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RESISTING INTERNALIZED STIGMA (RIS): ACCEPTABILITY AND FEASIBILITY OF A COGNITIVE BEHAVIORAL STIGMA INTERVENTION FOR EARLY PSYCHOSIS

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RESISTING INTERNALIZED STIGMA (RIS): ACCEPTABILITY AND FEASIBILITY OF A COGNITIVE BEHAVIORAL STIGMA INTERVENTION FOR EARLY PSYCHOSIS

by

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A Dissertation

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Abstract

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Thomas Dinzeo, Ph.D.
Ph.D. in Clinical Psychology

The clinical high-risk state for psychosis (CHR-P) was created to help identify individuals experiencing early signs of psychosis to help forestall worsening symptoms. CHR-P individuals may experience stigma that may stem from internal or external processes, including from receiving specialized care. Research has demonstrated associations between internalized stigma and psychosocial and functional outcomes, which underscores the need for interventions to help mitigate the impact of stigma while balancing the need for treatment. To date, there is only one stigma intervention specifically designed for individuals designated as CHR-P, which is psychoeducational in nature. Based on the recent call to action that highlights the need for specialized stigma interventions for CHR-P groups, this study piloted the first manualized, cognitive-behaviorally based stigma intervention designed for early psychosis, including those at risk. The study took place at the University of Pennsylvania's Psychosis Evaluation and Recovery Center and recruited 9 CHR-P and first episode psychosis subjects to participate in two simultaneously run groups. Psychosocial and functional outcomes were assessed at baseline and follow-up and demonstrated reductions in stigma and depression and elevations in sense of purpose, self-esteem, and social cognitive performance. Qualitative interviews showed acceptability, feasibility, and ideas for manual refinement.

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Chapter 1

Introduction

Schizophrenia is a chronic, debilitating condition that can have considerable impacts on all areas of an individual's life. Additionally, schizophrenia is associated with a large economic burden, costing the United States an estimated $155.7 billion in 2013 (Cloutier et al., 2016). Consequently, increased efforts to identify individuals likely to be diagnosed with schizophrenia have become more widespread in both research and clinical practice. The clinical high-risk state for psychosis (CHR-P) was introduced as part of a vanguard movement to identify youth experiencing subthreshold positive, negative, and disorganized symptoms to employ early intervention techniques aimed to forestall the progression to full psychosis and improve quality of life (Miller et al., 2003). CHR-P symptomatology is most often characterized by unusual thought content or beliefs, changes in behavior due to odd or intriguing experiences, and increased social withdrawal over a one-year period (Miller et al., 2003: McGlashan et al., 2010). Of note, CHR-P individuals tend to remain insightful to their experiences and, therefore, do not endorse full conviction for their presenting concerns. These individuals are typically assessed with structured clinical interviews, such as the Structured Interview for Psychosis Risk Syndromes (SIPS/SOPS; Miller et al., 2003), so that attenuated positive, negative, and disorganized symptom content can be reliably quantified to determine an individual's risk status.

Based on prior research, most structured interviews can accurately predict that up to 30 percent of individuals seeking prevention services will eventually go on to develop a psychotic disorder within two to three years. Consequently, 70 percent or more of individuals classified as CHR-P will likely not go on to develop any threshold level psychosis (Fusar-Poli et al., 2012; Ciarleglio et al., 2019). As a result, many individuals will go through this early identification process without ever being diagnosed with a psychotic disorder and could be unduly exposed to stigma associated with entering prevention programs for symptoms that may never fully manifest into a classifiable diagnosis (Yang et al., 2010; Corcoran, 2016). Although most CHR-P individuals are considered help-seeking (Millet et al., 2003), receiving treatment at specialized clinics can elicit stigma processes through labeling (i.e., labeling stigma). Once one is in treatment for a mental health problem, they are labeled as mentally ill by society simply because they have received services (Link et al., 1989). Additionally, emerging research has demonstrated that stigma also tends to be elicited through the experience of attenuated symptoms in CHR-P individuals (i.e., symptom stigma). In this case, CHR-P individuals may adopt negative beliefs about themselves prior to ever receiving specialized services due to the salience of their symptoms and their potential connections to stigmatizing beliefs (Yang et al., 2015; Deluca et al., 2021). For example, an individual identified as CHR-P may realize that they are having unusual experiences and subsequently think that they are "crazy" because of culturally bound beliefs related to mental illness, which can lead to the internalization of negative stereotypes. Not surprisingly, stigma processes in at-risk individuals can be multifaceted as many CHR-P individuals may exhibit internalized stigma through their individual experience of symptoms, by psychosis treatment itself, or both even though they have never met criteria for a schizophrenia-spectrum diagnosis. Thus, stigma processes in CHR-P youth can critically impact a myriad of factors associated with better or worse health outcomes.

Modified Labeling Theory (Link et al., 1989) is a prominent framework that was developed to understand underlying stigma processes and has been utilized in CHR-P research (Yang et al., 2019; Yang et al., 2015; Rusch et al., 2014). This theory posits that beliefs about mental health are developed as individuals are socialized in their communities, which often stem from stereotypical views of how people with mental illness should be treated. Furthermore, individuals with mental health problems may internalize negative stereotypes, which may lead to an expectation of discrimination and devaluation by members of society if their diagnosis becomes known. Consequently, individuals may employ positive or negative coping responses such as withdrawing from friends and family, becoming more secretive about their mental health status, or educating others about mental health in the community. The employment of negative coping responses coupled with internalized stigma can have a detrimental effect on social network ties, self-esteem, and educational and occupational opportunities (Link et al., 1989), which can hinder positive engagement in mental health services. Individuals identified as CHR-P might experience increased discrimination or feelings of shame because of being labeled and receiving treatment, which may lead to increased stigma stress that could exacerbate their symptoms (Link et al., 1989).

In addition to the exacerbation of clinical symptoms, stigma can negatively impact key psychosocial outcomes such as quality of life, mood, self-esteem, and lifestyle behaviors. Research has demonstrated that internalized stigma can increase depressed mood (Pyle et al., 2013), deplete self-esteem (Xu et al., 2016), decrease overall quality of life (Dengan et al., 2021), and affect the engagement in healthy lifestyle behaviors (Carney et al., 2017). More specifically, research has shown that stigma stress and internalized stigma are directly related to depressed mood and reductions in self-esteem (Pyle et al., 2013; Xu et al., 2016). Some underlying factors for the etiology and maintenance of depressive symptoms in CHR-P groups include negative cognitive appraisals about experiencing attenuated psychosis symptoms, perception of social status loss, and embarrassment associated with being labeled with an at-risk status (Pyle et al., 2013). Additionally, a recent meta-analysis (Dengan et al., 2021) confirmed that stigma was negatively associated with quality of life, and was robustly related to psychological, environmental, social, and physical domains. Furthermore, a qualitative study demonstrated that fear of judgment from others, the adoption of negative views about the self, and internalized self-stigma served as barriers for healthy lifestyle behaviors, which include regular physical activity, nutritious diets, and avoiding substance use (Carney et al., 2017). Importantly, even though research has established substantial links between internalized stigma and lower self-esteem, increased depression, worse quality of life, and poorer lifestyle habits, individuals with psychosis symptoms who exhibit stigma resistance (i.e., challenging and deflecting mental health stereotypes) often tend to have better psychosocial outcomes, including higher self-esteem and better quality of life (Thoits & Link, 2016). This underscores the positive impact that stigma interventions have on individuals with psychosis-related conditions.

In addition to psychosocial outcomes, experiences of stigma can have pervasive effects on functional outcomes, such as social cognition, and social and role functioning. More specifically, emerging literature has shown that decreased abilities in facial emotion recognition, Theory of Mind (ToM), and social relationship perception may be associated with higher levels of internalized stigma (Larsen et al., 2019; Herrera et al., 2022; Crump et al., in preparation). Although research to date is sparse, some studies have demonstrated a negative relationship between social cognitive abilities (e.g., facial emotion recognition accuracy and latency, intact ToM, etc.) and stigma domains (e.g., increased secrecy and discrimination). More specifically, CHR-P individuals who demonstrated more shame related to experiencing at-risk symptoms were less accurate at identifying fearful faces and often misattributed fear to non-fearful faces. For example, at-risk participants may endorse fear being present in a neutral face (Larsen et al., 2019). Taken together, these findings indicate that CHR-P individuals who exhibit internalized stigma might expect others to be fearful of them even when fear is not present, which bolsters the idea that stigma can impact social perception. Furthermore, direct relationships have been established in the literature between social cognition and social functioning in psychosis-risk groups whereby worse social cognitive abilities (e.g., ToM) typically result in poorer performance in social domains, such as with initiating and maintaining peer or intimate partner relationships (Glenthøj et al., 2016). Interestingly, self-stigma has also been linked to poorer functioning overall, including in social and role-related domains (Cavelti et al., 2014). For example, Cavelti et al. (2014) found that higher levels of internalized stigma at baseline predicted worse role functioning 12 months later, which further underscores the ubiquitous impact stigma can have on real-world outcomes when left untreated.

Stigma has held particular relevance for the CHR-P field since the clinical high-risk status was introduced as a potential diagnosis; however, its widespread use as a diagnostic category in the DSM-5 has been heavily debated (Nelson & Yung, 2011; Fusar-Poli & Yung, 2012; Corcoran et al., 2021). Historically, schizophrenia-related disorders have been among the most highly stigmatized conditions (Room et al., 2001). Consequently, individuals identified as CHR-P may adopt negative beliefs associated with their mental health status, which could deeply impact identity and self-esteem. While there is evidence that classifying an individual as CHR-P can bring about feelings of relief (Corcoran, 2016), it is also possible for negative mental health attitudes to be internalized, which may deter individuals from accessing care and lead to worsening of symptoms. More specifically, research has shown that stigma stress in CHR-P youth can impact their trajectory of illness by increasing the likelihood of transitioning to full-blown psychosis sooner (Rusch et al., 2015). Therefore, it is crucial to examine the effects of stigma on CHR-P populations and develop tools to mitigate its impact on health outcomes while balancing the apparent need for treatment.

While stigma interventions for schizophrenia and first episode psychosis (FEP) exist (Tsang et al., 2016; Best et al., 2018), to date, there is only one specifically designed for CHR-P and stigma, which is primarily a family-based psychoeducational intervention (McFarlane et al., 2012). Currently, no targeted stigma interventions exist for CHR-P groups. A recent call to action to implement stigma interventions for CHR-P youth garnered attention because studies have shown that standard interventions do not fully address the impact of stigma stress in this population (DeLuca et al., 2021). Furthermore, internalized stigma associated with labeling and symptom stigma in CHR-P groups can increase fear, suicidality, distress, withdrawal, disengagement with crucial services, and transition to psychosis (DeLuca et al., 2021; Colizzi et al., 2020; Rusch et al., 2015). Therefore, targeted stigma interventions for CHR-P individuals are urgently needed.

We proposed the first cognitive behavioral internalized stigma intervention for

CHR-P groups, which was adapted from models used with psychosis and empirically based stigma reduction strategies, including the combination of lecture, discussion, group support, problem-solving approaches, sharing of personal stories, and teaching and practicing of stigma-related skills (Lucksted et al., 2011). Additionally, we adopted a brief, group approach that aimed to facilitate dialogue amongst group members with the help of two clinicians and peer coleader who was identified has having an early psychosis status (CHR-P or FEP) and demonstrated stigma resistance. Based on a meta-analysis establishing the efficacy of peer contact when implementing stigma reduction strategies (Corrigan et al, 2012), and FEP stigma interventions that highlight the importance of including a peer facilitator to help normalize psychosis-related experiences and provide hope for the future (Best et al., 2018), the proposed stigma intervention ('Resisting Internalized Stigma' [RIS]) was led by three coleaders (i.e., a trained CHR-P peer and two clinicians). Additionally, RIS was created to have applicability to psychosis-spectrum disorders generally so that FEP and CHR-P individuals can both participate. Based on interest and enrollment, RIS was run as two combined CHR-P and FEP groups.

RIS is an 8-week, virtually held intervention integrating: 1) psychoeducation about the development of psychosis and at-risk states; 2) cognitive-behavioral skills to challenge inaccurate stereotypes of having a psychosis-related condition; and 3) coping skills for anticipated and experienced discrimination related to mental health, including anti-bullying strategies. Existing stigma interventions utilizing cognitive restructuring, building assertive communication skills, and peer support have proven to be successful at improving levels of internalized stigma, self-esteem, and life satisfaction for FEP groups

(Best et al., 2018); however, it is unknown if these strategies have utility in CHR-P populations.

One FEP and one CHR-P coleader each co-ran a mixed diagnosis (combined CHR-P and FEP) stigma intervention group separately. Due to low recruitment of CHR-P participants, we combined groups in analysis, including coleaders. It is important to note that serving as a coleader may elicit positive emotions related to taking on a leadership role that may be unrelated to the intervention. Although we combined coleaders and group participants in analysis because it is an acceptability and feasibility study with a small sample, we encourage future iterations of this study to rigorously test the impact of the coleader role before including them in analyses. We expanded on outcomes that have been used in FEP stigma interventions (Best et al., 2018) by including measures of social cognition, social and role functioning, and lifestyle behaviors. Other important outcomes included in RIS were assessments of stigma (e.g., symptom and labeling related stigma), psychological wellbeing, and depressed mood. This feasibility data, along with a finalized intervention manual, provides pilot data for a potential larger, randomized controlled intervention trial to rigorously test this stigma intervention for CHR-P and FEP groups.

There were 3 aims to this study:

1. Evaluate the feasibility and acceptability of a novel stigma intervention (RIS). To assess the feasibility and acceptability, we:
    a. Estimated recruitment, attendance, and drop-out rates.
    b. Established concurrent validity between a well-established stigma scale and the corresponding stigma scales utilized in this study.

    c. Described the appropriateness and acceptability of the intervention by utilizing the qualitative information collected at the end of the intervention.

2. Refine the manual based on participant feedback. To assess feedback, we:
    a. Coded themes for refinement utilizing the qualitative interview administered at the end of the intervention.
3. Explore changes in psychosocial and functional outcomes from baseline to follow-up. To assess for these changes, we:
    a. Explored associations between baseline stigma variables, psychosocial and functional outcomes.
    b. Explored associations between stigma variables, psychosocial and functional outcomes at follow-up.
    c. Compared baseline and follow-up intervention measures to assess for change over time.
    d. Graphically examined baseline and follow-up intervention measures to assess for trend change over time.
    e. Computed change scores in assessment measures from baseline to follow-up and explore associations.
    f. Performed a qualitative analysis to describe emerging trends related to changes in stigma from baseline to follow-up.

Hypotheses associated with each aim of this study include:

1. We expected the intervention to be acceptable and feasible.
    a. Based on prior studies (Villeneuve et al., 2010; Best et al., 2016), we

    expected there to be >70% recruitment rate, >70% attendance rate, and <15-20% drop out rate.

    b. We expected the Perceived Devaluation-Discrimination scale to exhibit concurrent validity with this study's experienced discrimination subscales of the stigma interview.
    c. We expected this intervention to be acceptable and appropriate in terms of content.
2. We expected participants to provide valuable information to help refine the manual and protocol.
3. By conducting exploratory Pearson correlations, we expected there to be improvements in various psychosocial and functional outcomes at post intervention compared to pre intervention in both FEP and CHR-P groups.
    a. We expected levels of depression to decrease (Griffiths et al., 2014) while levels of quality of life (Degnan et al., 2021), self-esteem (Best et al., 2018), positive lifestyle habits (Dinzeo et al., 2021), and areas of social and role functioning (DeTore et al., 2021) to increase.
    b. Although we did not expect clinical symptoms to directly improve due to the stigma intervention, we tracked them to monitor clinical stability from baseline to follow-up.
    c. Additionally, there is a dearth of literature examining the relationship between stigma and social cognition; however, there is emerging evidence that ToM, social relationship perception and facial emotion recognition are associated with internalized stigma (Barbato et al.,

2015; Larsen et al., 2019; Herrera et al., 2022; Crump et al., in preparation). Based on this work, we expected there to be mostly negative associations between stigma domains and social cognitive performance. However, some positive associations were expected to emerge, including those for social relationship perception.

d. Due to small sample size, we expected some quantitative analyses to demonstrate insignificant associations. Therefore, we expected some changes in psychosocial or functional outcomes based on graphic inspection alone.
e. We expected changes in psychosocial and functional outcomes to be associated with changes in stigma variables. For example, we expected that a reduction in shame would be associated with a decrease in depression. On the other hand, as positive symptoms increase, we expected depression to decrease.
f. We expected CHR-P and FEP groups to express relevant examples of stigma during the qualitative portion of the interview. We expected themes to emerge related to stigma, discrimination, stereotyping, family and peer-related impacts on self-esteem and views of mental health, etc. Because of the potential breadth of responses, we focused on themes that emerged specifically pertaining to pre vs. post stigma intervention (i.e., how stigma has changed from baseline to the end of the 8-week intervention period).

Chapter 2

Method

Recruitment Procedures

This study obtained approval from University of Pennsylvania's IRB (Protocol #832010) and served as the main site IRB. Reciprocal IRB approval was obtained through Rowan University (Protocol #PRO-2023-77) and a data sharing agreement was executed and signed by representatives at both institutions. Participants were recruited from the University of Pennsylvania's Psychosis Evaluation and Recovery Center (PERC) in Philadelphia, Pennsylvania. 3 PERC participants (2 FEP, 1 CHR-P) were approached to be co-leaders and 36 PERC participants (33 FEP, 3 CHR-P) were approached to be group members for the stigma intervention. Individuals were identified through flyers and outreach efforts conducted at PERC, which included staff members describing the study to potentially eligible participants. Inclusion criteria included: 1) age 16-35; 2) meet criteria for one or more of three CHR-P syndromes as assessed by the SIPS/SOPS or FEP as determined by clinical interview; 3) capacity to give informed consent or assent; 4) able to read, write, and speak in English. Exclusion criteria were: 1) risk of harm to self or others; 2) major neurological disorder or medical condition; 3) IQ<70.

Written informed consent and/or assent was obtained by all participants. For the participant that was under 18 years old, written informed consent was obtained from their parent. All participants remained in treatment at PERC throughout the duration of the study and clinical appropriateness for participation was continuously monitored.

All subjects who were interested in participating in this research study were given the contact information of the principal investigator (Monica Calkins, PhD) and Francesca Crump, MA to further describe the study. Other PERC staff members obtained written informed assent and consent for participation to avoid any potential effects of investigator influence on study participation.

Study Procedures

Three peer coleaders who were identified as CHR-P or FEP were recruited based on clinical stability and willingness to speak about experiences with stigma in a virtual, group format. Out of the three that were approached, two PERC participants were interested in being coleaders in the study. After providing consent, they met with a PERC staff member and were assessed with pre-stigma intervention measures and participated in the full stigma intervention with integrated peer coleader training from February to April of 2023. Coleaders were simultaneously trained on how to be a peer coleader over the course of 8 weeks (i.e., corresponding to the number of intervention sessions). Specific instances of experiences of stigma were elicited and coleaders learned anti-stigma strategies that they could share with the group. Francesca Crump, MA and another PERC staff member served as co-facilitators of this coleader stigma group. All intervention meetings took place virtually through University of Pennsylvania's HIPAA compliant Zoom platform.

Coleaders were asked to provide feedback on the intervention to help refine each session. After the 8-week intervention and training process ended, coleaders were assessed with all post-stigma intervention measures. During the post-assessment, Francesca Crump, MA evaluated whether the peer coleaders 1) had a full grasp of the intervention manual; 2) had a willingness to speak to potential group members about stigma experiences they have experienced; and 2) expressed agreement to continue with the study and co-lead intervention groups. Both coleaders agreed to co-lead an intervention group at the end of the assessment period.

During the 8-week co-leader intervention and training period, the PERC team discussed the recruitment of potential CHR-P and FEP participants based on fit, clinical stability, and interest. Thirty-six PERC participants (33 FEP and 3 CHR-P) were approached for the study. Of those 36, 12 PERC participants expressed interest. Of those 12, 7 were ultimately enrolled in the study. The enrolled participants were split into two groups that were run simultaneously from April to June of 2023. Participants were assigned to each group by participant availability. Each group contained 1 CHR-P participant to randomize distribution of CHR-P group members. Due to time constraints, another group was not able to be run despite interest from recruited coleaders. All recruited participants completed pre-stigma intervention measures before beginning the intervention. All participants who were willing to participate in the follow-up assessment completed post-intervention measures within one month of the intervention end dates.

An overview of each session of the stigma intervention is provided below while the full manual is attached in Appendix A.

Each session consisted of:

1. Psychoeducation and normalization of youth with mental health problems, stigma, and discrimination.
2. Psychoeducation on the stress-vulnerability model of mental illness, ways to cope with feeling different and tools to help prevent worsening symptoms.

3, 4, 5. Cognitive-behavioral strategies to counter internalized stigma through identifying inaccurate stereotypes related to mental health, understanding automatic thoughts, challenging stereotypes with evidence, and changing self-stigmatizing cognitions.

6, 7, 8. Discuss and provide cognitive behavioral strategies to help cope with anticipated and experienced forms of discrimination due to mental health problems through anti-bullying skills and role-playing to avoid or defuse confrontations.

Discontinuation procedures were created for participants that became clinically unstable (e.g., hospitalization, too symptomatic to participate, risk for harm to self or others, etc.). During the study period, no participants met these criteria. Additionally, participants continued to be offered services at PERC throughout the duration of their participation.

Measures

All measures depicted below were administered both before and after the stigma intervention except for the demographics form, which was only utilized as a pre-measure. Additionally, the qualitative assessment to better understand the appropriateness of the intervention was only asked as a post-measure. All measures were offered through a virtual format and were stored in the University of Pennsylvania's REDCap database.

All participants had to consent to a release of their records at PERC to gain access to symptom-related information obtained in the intake interview by PERC's psychiatry team and any relevant program evaluation measure completed as part of PERC's research protocol (e.g., SIPS/SOPS). Measures marked with an asterisk (*) indicate that this information is already collected by PERC. Therefore, participants' most recent scores were utilized for this study. Some measures were readministered for post intervention assessments and in some cases, PERC utilized those scores for their own purposes (i.e., program evaluation).

Demographics*. Characteristics such as age, race, ethnicity, gender, education, and income were collected as part of PERC's study procedures. This demographics form was also utilized for this study.

Stigma. A stigma interview (Mental Health Attitudes Interview) developed by Yang and colleagues (2015) was utilized. This interview is based on the Modified Labeling Theory (Link et al., 1989) for internalized stigma and differentiates between stigma associated with experiencing symptoms (i.e., symptom stigma) and being labeled (i.e., labeling stigma) with a mental illness. Participants were asked about their beliefs about being at-risk for or developing five conditions: depression, anxiety, bipolar, psychosis and schizophrenia. Participants were queried about which condition had the largest impact on how they think of themselves. They answered questions about symptom and labeling stigma experiences with this self-identified condition in mind. Subscales of the stigma interview included: stereotype awareness (awareness of stereotypes pertaining to people with mental health problems; labeling: α=.70), stereotype agreement (level of agreement with stereotypes associated with people with mental illness; labeling: α=.68), positive (labeling: α=.84; symptom: α=.65) and negative (labeling: α=.60; symptom: α=.74) emotions, secrecy (labeling: α=.60; symptom: α=.63), experienced discrimination (labeling: α=.84), and experienced support (Yang et al., 2015). This stigma interview included both quantitative and qualitative subscales and took approximately 30-40 minutes to complete.

The Perceived Devaluation-Discrimination Scale (Link, 1987; Link, 2017) measured perceptions of stigma associated with former or current psychiatric patients and included 12 items on a four-point Likert scale. High levels of perceived devaluation-discrimination indicate a high level of perceived stigma. This questionnaire took approximately 5 minutes.

Depression. The Beck Depression Inventory (BDI-2, α=.91; Beck et al., 1996) consisted of 21 items that aimed to assess the intensity of depressive symptoms and has demonstrated validity in clinical populations. This inventory took approximately 5 minutes.

Quality of Life. The World Health Organization-Quality of Life (WHOQOL-BREF; WHO, 2012) Scale was used to assess overall health and quality of life and satisfaction in these areas. The questionnaire is scored from 1 to 5 with varying anchors and took approximately 10 minutes to complete.

Self-Esteem. The Rosenberg Self-Esteem Scale (Rosenberg, 1965) is a 10-item self-report measure that assessed for global self-esteem and is scored from 1 (strongly agree) to 4 (strongly disagree). This scale demonstrates excellent internal consistency and stability and has been shown to significantly correlate with measures of anxiety and depression (Rosenberg, 1965). This questionnaire took approximately 5 minutes to complete.

Lifestyle & Habits. The Lifestyle & Habits Questionnaire-Brief Version (LHQ-B; Dinzeo et al., 2014) consisted of 42 items that asked about specific areas of quality of life including health & exercise, psychological health, substance use, nutrition, environmental concern, social concern, accident prevention/safety, and sense of purpose.

All questions are scored from 1 (strongly disagree) to 5 (strongly agree). This questionnaire took approximately 10 minutes.

Social and Role Functioning*. The Global Functioning: Social and Role Scales (Cornblatt et al., 2007) were used to assess CHR-P and FEP participants' social and role involvement with peers, intimate partners, relatives, colleagues, and employers. Current, highest, and lowest levels of functioning in the past year were assessed with scores ranging from 1 (poor) to 10 (superior) through clinician interview and took approximately 20 minutes to complete. This measure was completed as part of PERC's battery of assessments; however, was repeated if it was not administered within 3 months of last assessment.

Social Cognition. Social relationship perception was assessed with the Relationships Across Domains-15 (RAD-15; Sergi et al., 2009), which aimed to assess the ability to understand social relationships and make inferences about future behavior based on 15 vignettes given about a male-female dyad. This task took about 10 minutes.

Theory of Mind (ToM) was assessed by The Awareness of Social Inference Test (TASIT; McDonald et al., 2006). The TASIT consisted of 16 video-taped scenes meant to assess emotion recognition, the ability to interpret literal (sincerity and lies) and non-literal (sarcasm) conversational remarks and the ability to make judgments about the speakers' thoughts, feelings, and intentions. Participants were presented with a video-taped vignette, each lasting anywhere from 15-60 seconds, and then asked to answer 4 forced-choice (yes/no) questions. This task took about 15 minutes to complete.

Emotion recognition* was assessed with the Penn Emotion Recognition Task (ER-40; Gur et al., 2002), which is a computerized task that tests the accuracy of identifying five facial emotions (happy, sad, anger, fear, and neutral). There are 40 total faces and four races represented. This task took about 10 minutes to complete. Some participants were already assessed using this measure as part of another study that occurred at PERC. If completed within 3 months, their scores were used for this study.

Emotion differentiation* was assessed with the Penn Measured Emotion Differentiation Task (MEDF36; Kohler et al., 2000) computerized task, which presented emotional facial stimuli and asked participants to determine which face has more intensity of emotion (e.g., identify which face is happier). This task took about 10 minutes to complete. Some participants were already assessed using this measure as part of another study that occurred at PERC. If completed within 3 months, their scores were used for this study.

Qualitative Assessment. Acceptability and feasibility were assessed by qualitative questions and changes to the stigma intervention were considered based on participant feedback for future iterations of it. Participants were interviewed about their experiences with the intervention at the post-assessment and this took approximately 20 minutes to complete.

Clinical Symptoms*. The Structured Interview for Psychosis-Risk Syndromes (SIPS/SOPS; Miller et al., 2003; McGlashan et al., 2010c) was used to assess and characterize positive, negative, disorganized, and general symptoms for both FEP and CHR-P participants. Each symptom was rated on a scale from 0-6. CHR-P participants must receive a score of less than a 6 on any positive symptom to be considered CHR-P (Miller et al., 2003; McGlashan et al., 2015). FEP participants were evaluated based on a clinical interview completed by the psychiatrist team at PERC; however, were also administered the P section of the SIPS/SOPS to track specific psychosis-related symptoms over the course of the intervention to ensure they did not meet criteria for early discontinuation. Because PERC utilizes the SIPS/SOPS to determine eligibility for their program, CHR-P participants' scores on their most recent SIP/SOPS interview were used if completed within three months of enrollment in this study. If there was not a recent SIPS/SOPS (i.e., completed within a 3-month timeframe), another SIPS/SOPS was administered.

IQ*. As per PERC's protocol, participants with IQ<70 are deemed ineligible for their program. Therefore, CHR-P and FEP individuals recruited for this study had an IQ>70 to participate.

Chapter 3

Analyses

This study's first aim was to evaluate the feasibility and acceptability of RIS, a CBT-based stigma intervention. Our second aim was to collect feedback from participants in RIS to refine the manual and its procedures. Finally, the third aim was to explore potential changes in psychosocial and functional outcomes once the intervention was completed. Due to small sample size, certain statistical analyses were limited. Additionally, due to low recruitment of CHR-P individuals and similar linear trends between CHR-P and FEP participants, all study participants, including coleaders, were combined in analyses. Although the choice was made to include coleaders in analyses, it is important to consider the implications of this in future iterations with a larger sample. The impact of the coleader role may elicit benefits on its own due to taking on a leadership role; however, in this acceptability and feasibility study, those potential effects would be too small to statistically detect. Therefore, for the purposes of this study, group participants and coleaders were analyzed together for simplicity.

All analyses took place in R Statistical Software (R Core Team, 2021). To address each aim, we:

1a. Reported demographic information to characterize the sample and estimated recruitment, attendance, and drop-out rates using descriptive statistics.

1b. Established concurrent validity between the Perceived Devaluation-Discrimination Scale and the Experienced Discrimination subscales of the Mental Health Attitudes stigma interview through Pearson correlations at baseline.

1c. Coded and grouped information according to themes from participants regarding acceptability and appropriateness of the intervention.

2a. Coded and grouped themes for manual refinement based on participant feedback.

3a. Examined exploratory bivariate associations between stigma variables and other outcomes at baseline using Pearson correlations.

3b. Examined exploratory bivariate associations between stigma variables and other outcomes at follow-up using Pearson correlations.

3c. Compared pre and post stigma intervention measures using Wilcoxon Signed Rank Tests and computed effect sizes for significant findings and denoted as r. The effect size was calculated by dividing the Z statistic by the square root of the paired sample size.

3d. Examined pre and post stigma intervention measures from Wilcoxon Signed Rank Tests with graphics.

3e. Computed change scores by subtracting follow-up scores from baseline scores and examined bivariate associations between stigma variables and outcome measures using Pearson correlations.

3f. Performed qualitative analyses by first coding all interviews using an established codebook from previous studies (Yang et al., 2015). Once all interviews were coded, codes were grouped into major themes and described based on changes in stigma from baseline to follow-up.

Chapter 4

Results

The sample was primarily young (M=24.17, SD=4.98), white (77.78%), and male (55.56%). All study participants were never married, the majority of subjects were living with family (66.67%), and over half of subjects were unemployed or looking for work (55.55%). Most participants met criteria for a FEP diagnosis (77.78%), and more than half of individuals had one or more psychiatric hospitalizations. To assess aim 1a, we estimated recruitment, attendance, drop-outs rates. In terms of recruitment, coleaders agreed to participate 66.67% of the time while group participants agreed to participate almost 20% of the time on average. Only one group participant dropped out of the study after attending two sessions. Coleaders demonstrated 100% attendance while all group participants attended at least 5 out of 8 sessions. Group 1 had a higher overall attendance rate (83%) as compared to Group 2 (66.67%). All study participants remained functionally and clinically stable from baseline to follow-up. See Table 1 for further information regarding recruitment, attendance, drop out, and demographic characterizations.

Table 1

Sample Characteristics

Participants (n=9)	N (%)
Gender	
Male	5 (55.56%)
Female	3 (33.33%)
Transgender	1 (11.11%)
Age	24.17 (4.98)
Race	
White	7 (77.78%)

Participants (n=9)	N (%)
Race	
Asian	2 (22.22%)
Ethnicity	
Hispanic/Latino	1 (11.11%)
Marital Status	
Single, never married	9 (100.00%)
Employment	
Full-time	2 (22.22%)
Part-time	2 (22.22%)
Unemployed	4 (44.44%)
Looking for work	1 (11.11%)
Enrolled in School	
Yes	3 (33.33%)
Diagnosis	
CHR-P	2 (22.22%)
FEP	7 (77.78%)
Hospitalizations	
0	4 (44.44%)
1	3 (33.33%)
2	2 (22.22%)
Average SIPS scores for CHR-P (n=2)	*Baseline, Follow-up*
P1	4.5, 4
P2	2.5, 2.5
P3	1.5, 1.5
P4	4, 4
P5	2.5, 2.5
Average Functioning (n=9)	*Baseline, Follow-up*
Role	6.22, 6.38
Social	7.22, 8.00
Housing	
Living alone	1 (11.11%)
Living with partner/roommate	2 (22.22%)
Living with family	6 (66.67%)
Recruitment	*Total recruited (% acceptance)*
Coleaders (n=2)	3 (66.67%)
CHR-P (n=1)	1 (100.00%)
FEP (n=1)	2 (50.00%)
Participants (n=7)	36 (19.44%)
CHR-P (n=1)	3 (33.33%)
FEP (n=6)	33 (18.18%)
Drop-out	
Coleaders (n=2)	0 (0%)
Participants (n=7)	1 (14.29%)
Attendance	*Range of weeks (average %)*
Co-leaders	8 (100.00%)

Participants (n=9)	N (%)
Attendance	
Group 1	6-7 (83.00%)
Group 2	5-7 (66.67%)

Bivariate Associations

For a comprehensive overview of significant and trend findings, see Table 2 (baseline) and Table 3 (follow-up). To assess aim 1b, Pearson correlations were performed between stigma variables on the Mental Health Attitudes interview and other outcome measures at baseline and follow-up. Concurrent validity for stigma was established between the experienced discrimination subscales and the well-established perceived discrimination-devaluation scale (p=.022 (labeling), p=.040 (symptoms)).

To assess aim 3a-3b, we examined relationships between stigma, psychosocial and functional variables. Many of the bivariate relationships were associated with shame at baseline. In general, there were mostly negative associations between internalized stigma subscales and psychosocial and functional outcomes at baseline; however, there were also some notable positive associations. For example, higher levels of shame related to symptoms was associated with poorer psychological health, nutrition, psychological quality of life, and self-esteem. Additionally, more shame about mental health symptoms was strongly related to a reduced sense of purpose (p=-.001). Interestingly, higher levels of shame related to labeling was significantly associated with better role functioning and better ToM at the trend level. Furthermore, higher levels of experienced discrimination were related to more depressive symptoms and perceived discrimination and devaluation.

At follow-up, most of the associations between shame and other variables became non-significant. Instead, most variables were positively related to positive emotions about symptoms and labeling. For example, positive emotions related to labeling was significantly associated with better emotion identification, quality of life for physical health, self-esteem, and role functioning. Additionally, significant associations were demonstrated between positive emotions about symptoms and better social and role functioning, and less depressive symptoms.

Table 2

Baseline Bivariate Associations

	Ster. Aware	Ster. Agree	Shame	Pos. Emotion	Secrecy	Disc.	Support
Emo Identification					**0.737^** **(S)**		
Emo Differentiation						**-0.786*** **(L)** F=8.08	
Depression	**0.732*** F=8.08		**0.779*** **(S)** F=10.78			**0.802**** **(S)** F=12.65	**-0.729*** **(L)** F=7.93
Psychological Health	**-0.691*** F=6.39		**-0.891**** **(S)** F=26.88				
Nutrition			**-0.754*** **(S)** F=9.21				
Environmental Concern	**-0.769*** F=10.12						
Social Concern	**-0.705*** F=6.90						
Accident Prevention	**-0.734*** F=8.18						
Sense of Purpose			**-0.892**** **(S)** F=27.22				
Stigma (PDD)						**0.743*** **(L)** F=8.61 **0.688*** **(S)** F=6.30	
QOL Physical	**-0.748*** F=8.88					**-0.716*** **(L)** F=7.38	
QOL Psychological			**-0.710*** **(S)**				

	Ster. Aware	Ster. Agree	Shame	Pos. Emotion	Secrecy	Disc.	Support
QOL Psychological			F=7.12				
QOL Soc Relationships		**-0.696*** F=6.56					**0.639^** **(S)**
QOL Env						**-0.744*** **(L)** F=8.70	
QOL Overall					**0.812**** **(S)** F=13.59		
Ster. Aware	Ster. Agree	Shame	Pos. Emotion	Secrecy	Disc.	Support	
Soc Rel Perception			**0.701*** **(L)** F=6.75				
Self-Esteem			**-0.868**** **(S)** F=21.30				
Role Functioning			**0.714*** **(L)** F=7.29 **-0.126^** **(S)**	**0.642^** **(L)** **0.679*** **(S)** F=6.00			
Social Functioning						**-0.679*** **(L)** F=6.00	

Note. * p<.05, ** p<.01, ^ = trend (p<.09), L = labeling stigma, S = symptom stigma

Table 3

Follow-up Bivariate Associations

	Ster. Aware	Ster. Agree	Shame	Pos. Emotion	Secrecy	Disc.	Support
Emo Identification				**0.865*** **(L)** F=11.88			
Emo Diff CR		**0.824*** F=8.49	**-0.775^** **(L)**				
Depression				**-0.712^** **(L)** **-0.809*** **(S)** F=9.44			
Health & Exercise				**0.678^** **(L)**			
Psychological Health				**0.685^** **(L)**			

	Ster. Aware	Ster. Agree	Shame	Pos. Emotion	Secrecy	Disc.	Support
Environmental Concern			**-0.747^ (L)**				
Accident Prevention	**-0.841*** F=12.09				**-0.766* (S)** F=7.12		
Sense of Purpose							**0.822* (S)** F=10.38
Stigma (PDD)	**0.734^**						
QOL Psychological				**0.772* (L)** F=7.38 **0.696^ (S)**			
QOL Soc Rel				**0.710^ (S)**			
QOL Env				**0.675^ (L)**		**-0.726^ (L)**	
QOL Overall	**-0.755*** F=6.65	**-0.730^**					
Soc Rel Perception			**0.740^ (L)**		**-0.873* (S)** F=16.01		
Self-Esteem				**0.855* (L)** F=13.58 **0.901** (S)** F=21.45			
ToM							**0.719^ (L)**
Role Functioning				**0.905** (L)** F=22.59 **0.839* (S)** F=11.91			
Social Functioning	**-0.828*** F=10.92						

Note. * p<.05, **p<.01, ^ = trend (p<.09), L = labeling stigma, S = symptom stigma

Pre and Post Analysis

See Table 4 for a comprehensive account of pre and post comparisons. To assess aim 3c, Wilcoxon Signed Rank Tests were performed to examine changes in stigma, psychosocial, and functional outcomes across all participants from baseline to follow-up.

This analysis was chosen over independent sample t-tests because Wilcoxon Signed Rank Tests make less assumptions about the sample and is more appropriate to use for small sample sizes. Several significant findings emerged as well as trend findings. From baseline to follow-up, participants had less perceived discrimination and devaluation, which indicates an overall reduction in stigma. Additionally, they had higher positive emotions about their symptoms and a higher sense of purpose. Wilcoxon effect sizes were computed for significant findings. Reductions in stigma had a small to moderate effect while increased positive emotions about symptoms and elevations in sense of purpose demonstrated a close to moderate effect size. (Table 4). Trend findings included higher self-esteem and better ToM performance. Additionally, after visually inspecting pre and post comparisons (aim 3d), differences in other outcome variables were apparent but did not reach significance or trend level. These variables include a positive change in emotion identification, psychological health, social concern, and social relationship perception, and a reduction in labeling related stereotype agreement and experienced discrimination.

Table 4

Pre and Post Assessment Characteristics

	Baseline (n=9) M (SD)	Follow-up (n=7) M (SD)
Emotion Identification		
Correct responses	35.71 (2.98)	37.67 (2.07)
Reaction time	1890.07 (334.78)	1826.50 (495.51)
Emotion Differentiation		
Correct responses	30.50 (2.07)	30 (2.00)
Reaction time	2997.33 (767.79)	2245.42 (667.99)
Depression	20 (5.89)	13 (8.43)

Lifestyle & Habits		
Health & Exercise	20 (6.24)	18.43 (7.09)
Psychological Health	24.22 (2.94)	25.57 (3.15)
Substance Use	34.56 (3.75)	35.29 (4.46)
Nutrition	12.56 (2.59)	12.29 (2.21)
Environmental Concern	19.33 (3.06)	19.29 (3.09)
Social Concern	20.67 (2.98)	22.14 (3.18)
Accident Prevention & Safety	17.22 (2.48)	18 (2.08)
Sense of Purpose*, effect size r=0.37	**11.78 (1.99)***	**13 (2.65)***
Perceived Devaluation-Discrimination*, effect size r=-0.49	**1.89 (0.44)***	**1.39 (0.42)***
Quality of Life		
Physical	63.10 (16.24)	62.76 (19.87)
Psychological	62.96 (9.51)	62.50 (15.21)
Social relationships	52.78 (16.20)	53.57 (14.32)
Environment	68.06 (9.86)	70.98 (9.67)
	Baseline (n=9) M (SD)	Follow-up (n=7) M (SD)
Quality of Life		
Overall	4.11 (0.31)	4.29 (0.49)
Overall Health	3.33 (0.82)	3.43 (0.98)
Quality of Life		
Physical	63.10 (16.24)	62.76 (19.87)
Psychological	62.96 (9.51)	62.50 (15.21)
Social relationships	52.78 (16.20)	53.57 (14.32)
Environment	68.06 (9.86)	70.98 (9.67)
Overall	4.11 (0.31)	4.29 (0.49)
Overall Health	3.33 (0.82)	3.43 (0.98)
Social Relationship Perception	32.44 (5.72)	32.14 (6.44)
Self-Esteem^	**27.11 (3.51)^**	**30.29 (4.23)^**
Theory of Mind^	**49.55 (7.68)^**	**54.29 (6.82)^**
Global Functioning		
Role	6.22 (2.66)	6.375 (2.56)
Social	7.22 (1.93)	8.00 (1.31)
Stigma subscales		
Labeling		
Stereotype Awareness	43.00 (7.62)	40.00 (7.23)
Stereotype Agreement	17.89 (3.18)	16.29 (2.14)
Shame	8.44 (2.11)	9.14 (1.46)
Positive emotions	11.22 (3.49)	10.71 (3.25)
Secrecy	1.89 (0.99)	1.57 (1.13)
Experienced discrimination	13.22 (3.76)	10.29 (3.15)
Support	3.78 (0.63)	4.00 (0.58)
Symptoms		
Shame	9.44 (1.95)	8.71 (1.38)

Positive emotions*, effect size r=0.42	**8.11 (2.08)***	**9.00 (2.89)***
Secrecy	1.56 (1.50)	1.29 (1.25)
Experienced discrimination	14.00 (3.46)	13.29 (3.55)
Support	3.89 (0.57)	4.14 (0.69)
Impact	N (%)	
Psychosis/Schizophrenia	6 (66.67%)	5 (71.43%)
Anxiety	2 (22.22%)	1 (14.29%)
Depression	1 (11.11%)	1 (14.29%)

Note. * p<.05, ^ = trend (p<.09)

Change Score Analysis

To assess aim 3e, change scores were computed by subtracting follow-up scores from baseline scores. Then, Pearson correlations were conducted between change scores to determine if changes in one variable were related to changes in another variable. Several significant findings were found. For example, change in secrecy about symptoms was negatively related to change in psychological health and social concern while change in labeling secrecy was negatively related to change in accident prevention. A reduction in shame of labeling was associated with increased avoidance of substances and a decrease in depressive symptoms. Additionally, reductions in shame related to symptoms was associated with better nutrition and ToM. The strongest change score association revealed that improvements in psychological health was associated with decreases in labeling shame. For a more comprehensive account of change score analyses, refer to Table 5.

Table 5

Change Score Analysis

	Ster. Aware	Ster. Agree	Shame	Pos. Emotion	Secrecy	Disc.	Support
Depression			**0.869* (L)** F=15.49	**-0.751^ (S)**	**0.732^ (S)**		
Psychological Health			**-0.881** (L) F=17.42**	**0.678^ (S)**	**-0.783* (S)** F=7.90		
Substance Use Avoidance			**-0.858* (L)** F=13.98		**-0.745^ (S)**		
Nutrition			**-0.804* (S)** F=9.17				
Environmental Concern		**-0.758*** F=6.73					
Social Concern			**-0.732^ (L)**		**-0.821* (S)** F=10.31		
Accident Prevention	**-0.713^**			**0.790* (L)** F=8.33	**-0.838* (L)** F=11.83	**-0.682^ (S)**	
Sense of Purpose		**-0.721^**					
Soc Rel Perception			**0.738^ (L)**		**0.702^ (S)**		
Self-Esteem	**-0.722^**			**0.839* (S)**			
Self-Esteem				F=11.84			
ToM			**0.840* (S)** F=11.97		**0.707^ (S)**		**0.773* (S)** F=7.41
Social Functioning	**0.685^**						

Note. * p<.01, **p<.01, ^ = trend (p<.09), L = labeling stigma, S = symptom stigma

Qualitative Analysis

See Table 6 for a list of themes and corresponding quotes from the stigma interview and post interview.

Stigma Interview. To assess aim 3f, the qualitative portion of the Mental Health Attitudes Interview was analyzed by coding baseline and follow-up responses, grouping codes into themes, and comparing changes from baseline to follow-up. Due to the breadth and depth of the interviews, only the most prominent themes that related to changes from baseline to follow-up were included. Future qualitative analyses may continue for other projects. Seven prominent themes emerged from analyses, which include portrayal of psychosis in the media, stereotypes of psychosis, social connection, rebuilding self-esteem/identity, positive emotions related to labeling, accurate understanding of psychosis, and awareness of the public's inaccurate understanding of psychosis.

Portrayal of Psychosis in the Media. There were 8 total instances (1 positive, 7 negative) of media portrayals of psychosis across baseline and follow-up interviews. 4 out of 9 participants endorsed having seen stereotypical representations in television shows or movies, which affected how they viewed themselves and contributed to how the public tends to view individuals with mental health difficulties. At follow-up, one participant acknowledged the differences between western culture and other countries' views of mental health and was able to reimagine their experiences as an access point for creativity.

Stereotypes of Psychosis. Participants discussed stereotypes of psychosis throughout the interview; however, gave specific examples, such as being more dangerous or unpredictable, in 8 baseline responses and 5 follow-up responses. At follow-up, several participants endorsed no longer believing that they were more dangerous due to their symptoms and experiences from their participation in RIS.

Social Connection. There were 12 instances of social connection discussed by participants at follow-up. Most of these instances were related to decreased feelings of isolation and increased feelings of hope and inclusion after being in the intervention group or participating in other mental health groups, such as NAMI. One participant discussed their experience of social connection at baseline when they described how it made them feel to join PERC. They explained that entering the PERC program was one of the first times they felt like they fit in, which led to them accepting their diagnosis and being more receptive to treatment.

Rebuilding Self-Esteem/Identity. Two participants in particular demonstrated changes in their self-esteem and identity from baseline to follow-up. They indicated that found ways to rebuild a positive view of themselves through helping others with mental health difficulties and using therapeutic techniques, such as CBT.

Positive Emotions Related to Labeling. Half of participants endorsed feelings of relief, validation, or normalization of experiences after discussing their psychosis label in the group or with a mental health professional. Although negative emotions may result from labeling, many individuals can feel positively about their mental health status when discussing in a supportive space.

Accurate Understanding of Psychosis. Participants discussed several accurate depictions of psychosis, especially related to how to care for themselves. There were 3 instances depicting this in baseline interviews and 4 instances in follow-up interviews. Specifically, the most common responses were about maintaining a healthy sleep schedule and utilizing effective coping strategies in times of stress. Additionally, many participants also endorsed the necessity for consistent therapy and taking medications for their mental health.

Awareness of the Public's Inaccurate Understanding of Psychosis. Although this theme was not a common occurrence, it was significant in its relationship to the experience of internalized stigma. Two participants discussed their awareness of the public's lack of accurate understanding of psychosis, which contributed to their tendency to be more secretive about their experiences. They discussed a desire for the public to become more educated about psychosis, which could help alleviate stress associated with others finding out about their diagnosis.

Post Interview. To assess both aim 1c and aim 2, a semi-structured, open-ended interview was conducted as the last part of the post-assessment after the stigma intervention was completed. Participants were asked follow-up questions based on their answers to set questions pertaining to acceptability, feasibility, memory of techniques taught in sessions, and suggestions for improvement. Several important findings emerged that were not captured in the quantitative findings with themes related to group support, positive changes in perspective on medication, and increased family support. Additionally, quantitative findings demonstrated significant changes in sense of purpose and stigma after completing the stigma intervention. Qualitative analyses also revealed an elevated sense of purpose and changes in views of stereotypes related to mental illness.

Acceptability, Feasibility, and Length of Intervention. Overall, participants found the intervention to be acceptable in terms of content and length. Four out of 7 participants stated that meeting for 8 weeks was "just right" while 3 participants would have liked the intervention to span a longer length of time.

Techniques Remembered from the Intervention. All participants discussed useful techniques that were learned during the intervention. Six out of 7 participants stated that learning the 3Cs (catch it, check it, change it) was most memorable and useful for their daily lives when confronting stigmatizing beliefs. Two participants identified the psychoeducational portion (paint can slide) that included explanations related to the stress-vulnerability model as most helpful. Two participants stated that learning about automatic thoughts was also a useful tool.

Suggestions for Improvement. Participants discussed ways the stigma intervention could have improved, which mainly focused on incorporating stigma in popular culture or social media and having more participants in the group. One participant suggested including a structured way to increase engagement in conversations during group meetings.

Group Support. Every participant spoke about the benefit of participating in a group of their peers. Participants explained that they enjoyed hearing other people's experiences, and in some cases, it made them feel less isolated.

Positive Changes in Perspective on Medication. Two participants explained how the group discussion on stigma related to medication use helped shift their perspectives on taking psychiatric medication generally.

Family Support. Two participants discussed how they are able to participate in family events more or receive family support using specific skills learned from this intervention.

Sense of Purpose. Several participants discussed ways their knowledge of mental health can help others or lead to advocacy efforts. This finding also further contextualized findings related to the quantitative measures of sense of purpose.

Changes in Stigma. Most participants discussed how the group made them think more about their own experiences with stigma. Some stated how it decreased feelings of differentness and isolation while others explained that the group acted as a beneficial space for catharsis.

Table 6

Qualitative Themes from Stigma and Post Interviews

Baseline & Follow-up Stigma Interview	
Theme	**Quote**
Portrayal of psychosis in the media	*Baseline:* “I have seen people make it [mental health problems] like a personal fault in the media or in ads.” --CHR-P participant, 25-year-old male “In movies, I have seen people get experimented on for having mental illness. It makes me feel worried when I see that.” --FEP participant, 22-year-old male Follow-up: “I saw a film that spoke about how psychosis is seen differently in the west versus other countries. I saw it can be a source of creativity. It helps my imagination connect different ideas in my work. I can imagine complex virtual scenes and it helps me as a designer for work. I can understand things as a more creative thing instead of it being ominous.” --CHR-P participant, 25-year-old male
Stereotypes of psychosis	*Baseline:* “I see myself as someone to be wary of, somewhat of a loose cannon that can lose control at any time.” --CHR-P participant, 25-year-old male “Other people see me kind of like I’m always on the edge of the next big episode.” --FEP participant, 21-year-old female Follow-up: “It helped me to understand what I’m going through. I don’t see myself as more dangerous anymore.” --FEP participant, 34-year-old male

Baseline & Follow-up Stigma Interview	
Theme	**Quote**
Social connection	*Follow up:* “I started my mental health journey in 2019 and I felt alone but I realized there are a lot of other people who started their journey just like mine. It made me feel less ashamed.” --FEP participant, 22-year-old male “Knowing that there are all these groups nearby that I didn’t know of makes me feel more hopeful and glad. I makes me feel good that I am not the only one in my area who has this.” --FEP participant, 22-year-old male “In the group, I think as soon as I realized we had a similar thing, we felt understood. I was happy to have another person who understands me. I felt supported.” --FEP participant, 25-year-old female
Rebuilding self-esteem/identity	*Baseline:* “I lose confidence in myself when I experience auditory hallucinations partly because I wonder what others will think of me.” --FEP participant, 34-year-old male “I felt like I was becoming a stranger to myself, which was inferior or weaker than who I was before. Like I was a freak or something.” --CHR-P participant, 25-year-old male *Follow-up:* “I see myself more positively because I know there are other people out there going through the same thing. I have learned to see my symptoms in a positive way because I am able to help others through it.” --FEP participant, 34-year-old male “My view of myself has changed a lot. At first it affected my self-esteem and made it easier to feel hopelessness. Now, I see how it is connected to causes in the environment and I am less affected by the symptoms. This has restored my identity in some ways and gave me more self-worth. Using CBT to catch these things more easily has helped me restore my self-esteem.” --CHR-P participant, 25-year-old male

Baseline & Follow-up Stigma Interview	
Theme	**Quote**
Positive emotions related to labeling	*Baseline:* "I think it positively affected how I view myself because I think it makes sense. The diagnosis kind of validated my feelings." --FEP participant, 17-year-old transgender male *Follow-up:* "It let me know that this is a thing [symptoms and diagnosis] that exists because for a while I thought it was just me because no one talks about it. It made me feel more normal because there is a name for it." --CHR-P participant, 25-year-old male "When I first signed up for the group, I also signed up for another study and Dr. Calkins gave me personal feedback and told me that the risk of developing worse symptoms was pretty low. It made me feel really relieved and hopeful, less stressed." --CHR-P participant, 25-year-old male
Accurate understanding of psychosis	*Follow-up:* "I have to be more careful with my health. I need to get enough rest, maintain a healthy schedule and not have too much stress." --FEP participant, 22-year-old male "It has been helpful to think of [psychosis] as a spectrum." --CHR-P participant, 25-year-old male "Coming up with a new language around it [psychosis], especially the paint bucket (psychoeducation portion of the intervention), and hearing [group members'] stories helped to humanize the whole experience and accept it, even embrace it." --CHR-P participant, 25-year-old male
Awareness of public's inaccurate understanding of psychosis	*Baseline:* "People talk about depression and anxiety a lot but no one early talks about psychosis. I wish more people spoke about it so more people could understand it." --FEP participant, 21-year-old female "Most people don't understand what psychosis is, so it is complicated to even tell them or it is like a hassle to

Baseline & Follow-up Stigma Interview	
Theme	**Quote**
Awareness of public’s inaccurate understanding of psychosis	“…tell them. If I told them and they don’t understand, then I would feel alone.” --FEP participant, 21-year-old female
Post Interview	
Theme	**Quote**
Acceptability, feasibility, and length of intervention	“[The intervention] was very relevant to me. Going through the first half made me realize to not let stigma make me feel shameful about what I experience.” --FEP participant, 34-year-old male “Overall, [the intervention] exceeded my expectations and the impact it had emotionally. Mainly around the language I developed and how it held space or modeled how to not judge people was super helpful. I think [the length] was perfect…” --CHR-P participant, 25-year-old male “I think we should have met longer for more weeks. When I first joined, it took me awhile to get comfortable…I think it should have been more than 8 weeks. Maybe 12 weeks would have been better.” --FEP participant, 25-year-old female “The length maybe should have been longer. I liked having some structure every Tuesday…I felt satisfied with the 8 weeks, but I feel like it went quickly. I haven’t done other groups that were this long, but I could see it keep going and I want to keep having conversations for more than 8 weeks.” --FEP participant, 22-year-old male
Techniques remembered from the intervention	“The paint can and 3Cs were the main things to remember. I am using those two things constantly in my daily life. I am trying to catch my automatic thoughts every day. As soon as I am starting to get an automatic thought, I am like, no it is not true. I immediately stop it from happening. I really try to catch it before it gets worse.” --FEP participant, 25-year-old female “The paint can, automatic thoughts, and the catch it, check it, change it. These things stick out to me most. With the paint can, it was a really good visual for keeping track of how I’m feeling…It will help me

Post Interview	
Theme	**Quote**
Techniques remembered from the intervention	"…keep track of my symptoms and focus on de-stressing myself. I want to put the 3Cs into practice more. I feel like in the past, when I was first diagnosed, it would have been really helpful back then to realize what is more accurate so I could feel more positive faster about my diagnosis and condition." --FEP participant, 22-year-old male
Suggestions for improvement	"It would be cool to include pop culture. I think including social media would be especially helpful too." --CHR-P participant, 25-year-old male "Maybe we could look at stigma in popular culture more, like movies, tv shows, social media. We could bring up links and talk about specific examples together. Then, we could put the thoughts on trial about examples in popular culture." --FEP participant, 22-year-old male "Having more participants would be good, maybe one or two more [so there are] more participants than there are moderators." --FEP participant, 22-year-old male "I think having more participants would make it better." --FEP participant, 21-year-old female "I think we could do a circle share to have people participate a bit more. Include a structured way to share so everyone can speak up and if they are not comfortable then they can pass." --CHR-P participant, 25-year-old male
Group support	"I think the idea of peer support, experience of hearing from someone else who is in your similar shoes, being able to speak out loud what you're experiencing, and have people listen was helpful. I could try to do some things on my own but the acknowledgement from others was most impactful. The way I could connect with others paired with CBT was powerful to me. The social connection where these practices were channeled through was helpful." --CHR-P participant, 25-year-old male

Post Interview	
Theme	**Quote**
Group support	“I got more comfortable and confident as time went on. I liked hearing personal experiences [because] it made me feel supported and connected to others.” --FEP participant, 25-year-old female “I enjoyed hearing other people’s perspectives. Meeting other people with similar experiences or thoughts showed that it is more of a systemic experience. Before I knew people who experienced anxiety or depression, but I felt like an outcast because of my psychosis symptoms. [This group] helped me feel like less of an outcast.” --CHR-P participant, 25-year-old male
Positive changes in perspective on medication	“I think about my medication differently since being in the group. I thought I didn’t need medication before and that it was a scam but now I think it is good to take medication and it helps me. “ --FEP participant, 22-year-old male “I thought what everyone said was helpful, like hearing people’s experiences with taking medicine. I have a more forgiving view with how I see myself and others who take medications.” --FEP participant, 21-year-old female
Family Support	“I participate in family events more, like [my sister’s] graduation because I put my thoughts on trial.” --FEP participant, 22-year-old male “I might bring [automatic thoughts] up with my parents and family because I think they might benefit from knowing about automatic thoughts. They might help keep track of when any of us are having those thoughts. I feel like my mom will really appreciate it because she likes all the resources that I can bring to her from this group.” --FEP participant, 22-year-old male
Sense of Purpose	“[This intervention] made me realize that your mental health difficulties can be overcome, and they can be a good thing because you can help others.” --FEP participant, 34-year-old male

Post Interview	
Theme	**Quote**
Sense of Purpose	“It could be helpful to talk about larger societal stigma and learn ways to speak up for it or talk to others about it for advocacy. How can someone play a role in shifting or reducing stigma [in the larger culture]? [Stigma] holds people back to talk about it because of fear of judgment.” --CHR-P participant, 25-year-old male “I was offered to be a co-leader in February and I am disappointed that I didn’t try to be a co-leader. I feel like [the coleader] did a good job. Now I definitely want to be a co-leader if this intervention was done again so I can help others.” --FEP participant, 22-year-old male
Changes in Stigma (Post interview only)	“This intervention made me think about my own experiences more and made me think that I might not be as different as I thought after all.” --CHR-P participant, 26-year-old male I liked being able to share my personal stigma [with the group]. It feels better getting that off my chest and letting it out.” --FEP participant, 22-year-old male “It made me realize that some people can be empathetic about my mental health difficulties, and it makes me believe that I’m not alone. Those who do judge me don’t realize what I’m going through. There are people out there who view you as dangerous or violent [but] sometimes people’s beliefs about mental health are not accurate. I realize that stigma is out there, but I don’t have to internalize it.” --FEP participant, 34-year-old male

Chapter 5

Discussion

The first aim of this study was to determine if a group, CBT-based stigma intervention (i.e., RIS) was acceptable and feasible for FEP and CHR-P participants. Although the recruitment rate was less than anticipated for group members, the recruitment rate for coleaders was high. Additionally, most participants attended the majority of the intervention, and the dropout rate was lower than expected with only 1 participant dropping out after attending 2 sessions. As expected, participants found the intervention to be relevant to their experiences. In qualitative interviews, most participants found the intervention length to be appropriate while some thought it could have been longer in terms of weeks met. Furthermore, all participants discussed which techniques were most memorable and they indicated that cognitive restructuring was most likely to be utilized once the intervention ended. This finding provides evidence that there was uptake by participants of the main elements being tested (i.e., CBT components of the intervention) and suggests that the intervention likely demonstrated internal validity. Furthermore, most participants indicated that the group format had a positive impact on their experiences with some stating that the social connections helped to normalize symptoms and mitigate feelings of isolation. Taken together, these findings provide preliminary support for the acceptability and feasibility of the intervention in early psychosis groups, including individuals at CHR-P.

Although the sample was small, several important findings emerged. At baseline, most functional and psychosocial outcomes were related to higher levels of shame and stereotype awareness. Individuals who had elevated shame tended to be more depressed and have poorer psychological health, self-esteem, nutrition, sense of purpose, psychological quality of life, social cognitive abilities, and role functioning. Additionally, higher levels of stereotype awareness related to their mental health condition were associated with more depression, worse psychological health, and lower social concern. Literature has established relationships between levels of insight into illness, internalized stigma or shame, and impact on recovery outcomes in psychosis populations (Yanos et al., 2010). More specifically, individuals diagnosed with schizophrenia-spectrum conditions who have greater insight into their illness (i.e., awareness) and higher levels of internalized stigma (i.e., shame) tend to have more dysphoria (Mintz et al., 2003), lower self-esteem (Warner et al., 1989), and decreased well-being and quality of life (Hasson-Ohayon et al., 2006). Furthermore, individuals with higher insight also tend to be more socially isolative and have worse functioning when they adopt stigmatizing beliefs related to their identity as a person with mental illness (Lysaker et al., 2007). Based on the baseline findings from this study and established literature, because participants endorsed higher levels of shame and stereotype awareness, they were likely at a higher risk for a worse recovery trajectory if stigmatizing beliefs were not addressed.

After the 8-week intervention, most of the findings that were related to shame and stereotype awareness were no longer significant. Instead, positive emotions related to symptoms was associated with better emotion identification, less depressed mood, and higher levels of health and exercise, quality of life, and self-esteem at follow-up. Previous research examining the impact on recovery outcomes shows that individuals tend to have better self-esteem and quality of life, more hope, and better outcomes in terms of functioning when stigma is not internalized (Yanos et al., 2010). This suggests that the individuals who participated in the 8-week stigma intervention found ways to deflect stigmatizing attitudes away from their identity (i.e., resist stigma), which could lead to more positive outcomes and better recovery.

In comparisons between baseline and follow-up, there was an overall reduction in perceived devaluation and discrimination (i.e., stigma), which indicates that the intervention was successful at targeting overall levels of stigmatizing attitudes. As expected, individuals also demonstrated higher self-esteem, better ToM, and more positive emotions related to their symptoms from baseline to follow-up. This suggests that individuals were able to alter stigmatizing attitudes related to their mental health status, potentially due to the cognitive restructuring techniques that were included in the stigma intervention. Based on the qualitative interviews, participants endorsed changes in stigma at follow-up and challenged the accuracy of mental health stereotypes that exist in society, such as those related to dangerousness. Additionally, participants highlighted the impact that the media's portrayal of mental illness has on the public's understanding of psychosis. Some participants called for more education, which could help to address inaccurate information that often leads to stereotypes and stigmatizing beliefs. They acknowledged that negative attitudes related to psychosis exist but also indicated that they have a choice as to whether they internalize those beliefs themselves, which indicates the development of stigma resistance. Some participants also identified that their perspectives became more positive about taking medications for their mental health and discussed ways they were participating more in family activities because they could more readily challenge cognitive distortions in these contexts. Prior literature has established links between the development of stigma resistance, more hope, and better self-esteem leading to increased instances of personal recovery from serious mental illness (Yanos et al., 2010; Dubreucq et al., 2022). Taken together, these changes from baseline to follow-up suggest a better illness trajectory due to the positive impact of stigma resistance.

In addition to the expected findings described above, an unexpected finding also emerged. From baseline to follow-up, participants also demonstrated a higher sense of purpose after undergoing the group stigma intervention. Sense of purpose refers to having goals, intentions, and a sense of direction in one's life, which contribute to feelings that life is meaningful (Ryff, 1989). In contrast, psychosis has historically been viewed as a chronic, progressively debilitating condition, which has contributed to stereotypes that suggest individuals diagnosed with schizophrenia-spectrum disorders are likely to never recover and often lead to personal narratives that possess little sense of agency (Wiesepape et al., 2023). As the collective understanding of psychosis evolves away from deterministic views of illness, more person-first language and recovery-oriented treatments have emerged to instill hope for recovery. Consequently, there has been a movement to include personally defined, values-based goals in recovery-oriented early psychosis treatment. Accordingly, researchers have called for more interventions that promote a sense of purpose to increase meaning in life and emphasize the importance of subjective recovery in psychosis (Wiesepape et al., 2023). As such, targeted stigma interventions, like RIS, can be utilized as a tool for which sense of purpose may be increased and recovery-oriented views of illness can be promoted.

Incorporating CBT-based stigma interventions, such as RIS, into specialized treatment programs may help mitigate the impact of negative stereotypes related to illness trajectory in psychosis while providing individuals with tools to promote stigma resistance and potentially elevate a sense of purpose. Furthermore, based on the diathesis-stress model of psychosis (Walker & Diforio, 1997), stigma stress can increase an individual's lability for transition to or subsequent episodes of psychosis (Rusch et al., 2014). Preliminary findings from this study demonstrate that it may be clinically useful to offer specific stigma reduction strategies, such as those included in RIS, as part of recovery-oriented, coordinated specialty care models for early psychosis. Doing so may help alleviate the burden of stigma stress, which can improve overall course of illness by reducing the risk for exacerbation of symptoms. Furthermore, individuals who experience success in the reduction of symptoms coupled with the ability to challenge stigmatizing or inaccurate thoughts may elicit a higher sense of purpose, which could lead to more hope for recovery. In conclusion, stigma interventions like RIS seem to align well with the mission of recovery-oriented specialty care programs for early psychosis and offering them as part of their routine services may prove fruitful for helping to reduce the risk for new or worsening symptoms of psychosis.

Broader Contributions & Limitations

This study served as a pilot study for a targeted, CBT-based stigma intervention for early psychosis individuals enrolled in a specialized, coordinated specialty care program. There is a longstanding history of stigma serving as a main barrier to accessing adequate mental health care for serious mental illness (Thornicroft, 2008), which impacts recovery outcomes in early psychosis populations. Therefore, stigma reduction is necessary for individuals to become more engaged in their care and benefit from the range of services offered in coordinated specialty care clinics. This study provides preliminary evidence for a mechanism by which stigma can be reduced, social connectedness can be increased, and sense of purpose can be elevated in early psychosis populations. Identifying feasible and acceptable stigma reduction strategies, such as RIS, can help to alleviate the burden of stigma stress and contribute to the broader understanding of ways to reduce psychosis risk and chronicity. It is important to consider that even though this intervention may have an impact on those that participate, this is subject to self-selection bias. The most stigmatized may not present for care or volunteer for group interventions, such as RIS. Therefore, it is of particular relevance for stigma research to understand ways to engage these individuals in care and implement stigma reduction strategies.

Although this study revealed several important findings related to stigma reduction strategies for early psychosis, several limitations exist. First, the sample size was small for both the overall sample and of CHR-P participants. Therefore, statistical analyses were limited and causal conclusions about the intervention could not be explored. Due to the small sample and the central aim of determining acceptability and feasibility of the stigma intervention, coleaders and group participants were combined in analyses. It is important to note that serving as a coleader may elicit positive emotions related to taking on a leadership role that may be unrelated to the intervention, which could serve as a potential confounder. We encourage future iterations of this study to rigorously test the impact of the coleader role before including them in analyses. Furthermore, we also encourage future work to address whether coleaders are a necessary component to the stigma intervention (i.e., the effects are weakened without the presence of coleaders). Exploring the impact of coleaders on the outcomes of the stigma intervention can further improve the understanding of its feasibility in sites that may not have the resources or time to incorporate them. Future research should aim to recruit a larger sample that is racially and ethnically diverse and well-powered to determine causal changes in FEP, CHR-P, and coleader participants to delineate these effects.

Second, due to the lack of CHR-P participants, acceptability and feasibility for this specific group alone could not be established. Based on both quantitative and qualitative analyses, this intervention was determined to be acceptable and feasible for early psychosis populations as whole, including those at-risk for psychosis; however, this could not be determined for CHR-P groups alone. It is also important to consider the differential impact of running combined versus separate FEP and CHR-P groups as stigma can impact these populations differently due to course of illness. For example, if a CHR-P participant is in a group with a symptomatic FEP participant, they may feel negatively about their potential trajectory of illness. Although this did not specifically occur in our study, it is important to consider when recruiting and assembling group members. Researchers should consider running FEP and CHR-P groups separately to solidify the acceptability and feasibility for CHR-P groups alone and to determine if there is a significant difference in stigma outcomes between groups.

Third, no control group was used in this study, which limits the internal validity of the intervention. Due to this, it is difficult to determine if the changes in outcomes were directly related to the stigma intervention itself. Additionally, groups themselves can have an impact on outcomes because they can increase feelings of social connection and cohesion. Additionally, individuals recruited for this study were all interested in participating in a group, which could lend itself to self-selection bias that could limit the generalizability of this study. Future iterations of this intervention should include a control group to maintain the internal validity of the intervention and increase the likelihood that causal conclusions can be drawn without self-selection bias impacting results. To do this, researchers may run an 8-week, virtual group that does not contain CBT for stigma components. Alternatively, stigma group participants can be compared to treatment as usual coordinated specialty care participants who are administered a well-established stigma scale (e.g., PDD scale) at specified timepoints.

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