). Research with clinical samples may facilitate a better understanding of youth internalized stigma (Millman et al., 2019). Based on the few studies in this area, approximately 20%-30% of adolescents in general U.S. help-seeking samples report frequently experiencing internalized stigma due to having psychiatric diagnoses, including shame, embarrassment, and fear of peer rejection (Moses, 2009; 2010a). Evidence suggests that anticipating harmful consequences of stigma can exacerbate symptoms, predict conversion to psychosis, and increase the duration of untreated psychosis (Mueser et al., 2020; Rüsch et al., 2015). Less is known about the correlates of internalized stigma across the psychosis-continuum, including specific psychosis-spectrum symptoms and developmentally-relevant factors including family functioning.

Early Psychosis-Spectrum Symptoms and Internalized Stigma

Though early intervention services for youth on the psychosis-spectrum can be beneficial (Wright et al., 2020), research has found that experiencing psychosis-spectrum symptoms is associated with internalized mental health stigma (Yang et al., 2015), and stigma is a major impediment to care (Gronholm et al., 2017). Individuals at Clinical High Risk (CHR) for

psychosis (defined as experiencing attenuated psychosis symptoms that signify increased risk for full psychosis) tend to endorse greater awareness of stigmatizing stereotypes, more shame, and more internalized stigma than non-psychiatric controls or youth with other mental health conditions (Colizzi et al., 2020). Stigma-related concerns are also prevalent among individuals experiencing early psychosis (EP) and are related to poor recovery outcomes (Simonsen et al., 2019). Internalized stigma among individuals at CHR or experiencing EP is associated with greater anxiety and depression depressive symptoms, suicidal ideation, attenuated positive and negative symptoms, and diminished psychological well-being (Bornheimer et al., 2020; Ho et al., 2018; Stowkowy et al., 2015; Yang et al., 2015; Pyle et al., 2015; Pyle & Morrison, 2017; Norman et al., 2011; Xu et al., 2016; Yang et al., 2015). In particular, internalized stigma has been linked to higher suspiciousness, perceptual abnormalities, disorganized speech, non-bizarre ideas (e.g., ideas of guilt, odd somatic ideas), and lower grandiosity (Pyle et al., 2015; Stowkowy et al., 2015).

Stigma, Family, and Psychosis-Spectrum Symptoms

Families may play a key role during illness and recovery for youth with psychosis-spectrum symptoms. Families of youth at CHR report significant emotional distress in seeing a family member experience psychosis-spectrum symptoms and fears about how stigma might affect their family (Baron et al., 2019; Chen et al., 2016; Oluwoye et al., 2019; Mui et al., 2019). Studies have found that caregivers' stigma and concealment of their child's mental health problems are associated with more internalized stigma in their children, and stigma from family members is prevalent (Moses, 2010a; Moses, 2010b; Ross et al., 2019). Family functioning may moderate the impact of psychosis-spectrum symptoms on youths' social and role functioning (Thompson et al., 2019), and poor family functioning is associated with greater symptoms (Wüsten & Lincoln, 2017; Santesteban-Echarri et al., 2018). Thus, it is plausible that poor family functioning may contribute to increased internalized stigma in youth with psychosis-spectrum symptoms.

Current Study

Stigma among youth with psychosis-spectrum symptoms is relatively common and can interfere with recovery, yet most research on internalized stigma has been conducted with non-help-seeking controls and adults. The few studies that have sampled help-seeking youth have not considered psychosis-spectrum symptoms, which represent a rarer but often more stigmatizing concern, with the scant existing literature suggesting that internalized stigma related to them is associated with negative mental health outcomes. Certain positive psychosis-spectrum symptoms may be especially associated with internalized stigma, though findings are mixed. Further, no studies have examined the relation between family functioning and internalized stigma among youth experiencing psychosis-spectrum symptoms. The current study assessed family functioning (using similar methods to prior studies; e.g., Thompson et al., 2019) of individuals with varying degrees of psychosis-spectrum experiences (CHR, EP, and help-seeking controls [HSCs]). In this help-seeking, psychosis-risk enriched sample, we hypothesized that internalized stigma would be positively related to overall psychosis-spectrum symptoms. Further analyses assessed specific positive and negative symptoms associations with internalized stigma.

We additionally hypothesized that worse family functioning (reported by both youth and caregivers) and greater depressive symptomatology would predict higher internalized stigma. Lastly, we explored study variable associations with internalized stigma subscales (*Alienation, Stereotype Endorsement, Discrimination Experience, Social Withdrawal, Stigma Resistance*).

Materials and Method

Participants

The current sample comes from an ongoing study of CHR/EP at the YouthFIRST research lab ($N_{consented}$= 116); participants were excluded if they were missing significant data (see Results) or were a non-psychiatric control. The final analysis sample included 66 individuals (34 individuals at CHR; 16 individuals with EP; 16 HSCs). Socio-demographics are presented in Supplemental Table 1.

Procedure

Data collection was conducted through the University of Maryland, Baltimore County and the University of Maryland School of Medicine. Institutional Review Boards at both institutions approved research procedures. Recruitment included outreach events for community mental health providers, flyers around college campuses and the community, and online advertisements. Many participants were referred to the study for suspected psychotic-like symptoms by community providers, resulting in an enriched sample for psychosis-risk experiences. Eligible participants were 12-25 years old with a history of psychosis-related experiences and/or were currently receiving mental health services. Participants with prior diagnoses of psychosis were excluded; participants with EP in the current study were initially referred for suspected psychosis-spectrum symptoms and were ultimately identified as having already converted to psychosis. Assent/consent was obtained from all participants, and guardians when participants were minors.

Measures

The Internalized Stigma of Mental Illness Scale (ISMI; Ritsher et al., 2003) is a 29-item self-report measure assessing internalized stigma in clinical populations using a 4-point Likert scale (“strongly disagree” to “strongly agree”). To provide maximal response choices, we added a “don’t know” option. Participants are asked to consider their “mental health problems” or “whatever you feel is the best term for it” while answering each question. For the current study, we computed the total/overall scale score; it showed excellent reliability in our sample (α =0.94). The reliability of subscales ranged: *Alienation* (0.92), *Stereotype Endorsement* (0.68), *Discrimination* (0.84), *Social Withdrawal* (0.87), and *Stigma Resistance* (0.68).

The Structured Interview for Psychosis-Risk Syndromes (SIPS) is a semi-structured interview designed to diagnose psychosis-risk syndromes and rate their severity (Miller et al., 2003). It measures five positive symptoms, six negative symptoms, four disorganization symptoms, and four general symptoms. Depressive symptoms were measured by the dysphoric mood item within the general symptom domain, which has been shown to

adequately measure depressed mood (DeVylder et al., 2014). SIPS symptoms are rated on a scale from 0 (absent) to 6 (severe and psychotic). Participants met threshold for a SIPS-defined risk syndrome or EP based on their score on one or more positive symptoms. Participants who did not meet CHR or EP criteria were classified as HSC. All SIPS interviewers completed intensive training, certification, and reliability testing. We computed a positive symptom sum score (PSUM) and a negative symptom sum score (NSUM).

The McMaster Family Assessment Device (FAD; Epstein et al., 1983) is a self-report measure rating perceived family functioning by adolescents (age ≥12) and their family members. The FAD includes a 12-item general functioning scale – querying family communication, cohesion, problem solving, and support which is regarded as a measure of family functioning (Mansfield et al., 2015). Similar to Thompson et al. (2019), we adapted the FAD to include a "neutral" option within a five-point Likert scale (strongly agree to strongly disagree); higher scores reflect better family functioning. The current study collected a youth self-report FAD (Youth-FAD) and a caregiver self-report FAD (Caregiver-FAD; completed by one parent/guardian). Internal consistency was strong for both: Youth-FAD (α=0.90), Caregiver-FAD (α=0.82).

Covariates included binary gender, age, race/ethnicity, family history of psychosis (via the SIPS), income, psychiatric diagnosis (via Kiddie Schedule for Affective Disorders and Schizophrenia; Kaufman et al., 2013), and current social and role functioning (Global Functioning: Social and Role Scales; Cornblatt et al., 2007).[1] Group differences were also explored (CHR,EP,HSC).

Hypotheses were first tested through bivariate correlation then via multiple regression (IBM-SPSSv26). Statistical significance was set at $p<.05$ and p-values were adjusted using the Holm-Bonferroni method for regressions (Supplemental Table 2; Holm, 1979). Covariates that were significantly corelated with ISMI were entered in regression analyses.

Results

Variables were examined for skewness and kurtosis; they were within acceptable limits of normality (see descriptives in Supplemental Table 3). Assumptions of analyses were also ensured (e.g., normality, linearity, lack of multicollinearity). Mean imputation was used for missing ISMI items if participants responded to approximately 50% of the scale's items or more (i.e., ≥14 items) and had any missing items. This resulted in 10% of ISMI items being imputed across the analysis sample. After excluding participants with fewer than 14 responses (n=6), the ISMI completion rate was high ($M^{completion}$=90% of items; SD= 14%; range: 48%-100%). Many participants were legal adults who participated without caregiver involvement, making Caregiver-FAD data available for only 50% of the sample.

[1]Baseline social and role functioning were controlled for given that functioning might be lower for individuals in the early stages of psychosis who have higher levels of internalized stigma (Firmin et al., 2019).

Bivariate Correlation

Bivariate correlations (Supplemental Table 3) indicated that Youth-FAD, PSUM (and one positive symptom, *unusual thought content),* NSUM (and two negative symptoms, *avolition* and *experience of emotions and self*), and depressed mood were significantly associated with overall ISMI in expected directions. No other variables or covariates, including group status (CHR,EP,HSC), were significantly associated with ISMI total scores.

Multiple Regression

The regression models included all variables significantly correlated with ISMI scores. To account for multicollinearity and probe the nuances of psychosis-spectrum symptoms and ISMI, the following stepped approach was employed: The first regression models for each dependent variable included only the SIPS positive and negative summed scores (PSUM and NSUM) that were significant. If only one summed score was significant, significant individual items from the other summed scale were included in the first model. To then probe for individual item predictors, the second model only included significant individual positive and negative items.

With overall ISMI as the outcome in the first regression model (Table 1), no variables were significant after correction, and the model explained 18% of the variance in ISMI (adjusted R^2). Given the significant association between ISMI and *unusual thought content, avolition,* and *experience of emotions and self,* a second regression model was conducted with these individual symptoms in place of the sum scores, resulting in 27% variance explained. *Unusual thought content* (f^2=0.14) was the only significant predictor after correction. Youth-reported family functioning had a small to medium effect size in both models (f^2=0.08).

Exploratory Regression Analyses for ISMI Subscales

Consistent with the aforementioned regression entry method, variables that were significantly correlated with each ISMI subscale were entered into the models along with the positive and negative sum scores first. Next, specific positive and negative symptoms were explored. No variables significantly correlated with the *Stereotype Endorsement* subscale, and only one covariate–family income–significantly correlated with the *Stigma Resistance*[2] subscale. Thus, subsequent regression models were not conducted with these two subscales. Regression results for the *Alienation, Discrimination Experiences,* and *Social Withdrawal* subscales (Supplemental Tables 4,5,6) indicated that specific symptoms (*unusual thought content, avolition*) appeared to better explain ISMI scores than PSUM and NSUM. Higher role functioning also predicted *Alienation* and lower caregiver-rated family functioning predicted *Discrimination Experiences.* The variance explained by the predictors in these models ranged from 15%-49%.

[2]Significant group differences were found for the ISMI-Stigma Resistance subscale (but no other ISMI scales): $F(2, 63)=3.47$, $p=.037$. Tukey post-hoc testing revealed significant differences between the CHR and EP groups ($p=.028$) whereby EP participants reported significantly higher stigma resistance scores (eta squared=.10)

Discussion

This study aimed to better understand correlates of internalized stigma among help-seeking youth experiencing psychosis-spectrum symptoms, specifically the potential impact of family functioning and positive and negative symptoms. We found that greater positive and negative psychosis-spectrum symptoms predicted higher levels of internalized stigma, with specific symptoms (*unusual thought content, avolition*) appearing to be the strongest factors. Few studies have examined associations between specific psychosis-risk symptoms and internalized stigma, and comparisons across studies are limited due to divergent measurement tools. Our findings were consistent with Pyle et al. (2015) who found an association between internalized stigma and distress caused by "non-bizarre ideas," similar to the SIPS' *unusual thought content.* Given the nature of these experiences (e.g., feeling like something odd is going on; others telling you your beliefs are unusual), this item may capture an individual's emerging awareness and concern about mental health symptoms and potential stigmatizing responses from others. In contrast to prior studies (Pyle et al., 2015; Stowkowy et al., 2015), we did not find significant associations between internalized stigma and other attenuated symptoms. This might be because many past studies: conducted correlational analyses only, did not control for the effects of individual symptoms in an omnibus model and/or did not analyze individual symptoms, and/or that our study evaluated symptoms on a continuum. In our findings, avolition (an understudied variable in youth stigma studies) seemed to subsume the effects of other known predictors in one model. Further, although it is possible we were underpowered to detect a significant association between stereotype endorsement and covariates (some covariates correlated close to or at r=.20), our finding in this regard is consistent with prior work (Yang et al., 2015) showing low stereotype agreement in a CHR sample.

Regarding findings linking avolition to the ISMI, decreased motivation for daily activities and/or needing assistance from others to complete tasks may be bidirectionally related to internalized stigma. This finding is consistent with research on the "why try" effect, whereby individuals with mental illness who internalize stereotypes experience a cycle of lowered self-esteem and self-efficacy, increased anticipated stigma, and lowered participation in pursuit of life goals (Corrigan et al., 2013). For youth, increased avolition may also indicate less participation in activities and therefore less positive feedback to contradict negative self-image thoughts (although we found no association between social functioning and internalized stigma when controlling for other factors). In sum, individual psychosis-spectrum symptoms appeared to more precisely predict internalized stigma than positive and negative sum scores. Dysphoric mood did not significantly predict internalized stigma (contrary to hypotheses) when controlling for other variables. It is possible that a related experience, avolition, accounted for overlapping variance and better explained internalized stigma in these models.

Regarding family functioning, we found that worse family functioning was associated with higher internalized stigma (discrimination experiences subscale), consistent with hypotheses. This corroborates prior studies that demonstrate deleterious effects of poor family functioning for individuals experiencing psychosis-spectrum symptoms (Thompson

et al., 2019); however, our results are limited by the small number of caregivers who participated in this study and the self-report nature of this scale.

Lastly, role functioning was positively associated with internalized stigma-related feelings of alienation. Individuals with better role functioning may be more aware of their mental health symptoms and experiences with stigma, which would align with the "insight paradox" (Lysaker et al., 2007), whereby such insights may be associated with positive outcomes (e.g., functioning) but also decreased hope and self-esteem. Of note, the SIPS may conflate symptom severity and loss of insight; future research is needed to disentangle these constructs.

Limitations and Future Directions

Although we controlled for mood disorder diagnoses, this study's main measure of depression was dysphoric mood captured through interview rather than self-report like the ISMI. These circumstances may have limited the predictive power of dysphoric mood, although prior research has found that this measure adequately measured depression severity in a CHR sample (DeVylder et al., 2014). A more sensitive measure shown to relate to internalized stigma in prior literature may be useful to consider for future studies (e.g., Beck Depression Inventory used by Yang et al., 2015). Further, although the ISMI had excellent internal consistency, internalized stigma is nuanced and intersects with self-labeling and labeling by others (e.g., Uttinger et al., 2018). Future research with larger samples should continue exploring how diagnostic labels impact internalized stigma (e.g., Yang et al., 2015; 2019)

Future research is also needed to determine the temporal nature of variables in this study, including bidirectional influences on unusual thought content and avolition, and the potential differential impact of family factors by culture (e.g., Chapman & Woodruff-Borden, 2009), living situation, parental insight and self-stigma, specific dyads within the family, family trauma[3], and youth coping skills. Longitudinal studies can inform models of youth internalized stigma by uncovering changes in internalized stigma, symptoms, and family functioning over time.

Some participants in the current study were referred for suspected psychosis-spectrum symptoms but ultimately categorized as HSCs because their symptoms did not meet CHR criteria. Our HSC group may therefore include people with higher levels of attenuated psychosis symptoms than other help-seeking samples in the general population. Our three groups had similar internalized stigma scores (except for Stigma Resistance), and were similarly aged. Our CHR and EP groups were also specialty-treatment naïve and had not yet received systematic feedback related to high-risk criteria or full psychosis. Our internalized stigma measure also referred to "mental health problems," but did not specify current or past symptoms (all CHR participants had current symptoms, and 75% of the EP group had current psychosis). Nonetheless, limitations also exist regarding our continuum approach. The continuum approach may be limited by changes individuals experience in regard to symptom onset and severity, symptom fluctuation and recovery status, functioning, and age/

[3]A trauma-related diagnosis per the KSADS for youth was unrelated to family functioning in the current study.

developmental considerations. Future research in this area should recruit a larger sample of help-seeking individuals with varying psychiatric diagnoses and levels of psychosis experiences to better understand these aspects.

Lastly, our results suggest that help-seeking youth with psychosis-spectrum symptoms may benefit from stigma reduction strategies. Internalized stigma interventions for adults are well-documented (Yanos et al., 2015) and one research group recently designed an internalized stigma intervention for individuals experiencing EP (Best et al., 2018). However, there have been no interventions to-date designed to target internalized stigma among a broader group of youth. Such interventions may benefit from focusing on family functioning/adaptive coping strategies (e.g., Landa et al., 2016), role functioning, and culture-specific aspects of stigma (Wong et al., 2009). Cognitive therapy and mindfulness may also be effective in reducing internalized stigma among individuals experiencing psychosis-spectrum symptoms (Mersh et al., 2015; Morrison et al., 2013), and improving other correlates of internalized stigma.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

This work was supported by the National Institute of Mental Health (grant R01MH112612 J.S.), the Maryland Department of Health and Mental Hygiene, Behavioral Health Administration through the Maryland Center of Excellence on Early Intervention Program (MEIP) (OPASS# 14-13717G/M00B4400241), and the Substance Abuse and Mental Health Services Administration (Community Intervention for those at Clinical High Risk for Psychosis, vis a vis MD State Dept of Health, SM081092-01).

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Table 1

Multiple Regression Predictors of the Internalized Stigma Total Scale

Internalized stigma				
Model 1	R^2	F (df)	p	
	.18	4.07 (4, 54)	.006*	
Predictors	b (95% CI) [s_b]	t	p	f^2
Positive Symptom Sum	0.01 (−.01 to .04) [0.14]	1.08	.286	0.02
Negative Symptom Sum	0.02 (−.01 to .04) [0.16]	1.09	.281	0.02
Family Functioning (youth-rated)	−0.19 (−.36 to −.01) [−0.26]	−2.13	.038	0.08
Dysphoric Mood	0.06 (−.04 to .16) [0.18]	1.22	.227	0.03
Model 2	R^2	F (df)	P	
	.27	5.33 (5, 53)	<.0005*	
Predictors	b (95% CI) [s_b]	t	p	f^2
Unusual Thought Content	0.12 (.03 to .21) [0.35]	2.75	.008*	0.14
Avolition	0.06 (−.04 to .15) [0.16]	1.20	.234	0.03
Experience of Emotions and Self	−0.01 (−.10 to .09) [−0.02]	−0.13	.894	<0.01
Family Functioning (youth-rated)	−0.18 (−.35 to −.004) [−2.05]	−2.05	.045	0.08
Dysphoric Mood	0.06 (−.02 to .15) [0.19]	1.45	.153	0.04

Note.

*Model 1: Holm-Bonferonni correction-significance level ($p < .0100$). Model 2: Holm-Bonferonni correction-significance level ($p < .0083$).