Early detection of possible psychosis in young people: Is stigma linked with symptoms or at-risk identification?

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Acknowledgment

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At the time of this publication, Miriam E. Delphin-Rittmon, Ph.D, served as Assistant Secretary for Mental Health and Substance Use in the U.S. Department of Health and Human Services and the Administrator of the Substance Abuse and Mental Health Services Administration.

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Presented 2021

The MHTTC Network uses affirming, respectful and recovery-oriented language in all activities. That language is:

- Strengths-based and hopeful
- Inclusive and accepting of diverse cultures, genders, perspectives, and experiences
- Healing-centered and trauma-responsive
- Inviting to individuals participating in their own journeys
- Person-first and free of labels
- Non-judgmental and avoiding assumptions
- Respectful, clear and understandable
- Consistent with our actions, policies, and products

Adapted from: https://mhcc.org.au/wp-content/uploads/2019/08/Recovery-Oriented-Language-Guide_2019ed_v1_20190809-Web.pdf

Research Background

I) Social Factors that influence course of schizophrenia

II) Training in clinical psychology, anthropology and psychiatric epidemiology (**Clinical Fellow– Massachusetts MH Center**)

III) NIH funding:

- **R01– Stigma associated with prodromal psychosis (completed)**
- **R21– Stigma of genetic attributions in prodromal psychosis**
- 2 R01's– Cognition of Untreated Psychosis in China
- R01– Measurement of Task Sharing Global Mental Health (Implementation Science)

- *2021 Maltz Prize for Innovative and Promising Schizophrenia Research*

  (Brain and Behavior Research Foundation)

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Overview

I: Stigma's Effects on Mental Health

- –Public stigma
- –Experienced Discrimination & Self stigma
- –Structural stigma

II: Stigma and the Clinical High Risk State for Psychosis

- –Initial Quantitative Findings (R01)
- –Qualitative Findings
- –Clinical Implications

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Definition

Stigma - set of interrelated social processes.

Including: labeling, stereotyping, cognitive separating, emotional reactions, status loss and discrimination, and power (Link and Phelan, 2001)

Leads to poorer symptomatic and social outcomes (Link et al, 1989, Corrigan, 2006)

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Public Stigma

The process in which the general public stigmatizes individuals with mental illness and which consists of processes of stereotyping, prejudice, and discrimination

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Experienced Discrimination

Experienced discrimination is when an individual is unfairly treated by another individual based on their status of having mental illness

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Internalized Stigma

Internalized stigma takes place *through stigmatized individuals themselves* once they become aware of stereotypes and apply stereotypes to themselves.

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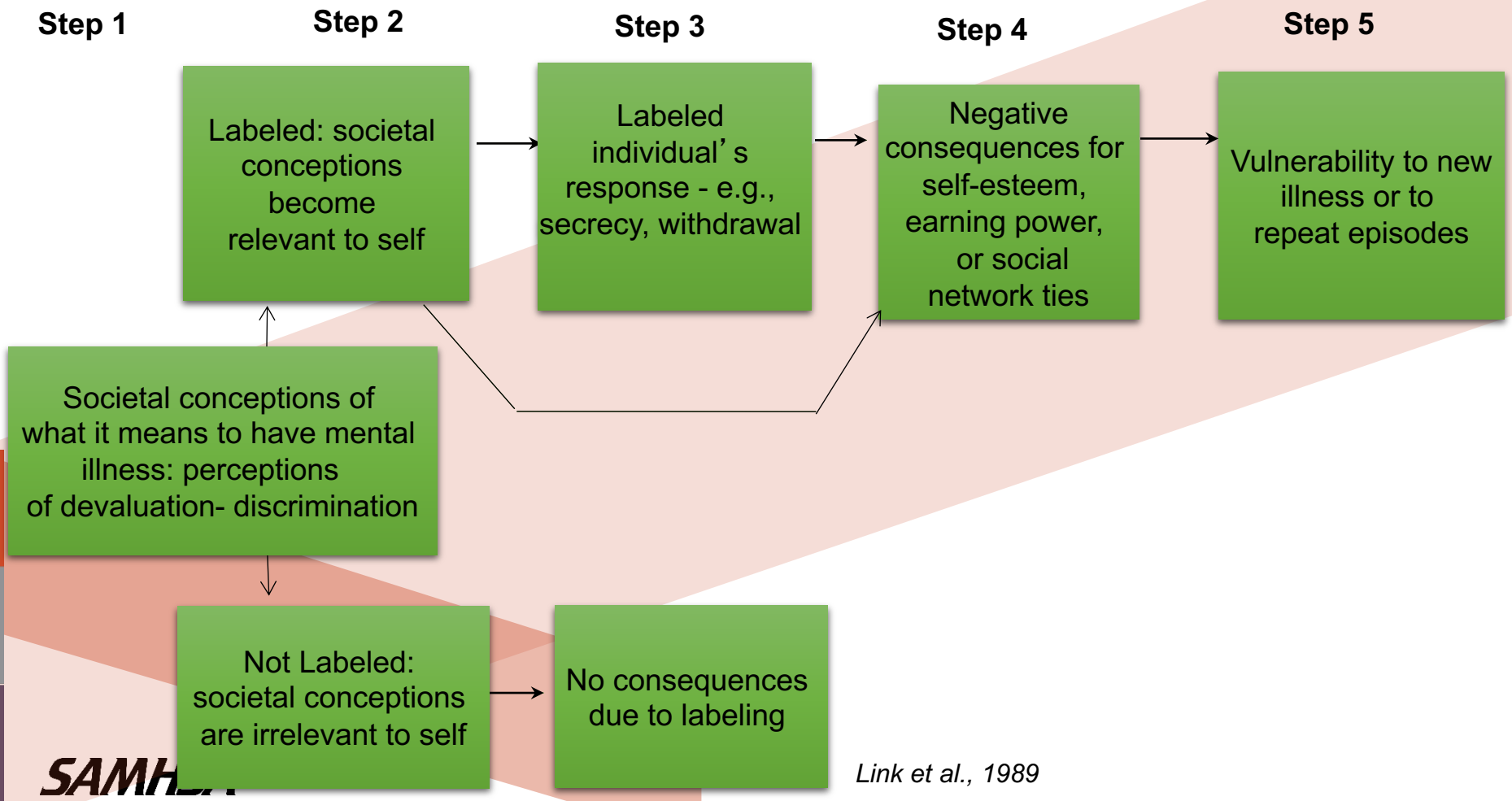
Modified Labeling Theory



Link et al., 1989

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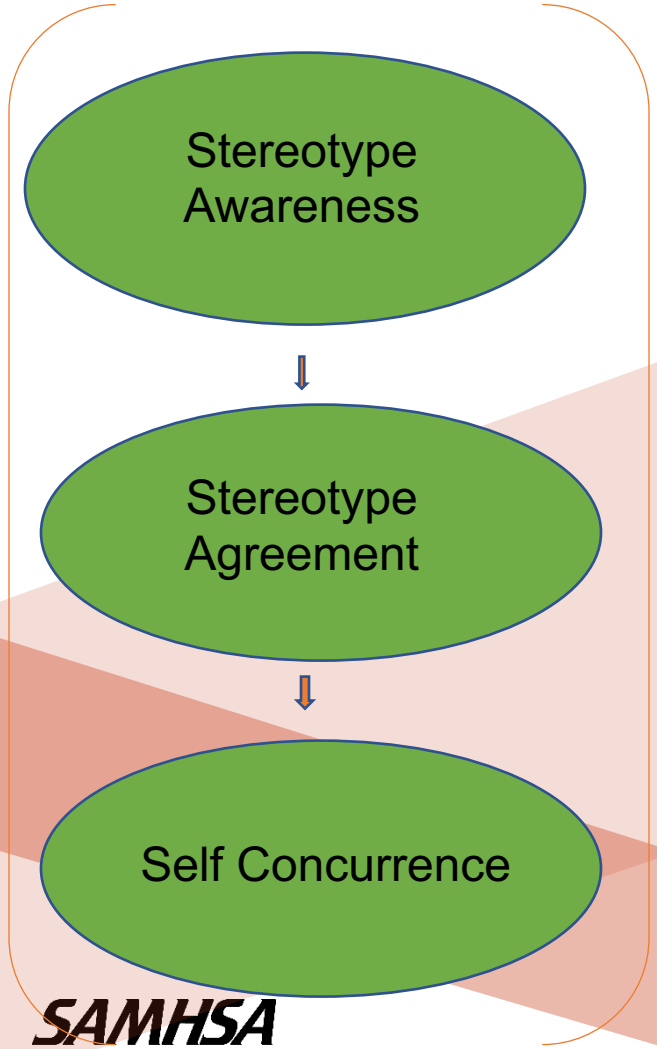
Internalized Stigma

Livingston and Boyd, *et al.*, 2010



Self Esteem
Self Esteem (19 Studies) r = -.55
Self-Efficacy (7 Studies) r = -.54

Quality of Life
(13 Studies) r = -.47

Depressive Symptoms
(11 Studies) r = .41

Treatment Adherence r = -.38
Psychosocial (4 Studies)
Medication (3 studies)

Social Support (3 Studies) r= -.28
Social Integration
Social Network

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Structural Stigma

Institutional practices that work to the disadvantage of the stigmatized group or person

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Background: Stigma and CHR

'**Clinical High Risk State for Psychosis**' (CHR)–Category to identify youth (12-25 years old) *who may develop psychosis*

Earliest Identification of Pre-psychotic Signs; 29% transition to psychosis within 2 years

Particular concern: Stigma that may be associated with **identification (new "label")**

>70% '*False Positives*' (Carpenter, 2010)

Public stigma *(Yang, 2013)* and **Self-Stigma** *(Rusch, 2014; Rusch, 2015, Gronholm, Thornicroft, Laurens, Evans-Lacko, 2017)* have been identified as salient for CHR

Stigma effects **help-seeking and service contact** for CHR (*Gronholm, Thornicroft, Laurens, Evans-Lacko, 2017*)

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Being “most impacted” by Psychosis?

Study 1

Assess to what extent are CHR youth ‘most impacted’ by psychosis / schizophrenia?

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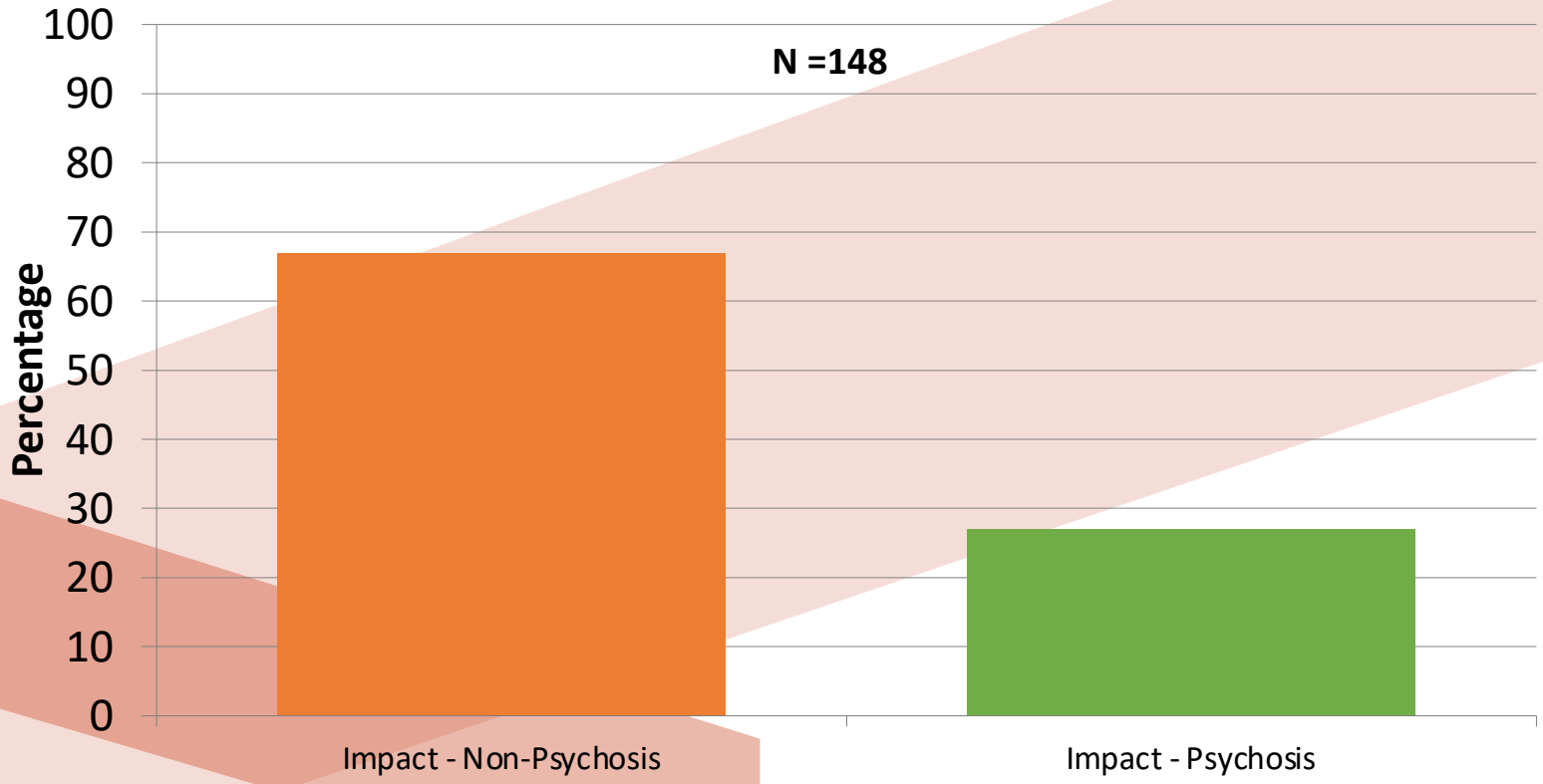
What had the biggest impact on how you think of yourself?



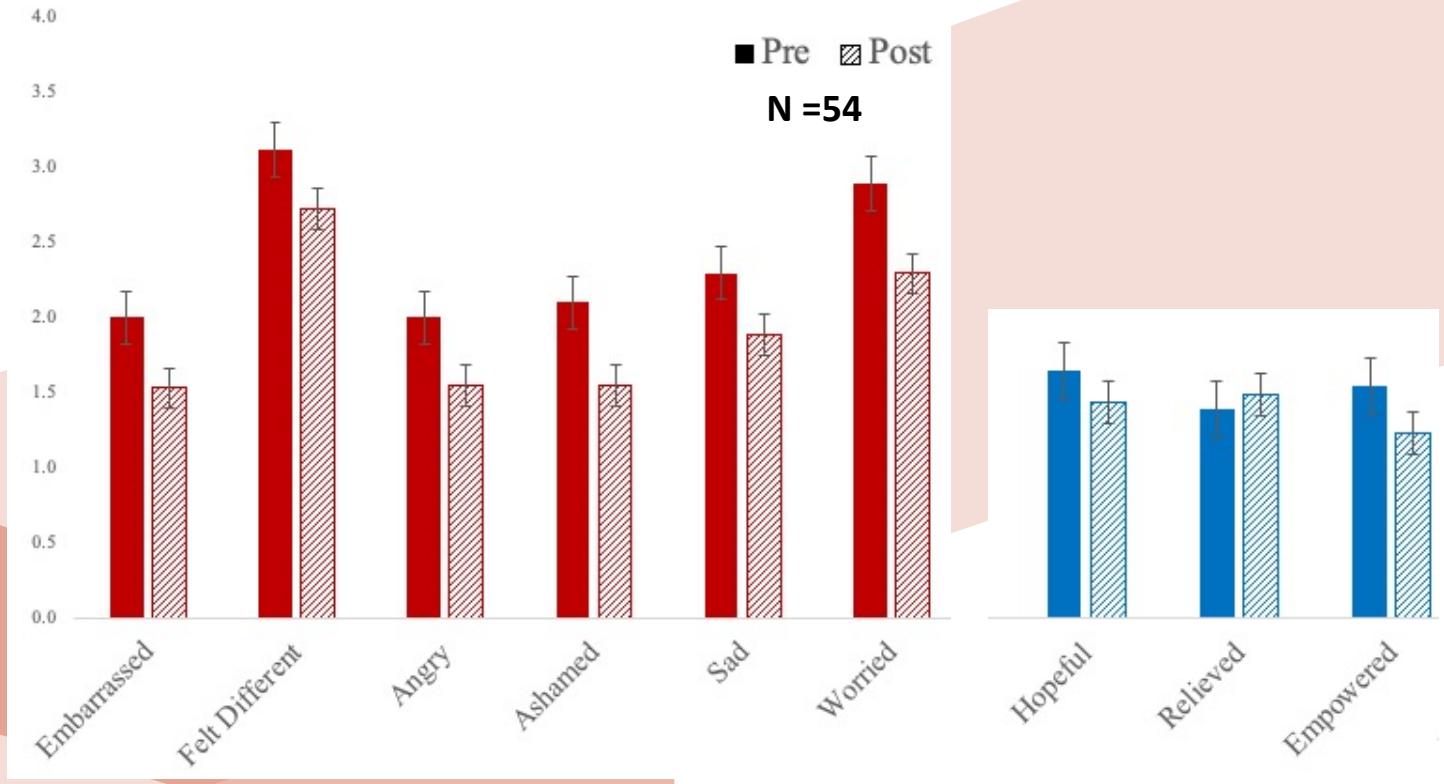
Yang et al., SCZ Research (2019)

What is the emotional impact of identification?

Study 2

To assess changes in emotions *after* participants are given feedback about their CHR status compared to *before* they are given this feedback.

Positive and negative emotion ratings before and after receiving feedback about psychosis risk



Woodberry et al., SCZ Research (2021)

Background

- **Limitation of Prior Studies: "At-Risk Identification"/"Label" vs. "Symptom" Stigma**

Ramifications for Field:

CHR youth are identified when they are help-seeking for active + worsening symptoms/experiences

Earliest identification and treatment is intended to mitigate symptoms, which may avert significant stigma (e.g., psychiatric hospitalization; SCZ diagnosis)

If symptom stigma is primary correlate of outcomes at baseline, consistent with earliest identification efforts

Stigma of at-risk identification (labeling stigma) could add new stigma via CHR services

May be particularly concerning to field and shape potential inclusion of CHR in future diagnostic systems (e.g., DSM)

Background

- **No consensus on standardized way of communicating the CHR status for all participants in CHR programs**

Specialized CHR program clinicians are typically trained to give individualized feedback based on a wide range of factors:

the individual and family's concerns

treatment engagement

cultural background

estimated risk within the CHR classification

*Recovery orientation and mitigating functional deficits of CHR

Advance: Stigma – "Labeling"

"About being told I am at-risk for developing psychosis…"

(Yang, Link, Corcoran et al, 2015, SCZ Research)

1) '**Negative emotions** (shame)'
"[X], I have felt ashamed." (3 items)

2) '**Secrecy**'
"I have told no one that [X]." (5 items)

3) '**Experienced Discrimination**'
"[X], people are a little afraid of me." (5 items)

Stigma – "Symptoms"

"About my symptoms and experiences…"

1) '**Negative emotions** (shame)'
"[X], I have felt ashamed." (3 items)

2) '**Secrecy**'
"I have told no one about [X]." (5 items)

3) '**Experienced Discrimination**'
"[X], people are a little afraid of me." (5 items)

Main Hypotheses:

#1) *Compare* Labeling vs. Symptom-related stigma

#2) *Assess to what extent* labeling vs. symptom stigma is associated with psychological (self-esteem, quality of life) and social (social functioning, social networks) outcomes in CHR youth

Sample

169 'Clinical High Risk (CHR)' individuals

given **stigma assessment** at CHR identification and then 6-month follow-up at Harvard, Maine, and Columbia University Medical Centers

Study Period: 2012-2017

Baseline Data Only presented (those who meet COPS criteria)

Help seeking participants who met ≥1 SIPS/SOPS criteria:

(1) attenuated positive symptom syndrome

(2) genetic risk and deterioration syndrome

(3) brief intermittent psychotic syndrome. *(Miller, 2003)*

Included those CHR individuals **who perceived psychosis risk**; excluded those who were not aware of or did not endorse psychosis-risk

Sample Characteristics

	Participants (n=113)	
Variable	**N**	**M (SD)**
Age (years)	112	18.59 (3.71)
Years of Education	111	11.95 (2.90)
Symptoms		
Total Positive	113	14.19 (3.55)
Total Negative	107	15.27 (6.52)
Total Disorganized	107	7.35 (3.90)
Total General	107	11.54 (4.11)
Current GAF	112	46.35 (10.02)

Variable	**N**	**n (%)**
Sex: Male	111	70 (63.1%)
Recruitment Site	113	
Boston		48 (42.5%)
Maine		37 (32.7%)
New York		28 (24.8%)
Born in the U.S.	111	104 (93.7%)
Preferred Language: English	111	108 (97.3%)
Income (dollars/year)	111	
Less than $19,999		16 (14.4%)
$20,000 - $59,999		17 (15.3%)
Greater than $59,999		35 (31.5%)
Comorbid Axis I Symptoms		
Depression/MDD	95	63 (66.3%)
Anxiety Disorders	96	57 (59.4%)
ADHD	95	15 (15.8%)
Marital Status: Not Married	111	108 (97.3%)
Currently Employed (full/part)	111	35 (31.5%)
Enrolled as a student	111	91 (82.0%)
Race/Ethnicity: White Non-Hispanic	111	70 (63.1%)

Outcomes

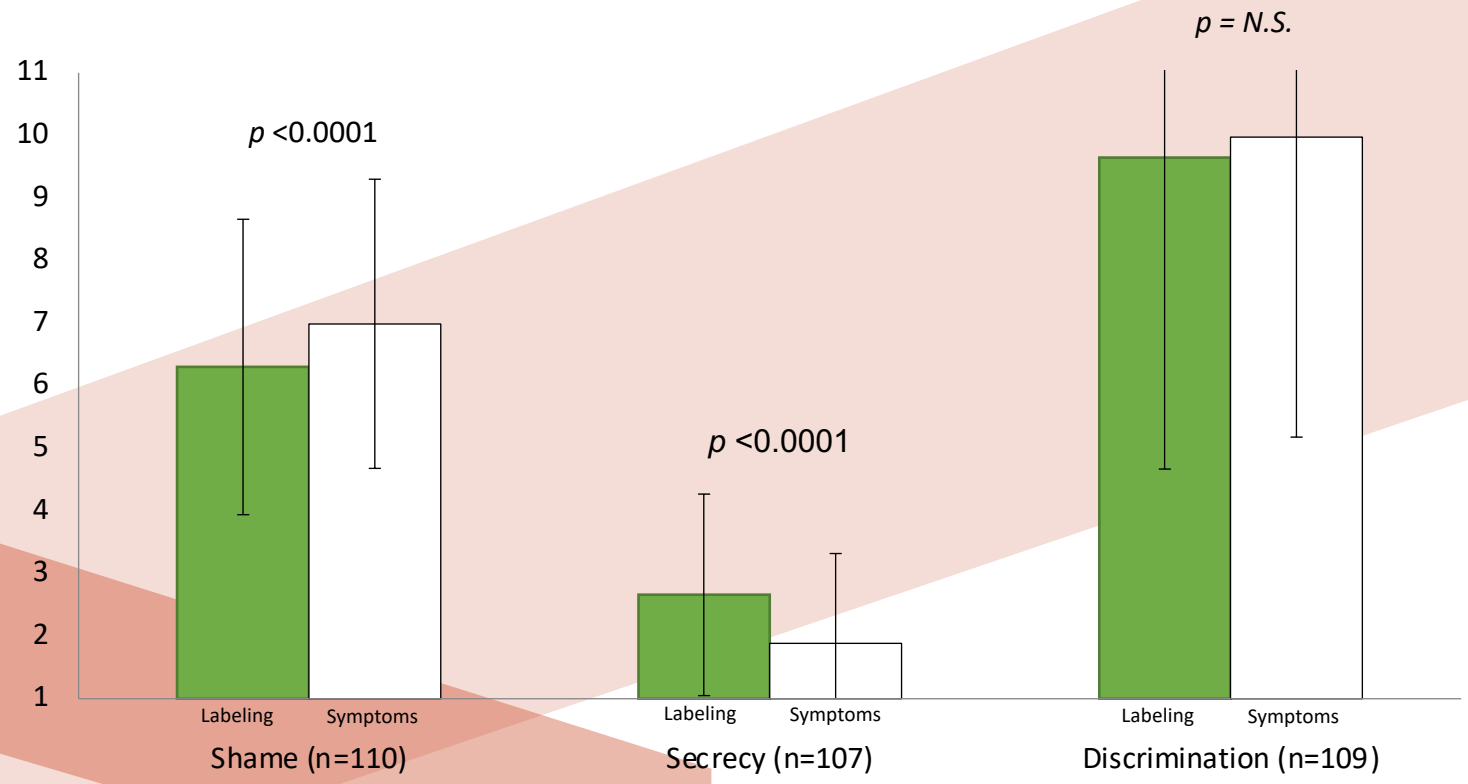
Psychological

- **Self-Esteem** (Rosenberg Self-Esteem, 1965)
- **Quality of Life** (WHO Quality of Life Scale- BREF, 1994)
  - Depressive Symptoms + Functioning; Enjoyment with Life + Personal Relationships; Environmental; Satisfaction with Overall Health

Social

- **Global Functioning: Social Scale** (Cornblatt et al, 2007)
- **Loss of Social Networks** (Norbeck Social Support Questionnaire; Total "loss of relationships/support" due to stigma)

Hypothesis #1: Labeling vs Symptoms Stigma



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Self Esteem and Social Outcomes

	Self Esteem	Social Support Loss	Current Social Functioning
	B (SE), (95% CI)	*B* (SE), (95% CI)	*B* (SE), (95% CI)
Panel A: Shame			
Combined Effects Model [Model 3]			
Labeling	-0.038 (0.352) (-0.738, 0.662)	0.069 (0.043) (-0.016, 0.153)	0.049 (0.091) (-0.132, 0.229)
Symptom	**-1.035 (0.356)*** (-1.742, -0.329)	**0.129 (0.043)*** (0.043, 0.215)	-0.098 (0.092) (-0.281, 0.084)
Final Model [Model 4]			
Final Subscale:	***Symptom***	***Symptom***	--
Final Subscale + Covariates	-1.172 (0.262)*** (-1.693, -0.650)	0.163 (0.036)*** (0.092, 0.235)	--
Panel B: Secrecy			
Combined Effects Model [Model 3]			
Labeling	0.122 (0.504) (-0.879, 1.123)	0.102 (0.065) (-0.026, 0.231)	-0.207 (0.113)^{t} (-0.431, 0.018)
Symptom	0.212 (0.556) (-0.893, 1.318)	-0.075 (0.072) (-0.218, 0.069)	-0.156 (0.125) (-0.404, 0.092)
Final Model [Model 4]			
Final Subscale:	--	--	***Labeling***
Final Subscale + Covariates	--	--	-0.185 (0.080)* (-0.344, -0.027)
Panel C: Discrimination			
Combined Effects Model [Model 3]			
Labeling	**-0.329 (0.145)*** (-0.618, -0.040)	-0.026 (0.017) (-0.059, 0.007)	0.028 (0.034) (-0.040, 0.096)
Symptom	-0.171 (0.157) (-0.483, 0.141)	**0.107 (0.017)***** (0.073, 0.142)	-0.101 (0.036)* (-0.173, -0.028)
Final Model [Model 4]			
Final Subscale:	***Labeling***	***Symptom***	--
Final Subscale + Covariates	-0.370 (0.126)* (-0.620, -0.120)	0.093 (0.017)*** (0.060, 0.126)	--

Note. Betas are unstandardized. Significant at the *p<0.05, **p<0.001, ***p<0.0001; ^{t}trend p<0.1. **Final Model** adjusts for: **site, age, sex, race, total positive symptoms, total negative symptoms, and total disorganized symptoms**

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Quality of Life Outcomes

	QOL: Satisfaction with Health	QOL: Depressive Symptoms & Functioning	QOL: Enjoyment with Life & Personal Relationships	QOL: Environment
	B (SE), (95% CI)	*B* (SE), (95% CI)	*B* (SE), (95% CI)	*B* (SE), (95% CI)
Panel A: Shame				
Combined Effects Model [Model 3]				
Labeling	0.096 (0.055)^{t} (-0.012, 0.205)	0.057 (0.037) (-0.016, 0.130)	-0.005 (0.043) (-0.090, 0.079)	-0.014 (0.040) (-0.094, 0.066)
Symptom	**-0.192 (0.056)**** (-0.302, -0.081)	**-0.160 (0.037)***** (-0.234, -0.085)	-0.073 (0.043)^{t} (-0.158, 0.012)	-0.050 (0.041) (-0.132, 0.031)
Final Model [Model 4]				
Final Subscale: Final Subscale + Covariates	***Symptom*** -0.115 (0.044)* (-0.203, -0.028)	***Symptom*** -0.100 (0.028)** (-0.156, -0.044)	***Symptom*** -0.066 (0.031)* (-0.128, -0.003)	-- --
Panel B: Secrecy				
Combined Effects Model [Model 3]				
Labeling	0.017 (0.073) (-0.128, 0.162)	0.085 (0.053) (-0.021, 0.191)	-0.064 (0.057) (-0.178, 0.050)	0.036 (0.055) (-0.073, 0.144)
Symptom	**0.219 (0.082)*** (0.055, 0.382)	-0.012 (0.060) (-0.131, 0.107)	0.078 (0.064) (-0.049, 0.204)	-0.015 (0.061) (-0.137, 0.107)
Final Model [Model 4]				
Final Subscale: Final Subscale + Covariates	***Symptom*** 0.225 (0.072)* (0.082, 0.368)	-- --	-- --	-- --
Panel C: Discrimination				
Combined Effects Model [Model 3]				
Labeling	-0.004 (0.022) (-0.047, 0.040)	-0.006 (0.015) (-0.037, 0.024)	-0.012 (0.016) (-0.044, 0.020)	0.026 (0.015) (-0.003, 0.055)
Symptom	-0.056 (0.024)* (-0.103, -0.009)	**-0.044 (0.016)*** (-0.076, -0.011)	-0.044 (0.017)* (-0.079, -0.010)	**-0.064 (0.016)***** (-0.095, -0.033)
Final Subscale: Final Subscale + Covariates	-- --	***Symptom*** -0.039 (0.014)* (-0.067, -0.010)	-- --	***Symptom*** -0.042 (0.015)* (-0.072, -0.012)

Note. Betas are unstandardized. Significant at the *p<0.05, **p<0.001, ***p<0.0001; ^{t}trend p<0.1. **Final Model** adjusts for: **site, age, sex, race, total positive symptoms, total negative symptoms, and total disorganized symptoms**

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Hypothesis #2: Summary

	Outcomes						
Predictors	Self-Esteem	Social Support Loss	Current Social Functioning	WHO-Single Item	WHO-Factor 1	WHO-Factor 2	WHO-Factor 3
Panel A							
Labeling Shame	-	-	-	-	-	-	-
Symptom Shame	**<0.0001 (-)**	**<0.001(+)**	-	**0.011 (-)**	**0.001(-)**	**0.039 (-)**	-
Panel B							
Labeling Secrecy	-	-	**0.022 (-)**	-	-	-	-
Symptom Secrecy	-	-	-	**0.002 (+)**	-	-	-
Panel C							
Labeling Discrimination	**0.004 (-)**	-	-	-	-	-	-
Symptom Discrimination	-	**<0.001(+)**	-	-	**0.008 (-)**	-	**0.007 (-)**

Note. in populated cells, (-) indicates an inverse relationship; (+) indicates a positive relationship.

Qualitative: "Most Impacted" by Psychosis

Purpose: To examine the nature of labeling-related stigma

Subjective Experience *of being told at CHR* (*Yang et al, 2019, SCZ Research*)

Qualitatively examine processes including

--**Positive effects** (i.e., operating through direct interaction with specialized CHR clinicians)

--**Negative effects** (i.e., operating as anticipated stigma through CHR individuals themselves).

--***Co-occurrence*** of these

Sample: Thirty-eight (n=38) semi-structured qualitative interviews (2009-2010) to examine the meaning *of being told they are at CHR*

Conducted after CHR identification, *on average 11.5 (SD=11.7) months* after entering the Columbia site.

Qualitative Questions

#1) Any direct treatment from others related to the CHR identification:

"*Is there anything that happened to you in terms of how people treated you, good or bad, as a result of being in this (CHR) program*?"

Probes:

"*Can you give me an example of when you were treated this way*?",

"*Who treated you this way*? *Where/when*?",

"*How did it make you feel? How did you respond to it?*

Qualitative Questions

#2) Any potential effects via internalized processes that were related to CHR identification:

> "*In being in this program, you were told you have 'an increased risk of psychosis compared to your peers.' How has this affected how you see yourself and how others see you*?"
>
> Probes:
>
> > "*Did being told you are 'at-risk' for psychosis change the way you thought about yourself? If so, how*?"
> >
> > "*Are you concerned about how others might react to knowing your at-risk status*?", "*Would others treat you any differently*?"

Qualitative Analyses

NVivo software (V. 11.0) utilized:

-- Methodological advantage of ***quantifying overlap*** between major codes

Focused on the intersection between: 1) *Positive* and; 2) *Negative Labeling Experiences*

Jaccard's similarity index (j-index), a measure of similarity indicating percentage overlap (range = 0% - 100%) of selected themes.

Results

Theme	J	Definition	Examples
Overall Positive	0.93	**Endorsed a positive experience** from being identified as CHR	Reflects any one of the below positive code categories
Accurate Understanding of CHR Risk	0.59	Demonstrates **a correct understanding of what it means to have a CHR status** using specific language about risk	"*It's* (being identified as at "psychosis-risk" is) *like having a sore throat.* You don't know it will lead to strep throat, *you have something indicating something is wrong but it might not develop into strep throat*."
Interpersonal Benefits of Disclosure	0.50	Disclosure of CHR identification leads to **more supportive relationships**	"*Other people* (friends and family) *are more aware of what I am thinking and feeling because of my CHR status*. It is something like *they may be more sensitive to me* (about)…They are more supportive."

Results

Theme	J	Definition	Examples
Benefits of Specialized CHR Treatment	0.33	**Endorsing more tailored treatment** due to receiving specialized CHR services through "psychosis-risk" identification	"Treatment at COPE (the CHR program) has been absolutely amazing. *Talking to my therapists, reading different studies, I can think about (my) symptoms and feelings in a different way."*
Explanation and Legitimization of Symptoms	0.25	Being identified as at CHR **explains and/or legitimizes previous experiences of symptoms**	*"I sometimes use coming to COPE* (the CHR program) *as a way to convey the severity of my problems. I have an illness with symptoms that's being treated medically, and that it's* (my symptoms are) *legitimate* (in response to a co-worker's delegitimizing reaction)."

Results

Theme	J	Definition	Examples
Overall Negative	0.62	**Endorsing a negative experience** from being identified as CHR	Reflects any one of the below negative code categories
Shame and Internalized Stigma	0.55	The CHR label **induces shame and internalized stigma** due to stereotypes of psychosis	**"**When I first came to COPE (the CHR program), *I had some feelings of embarrassment and shame when talking to friends* about coming to NYC. I wouldn't tell others I was there to visit COPE. *There is a stigma with mental illness. Schizophrenia is a conversation stopper*."
Perceived Exacerbation of CHR Experiences	0.41	**Over-monitoring of CHR symptoms** and interpreting them as signs of full psychosis after "psychosis-risk" identification	*"I've become one with the symptoms I've read about.* I am constantly on the lookout to see if I have schizophrenia. *I have looked so much into my symptoms of schizophrenia, that it has fueled perceptual disturbances I have had*."

Results

Theme	J	Definition	Examples
Structural Discrimination	0.27	Fears of being **treated differently by institutions** due to CHR identification	"The whole notion that I might have schizophrenia someday—will I be able to achieve certain things I set out to do? *Government rules for security clearance are based on mental stability. The fact I was once on antipsychotic drugs is on my record forever*. Even if I successfully recover and (hypothetically) want to get a job in the government, *it would still be on my record."*
Anticipated Stigma and Discrimination	0.22	Expecting that **people will think about or treat you differently** due to CHR identification	"If I tell them (that I am "at risk" for developing psychosis), *they may think of me as a mental patient—that I am dangerous,* they shouldn't be around me, afraid of me."

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Results

Co-Occurring Positive and Negative Themes:

>50% of transcripts expressed overlap between positive and negative themes (Jaccards Coefficient=0.55).

--**"Interpersonal Benefits of Disclosure"** co-occurring with **"Altered Perception and/or Negative Treatment from Others"** (J=0.5).

--Individuals perceived interpersonal benefits of disclosure, joined by a threat of being negatively treated or perceived by others, upon disclosure.

"To talk about my at-risk status, there was stigma I had... **Having this new status (being identified as at CHR) also scared my mom as well**. My mom has a sister with schizophrenia... Being identified as 'at risk' equals **people thinking you are really developing something…. I sometimes use coming to COPE as a way to convey the severity of my problems. People try to be supportive. People make extra efforts, They would check in on me more."**

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Results

--"*Accurate Understanding of Risk Status*" Co-occurring with "*Perceived Exacerbation of CHR Experiences*" (J=0.4).

--Individuals with an accurate understanding of their risk status were likely to benefit from specialized CHR treatment; however, this increase in monitoring may contribute to developing anxiety over their experiences.

"[I now know that] Being **CHR conveys a slightly greater risk for a disease.** But it is a very complicated concept to explain to people…Dr. Kelly (CHR program psychiatrist) asks me about **perceptual difficulties**. **I worry that these might be signs of psychosis... At first identification, I was more worried because I thought it meant I was psychotic, and that there was an increase in the possibility that it's (psychosis) really happening**… "

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Discussion

Main Findings (Quantitative):

Concerns re: "Labeling" Stigma

Which form of stigma is higher?: **Mixed**: Symptom Shame higher; but Labeling Secrecy higher

Which form of stigma is more strongly associated?: Of **11 positive associations** with outcomes, **9 have symptom stigma** as stronger correlate (*Quality of Life)*

- Stigma matters for CHR
- On balance, **symptom stigma** appears to be more salient at baseline
  - -- >66% respondents comorbid for ≥1 nonpsychotic disorder
  - --may be a **target** for CHR treatment
- However, **labeling stigma** is present
  - --might grow as youth become more familiar with identification status

Discussion

Qualitative Findings:

Being told that one is "at risk for psychosis" is most likely linked with *positive and negative experiences*, which commonly overlap

- **-- Goal: Minimize negative effects while accentuating the positive benefits of CHR identification**

Discussion

Implications for clinical care (”Labeling-related” stigma):

Being identified as at CHR can provide **relief, improve accurate understanding, elicit interpersonal support, and enhance engagement in treatment** *(Woodberry et al, 2021, SCZ Research)*

Specialized CHR programs could be careful to avoid a singular focus on “psychosis-risk” and attend to what is most distressing to each individual (e.g., nonpsychotic disorders) *(Yang et al, 2019, SCZ Research)*

Labeling-related stigma could be potentially mitigated via specialized communication of the CHR state:

-- focus on **adopting the individual’s language and explanations** that allows for non-diagnostic and person-centered terminology

-- **do not need to explicitly focus on** a potential future diagnosis of psychosis.

-- instead, determines if eligibility is met **and focuses on how can help with individualized goal attainment**.

Discussion

Implications for clinical care (”Symptom-related” stigma):

”**Symptom-related” stigma** as a new **target** for CHR treatment

-- **symptom stigma may be pre-existing** and present up to several years prior to CHR identification

-- symptom stigma may also be **informally labeled** (e.g., ‘weirdo’) and lead to unfair ostracization and **bullying**

Clinician support around **shame** and **discrimination** **related to symptoms**

CHR stigma intervention (Lucksted, “Ending Internalized Stigma”)

-- **Modules** to address **shame of symptoms (‘cognitive restructuring’)** and **discrimination based on symptoms (‘coping strategies’)**

-- Could be **adapted for clinical practice**

****Peer support**

MHTTC
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MHTTC

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The purpose of the MHTTC Network is technology transfer - disseminating and implementing evidence-based practices for mental disorders into the field.

Funded by the Substance Abuse and Mental Health Services Administration (SAMHSA), the MHTTC Network includes 10 Regional Centers, a National American Indian and Alaska Native Center, a National Hispanic and Latino Center, and a Network Coordinating Office.

Our collaborative network supports resource development and dissemination, training and technical assistance, and workforce development for the mental health field. We work with systems, organizations, and treatment practitioners involved in the delivery of mental health services to strengthen their capacity to deliver effective evidence-based practices to individuals. Our services cover the full continuum spanning mental illness prevention, treatment, and recovery support.

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