

Psychosis-Risk Stigma

Joseph S. DeLuca, Ph.D.

Fairfield University

October 12, 2022



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Mental Health Technology Transfer Center Network

Funded by Substance Abuse and Mental Health Services Administration

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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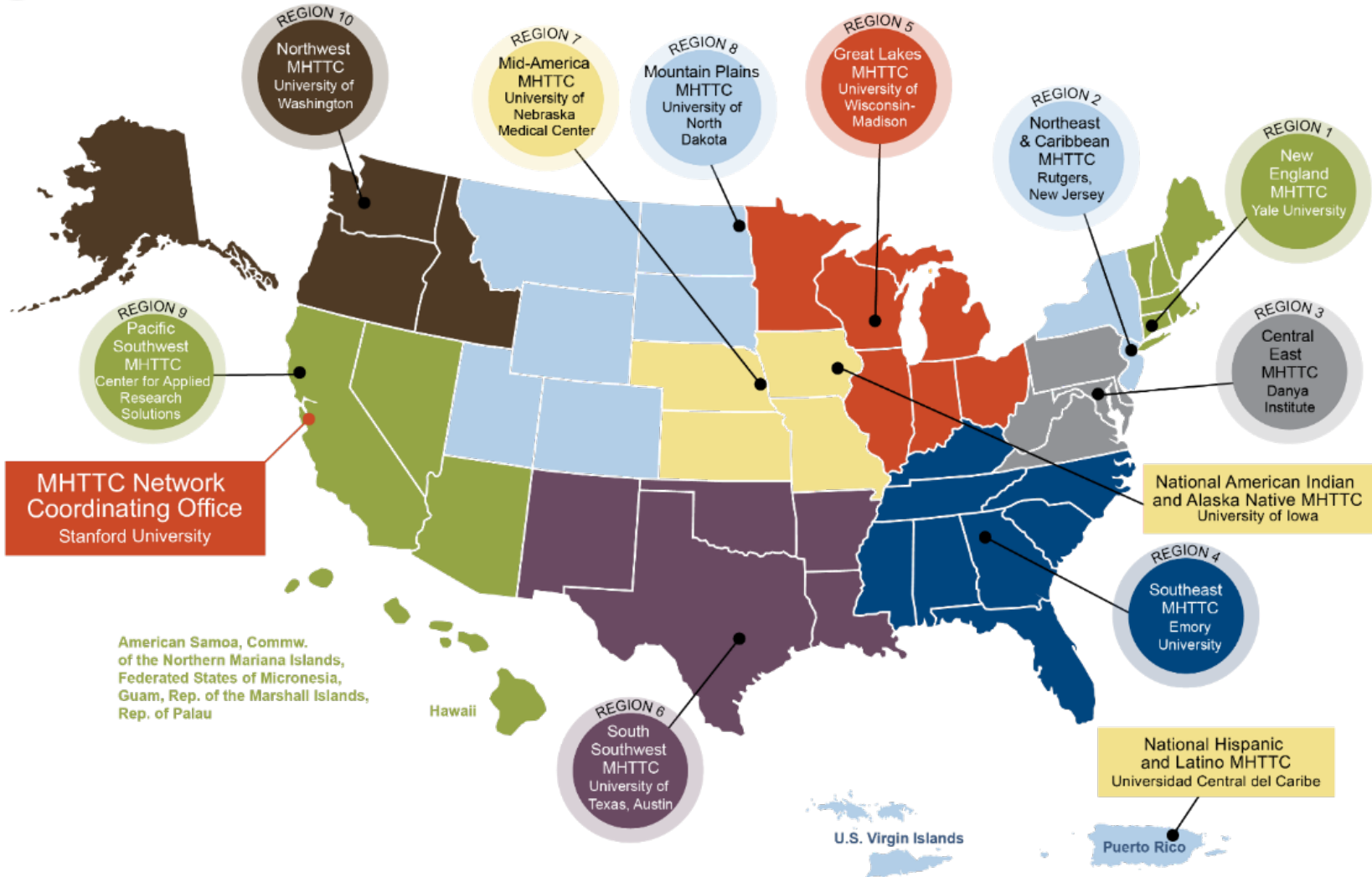


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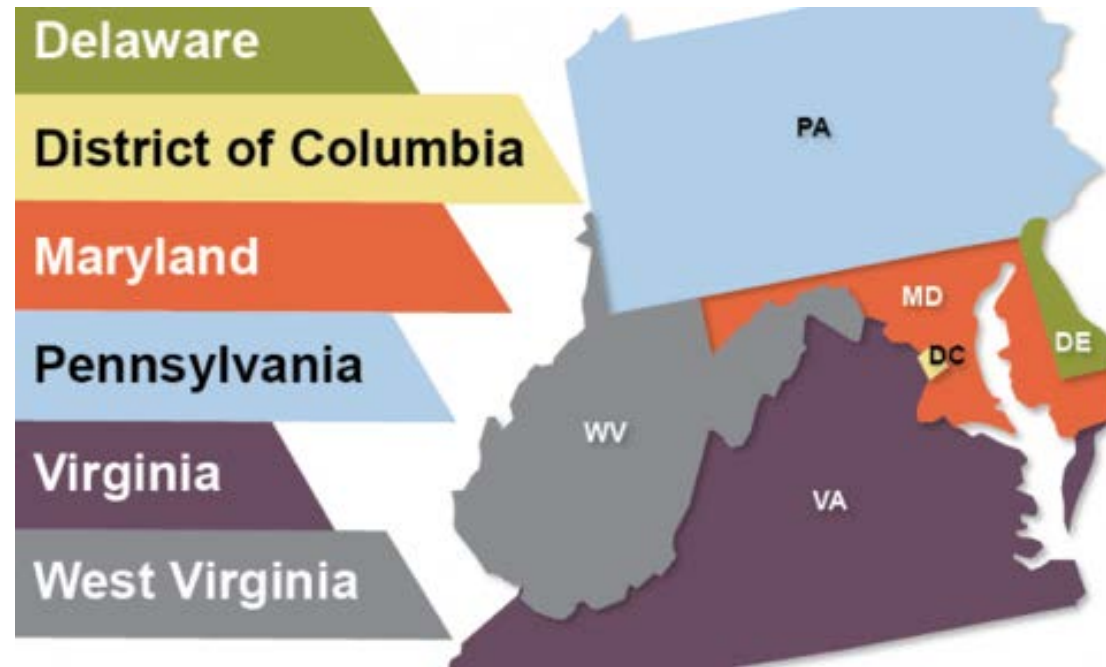
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MHTTC Network



Central East Region 3



Central East (HHS Region 3)

MHTTC

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TRAUMA-RESPONSIVE

INVITING TO INDIVIDUALS
PARTICIPATING IN THEIR
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Acknowledgment

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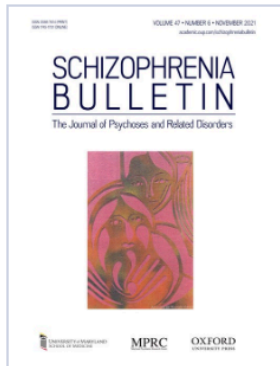
This work is supported by grant SM081785 from the Department of Health and Human Services, Substance Abuse and Mental Health Services Administration.

Presented 2022

Background



- Clinical psychologist by training, specializing in youth mental health, early serious mental illness, and stigma.
- Assistant Professor at Fairfield University, and Assistant Clinical Professor (voluntary track) at Mount Sinai's School of Medicine (*Psychosis-Risk program*).
- Passionate about mental health education (particularly around psychosis), stigma reduction, and equitable, culturally responsive, evidence-based care.



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JOURNAL ARTICLE

Reducing Stigma Among Youth at Risk for Psychosis: A Call to Action

Joseph S DeLuca , Lawrence H Yang, Alicia A Lucksted, Philip T Yanos, Jordan DeVylder, Deidre M Anglin, Yulia Landa, Cheryl M Corcoran

Schizophrenia Bulletin, Volume 47, Issue 6, November 2021, Pages 1512–1514,
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Published: 17 August 2021

Agenda

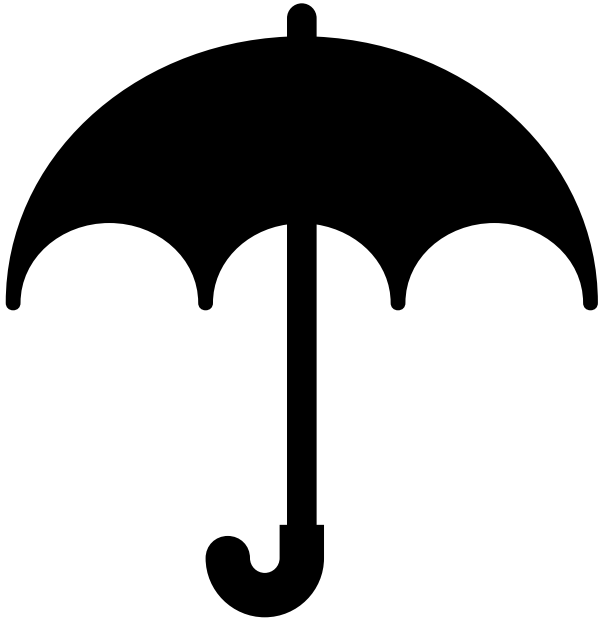
- 1. What is psychosis-risk?**
- 2. What is stigma?**
- 3. What is psychosis-risk stigma?**
- 4. What can we do about it?**
- 5. Summary & Q&A**

Psychosis: Big picture

- Approximately 1%-3% develop a psychotic disorder in their lifetime.
- 100,000 adolescents and young adults develop a first episode of psychosis each year in the US.
- Estimated economic burden of \$156 billion in the US.
- Significant individual impact (earlier mortality, lower QoL).
- Although there are negative outcomes associated with psychosis, it is important to note that many individuals who experience psychosis can and do lead full and successful lives.
- **Early identification and intervention are essential.**



Psychosis



- Not a diagnosis
- Diverse set of experiences, including loss of touch from reality (hallucinations, delusions)
- Commonly associated with schizophrenia-spectrum disorders, but may be present in mood disorders, trauma, substance use, etc.
- ***“Psychosis-risk”*** = warning signs
- ***“First-episode psychosis”*** = first experiences of threshold symptoms

We view psychosis on a spectrum

Hallucinations: Perceptual/Sensory Abnormalities



e.g., seeing indistinct shadows out of the corner of your eye

e.g., seeing a person hovering on top of your house

Psychological Medicine (2018), 48, 229–244. © Cambridge University Press 2017
doi:10.1017/S0033291717001775

REVIEW ARTICLE

The slow death of the concept of schizophrenia and the painful birth of the psychosis spectrum

S. Guloksuz^{1,2} and J. van Os^{1,3,4*}

Other recent studies of psychotic experiences or “psychotic-like experiences” (PLE) in the general public:

- **6-27%** of individuals report at least one type of PLE in their lifetime (Bourgin et al., 2020; Isaksson, Vadlin, Olofsdotter, Åslund, & Nilsson, 2020; Kelleher et al., 2012a, 2012b; McGrath et al., 2015; van Os et al., 2009)
- **Most transitory and non-distressing** (van Os et al., 2009)
- **Some persist, can be distressing,** and are associated with: depression, low self-esteem, and other psychiatric disorders and service use (e.g., Dolphin et al., 2015; Rimvall et al., 2020) – particularly when influenced by environmental risk factors (van Os et al., 2009)

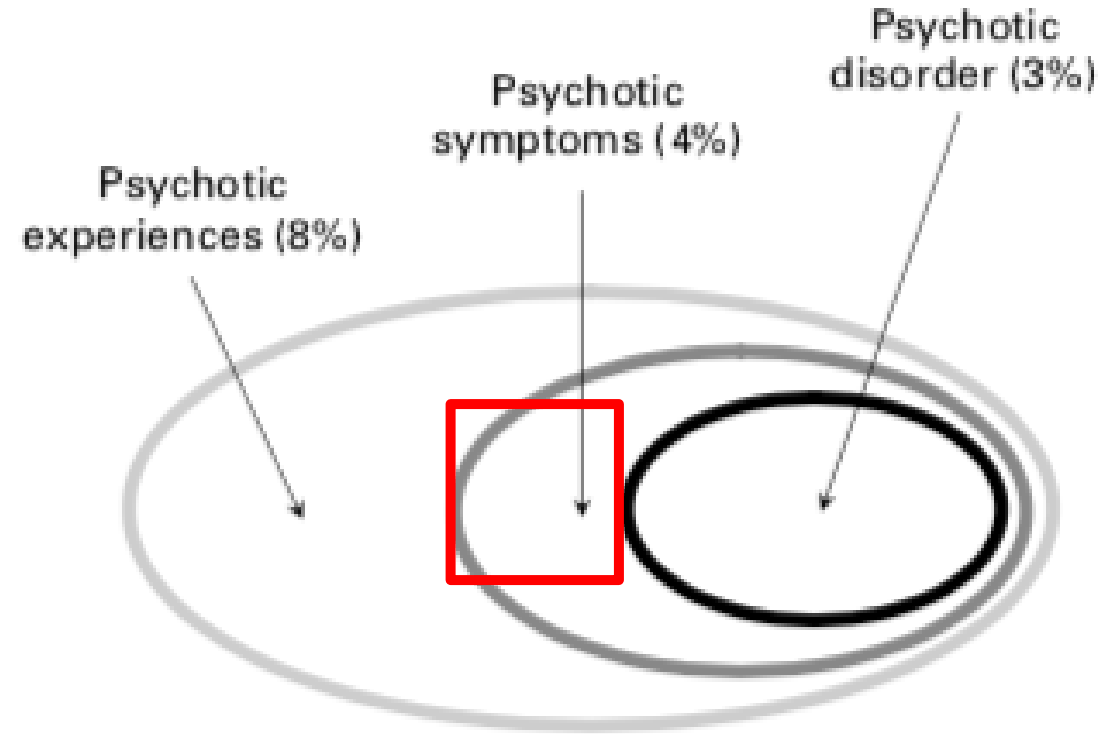


Fig. 4. Psychosis: variation along a continuum.

van Os et al., 2009

Why does this matter?

- Psychotic-like experiences and psychosis-risk states can predict future psychopathology (Lindgren et al., 2022; McGorry et al., 2018; Staines et al., 2022).
- Identifying these early warning signs early can curb negative outcomes (Fusar-Poli et al., 2020).
- However, stigma is associated with these experiences on societal and personal levels, and interferes with identification & care (DeLuca et al., 2021; Lien et al., 2015).

Psychosis-risk: history

- Long history of interest in the “prodrome” (Mayer-Gross, 1932; see Fusar-Poli, 2013 for review) and preventive psychiatry.
- First psychosis-risk service in the 90s in Australia (Yung et al., 1996).
- Specialized assessment tools were then developed, and specialized clinics continue to proliferate.

Psychosis-risk

- **Psychosis-risk (aka Clinical High Risk [CHR] for psychosis, or... ultra-high risk... “prodrome” ... etc.)**
 - warning signs; sub-threshold
 - psychosis-like experiences that resemble psychosis, but do not rise to the same level of severity and frequency; doubt is also intact
 - E.g., a family history & functional decline in last year, or recent transient symptoms (~weekly) or worsening of symptoms in last year
 - Not seriously disorganizing or dangerous
- **v. *First-Episode Psychosis (FEP)***
 - *first signs of a threshold/full psychosis (e.g., DSM-5 criteria) psychotic episode*



**Onset of
Psychosis
Risk State**



**Onset/First
Episode of
Psychosis**



Premorbid

**Risk
Syndrome**

Psychosis

Screeners: PQ-B, Prime, etc.

Psychosis-risk: trajectory

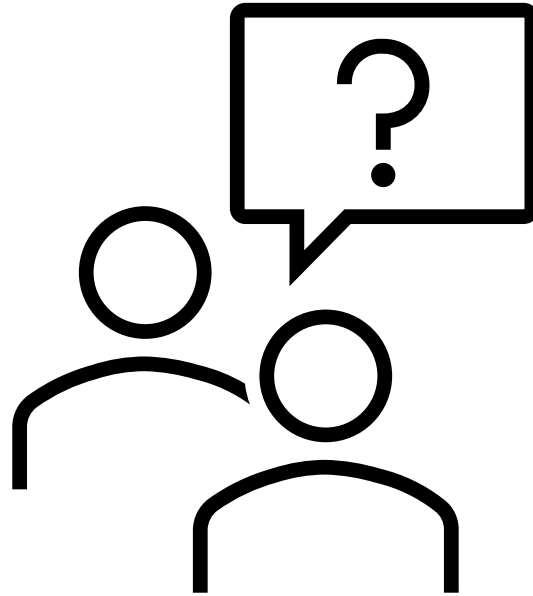
- A substantial minority (**22-25%**) of individuals determined to be at *psychosis-risk* develop a psychotic disorder within three years, and **35%** develop a psychotic disorder within ten years (Fusar-Poli et al., 2020; Salazar de Pablo et al., 2021).
- Often comorbid psychological and behavioral challenges such as depression, anxiety, impaired social and role functioning, and a history of trauma.

Prevalence of psychosis-risk

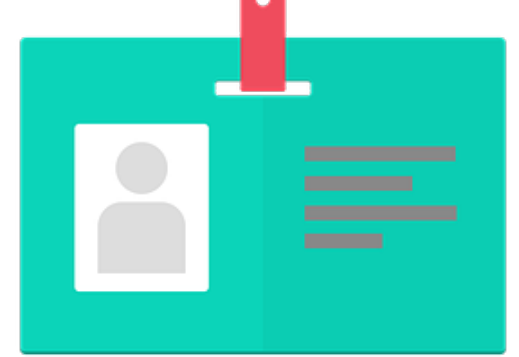
- **DSM-5 psychotic disorders = 1-3% lifetime prevalence**
- **Psychosis-risk in general population = 2-3%** (Salazar de Pablo et al., 2021; Woods et al., 2019)
- **Psychosis-risk in clinical samples = 19-20%** (Salazar de Pablo et al., 2021; Woods et al., 2019)
 - In one study, 1 in 4 non-psychotic adolescent inpatients met psychosis-risk criteria (Gerstenberg et al., 2015)
- **Conclusions = not rare & likely under-detected**
- **& earlier identification leads to best treatment outcomes!**

Stigma

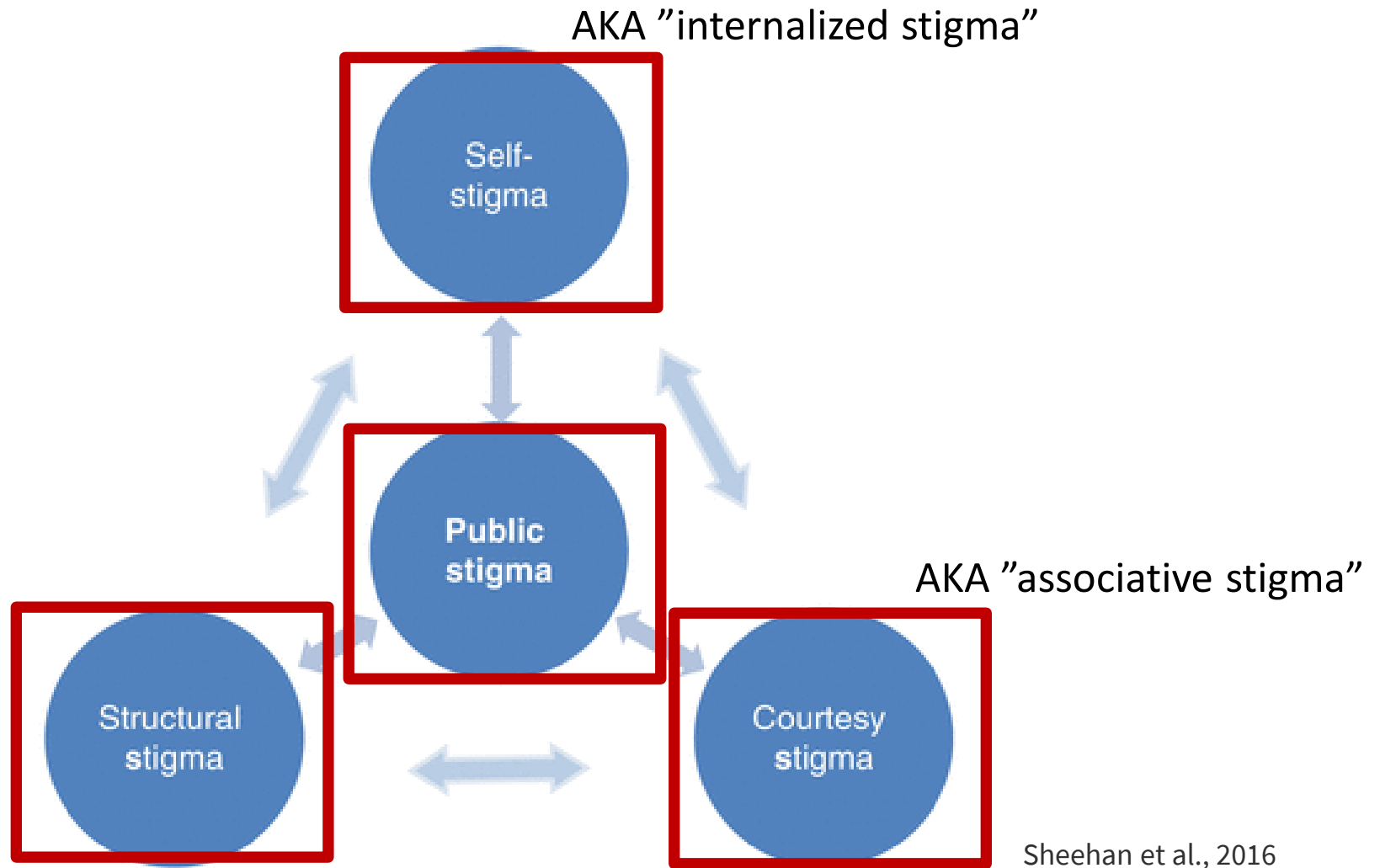
- How do you define it?



Stigma (continued)



- A process of assigning labels to people (Link & Phelan, 2001; Pescosolido & Martin, 2015)
- These labels gain power when linked to stereotypes (e.g., dangerousness, weakness) Labels + stereotypes/prejudice = discrimination
- Also: “spoiled identity” (Goffman, 1963)



Sheehan et al., 2016

Stigma (continued)

- **Q:** Over the past few decades in the US, do you think **public stigma** toward psychosis has been decreasing, increasing, or staying about the same?
- **A:** Perceived relationship between psychosis and violence is **increasing** (Pescosolido et al., 2019, 2021); **continuum beliefs are decreasing** (Schomerus et al., 2022)
- ***Structural stigma:** *Schizophrenia more likely to be spared from financial cuts during the pandemic (v. pre-pandemic public attitudes).* (Schomerus et al., 2022)



Stigma (continued)

- **However... structural stigma** remains prevalent in other ways, as evidenced by continued stigmatizing language in mental health legislation in the US (Conley, 2021) .
- **Internalized stigma:** one large study of 14 European countries found that >40% of individuals with psychotic-spectrum disorders have moderate to high levels (Brohan et al., 2010) v. ~20% of those with mood disorders (Brohan et al., 2011).

Psychosis-risk stigma

- Field has had concerns about labeling psychosis-risk, due to fears of stigma and negative outcomes.
- **Many of these initial concerns have been unfounded by research, and it does appear that specialty psychosis-risk services tend to have more pros than cons** (Woods et al., 2021).
- *Nonetheless, questions do remain re: the psychosis-risk stigma process and its negative associations* (Colizzi et al., 2020).

Psychological Medicine

[cambridge.org/psm](https://www.cambridge.org/psm)

Review Article

Cite this article: Colizzi M, Ruggeri M, Lasalvia A (2020). Should we be concerned about stigma and discrimination in people at risk for psychosis? A systematic review. *Psychological Medicine*

Should we be concerned about stigma and discrimination in people at risk for psychosis? A systematic review

Marco Colizzi^{1,2} , Mirella Ruggeri¹ and Antonio Lasalvia¹

¹Section of Psychiatry, Department of Neurosciences, Biomedicine and Movement Sciences, University of Verona, 37134 Verona, Italy and ²Department of Psychosis Studies, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London SE5 8AF, UK

Psychosis-risk public stigma

- Emerging evidence appears to indicate that there is significant public stigma (Colizzi et al., 2020)
- Psychosis-risk experiences are as stigmatized as other mental health conditions such as depression (Lee et al., 2016; Wang et al., 2020) and potentially as stigmatized as schizophrenia (Parrish et al., 2019; Yang et al., 2013)
- Also: a lack of knowledge among the public (and MH professionals)

Psychosis-risk associative stigma

“Antipsychotics were being suggested for our daughter. So yeah, that struck fear into me. The thought that she might be headed towards schizophrenia, as opposed to—I felt like depression and anxiety are fairly common, I felt that they were more manageable.”

ORIGINAL ARTICLE

Experience of associative stigma in parents of adolescents at risk for psychosis

Julia Baron¹ | Melina Salvador² | Rachel Loewy³

“I'm still concerned that people who are not enlightened wouldn't take it well [psychosis-risk status]... I'm still reluctant to talk about it.”



[Full Access](#)

Stigma in families of individuals in early stages of psychotic illness: family stigma and early psychosis

Celine Wong, Larry Davidson, Deirdre Anglin, Bruce Link, Ruth Gerson, Dolores Malaspina, Thomas McGlashan, Cheryl Corcoran 

Psychosis-risk stigma awareness?

N=38 psychosis-risk patients in NYC (32% white) (Yang et al., 2015)

- Moderate awareness of public stigma (44% overall; *84-87% *regarding dangerousness, taking care of self*)
 - *Higher awareness than adolescents without psychosis (Moses, 2009)
- Low-ish agreement (21% overall; 63-76% *regarding dangerousness, taking care of self*)

Strategies

- Clinical interventions
- Public/societal interventions
- Structural interventions

Clinical: symptom experiences matter

(Yang et al., 2015)

- Main findings from this study re: internalized stigma:
 - label shame associated with anxiety (regression)
 - e.g., *“About coming to this program, I have felt ashamed” (26.3%)*
 - symptom shame associated with depression (regression)
 - e.g., *“About my symptoms and experiences, I have felt ashamed” (68.4%)*

Symptom experiences matter (DeLuca et al., 2021)

- *N=66 youth patients w/ psychosis-spectrum sx's (53% white, n=34 at CHR)*
- What specific symptoms predict internalized stigma? Does family functioning play a role?
 - e.g., *“I can't contribute anything to society because I have a mental illness.”*
 - *“In times of crisis we can turn to each other for support”*



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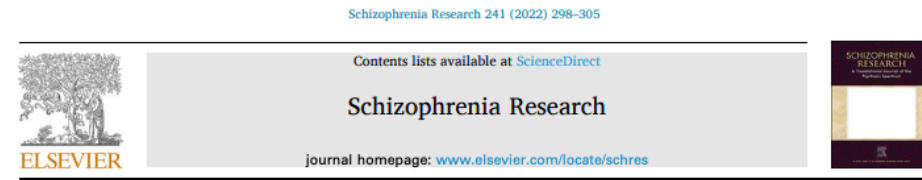
Predictors of Internalized Mental Health Stigma in a Help-Seeking Sample of Youth: The Roles of Psychosis-Spectrum Symptoms and Family Functioning

Joseph S. DeLuca^{1, 2}, LeeAnn Akouri-Shan¹, Samantha Y. Jay¹, Samantha L. Redman¹, Emily Petti¹,
Alicia Lucksted³, Pamela Rakhshan Rouhakhtar¹, Mallory J. Klaunig¹, Sarah M. Edwards²,
Gloria M. Reeves², and Jason Schiffman¹

So, do we just need to be targeting symptoms in treatment to reduce internalized stigma?

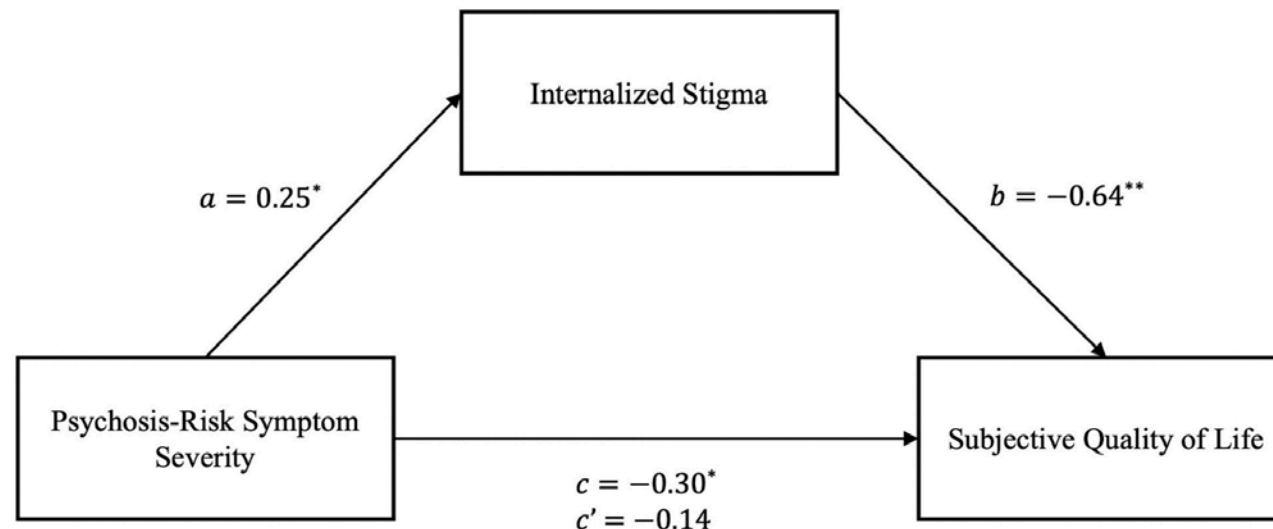
No. Directly targeting internalized stigma is likely necessary, too.

N=72 youth patients w/ psychosis-spectrum sx's (54% white, n=39 at CHR) (Akouri-Shan et al., 2022)



Internalized stigma mediates the relation between psychosis-risk symptoms and subjective quality of life in a help-seeking sample

LeeAnn Akouri-Shan^a, Joseph S. DeLuca^b, Steven C. Pitts^a, Samantha Y. Jay^a, Samantha L. Redman^a, Emily Petti^c, Miranda A. Bridgwater^c, Pamela J. Rakhshan Roubakhtar^{a,d}, Mallory J. Klaunig^c, Doha Chibani^a, Elizabeth A. Martin^c, Gloria M. Reeves^d, Jason Schiffman^{c,*}

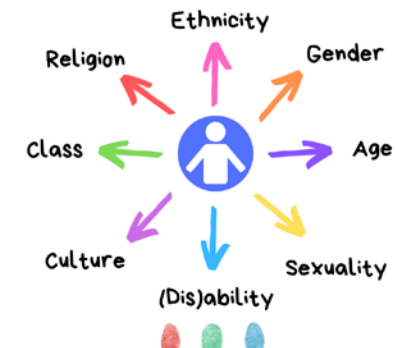
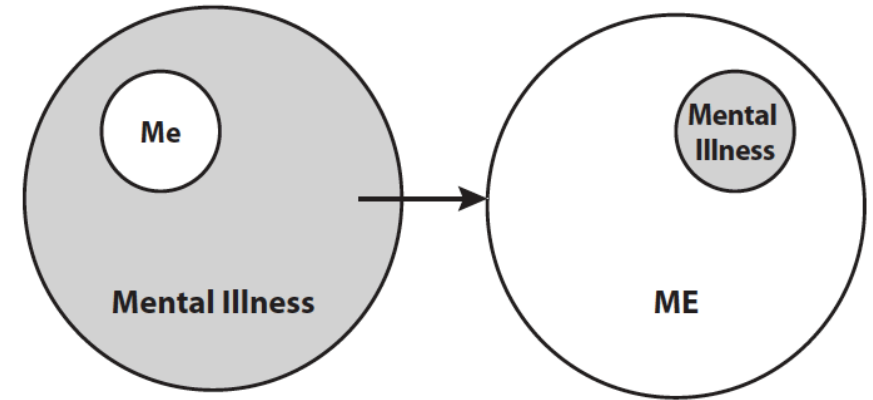


Free access to the internalized stigma of mental illness scale (ISMI)

- [Free access here.](#)

Other clinical considerations

- Public stigma reduction (see Yang et al., 2013), as well as psychosis-risk provider training (see Kline et al., 2019) and work to reduce inequities (see DeLuca et al., 2022)
- Clinical interventions** to help patients and families manage and navigate stigma (e.g., NECT, ESS, BEGIN, HOP, CFI, etc.) and build resilience (DeLuca et al., 2021; Moses, 2015)
- **Communicating risk matters, too!** (Woodberry et al., 2021)



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Psychological Services

2022, Vol. 19, No. S1, 120-138
<https://doi.org/10.1037/ser0000585>

Psychosis-Like Experiences and Resilience: A Systematic and Critical Review of the Literature

Joseph S. DeLuca¹, Pamela Rakhshan Rouhakhtar^{2, 3}, Mallory J. Klaunig³, LeeAnn Akouri-Shan³, Samantha Y. Jay³, Therese L. Todd¹, Cansu Sarac¹, Nicole D. Andorko³, Shaynna N. Herrera¹, Matthew F. Dobbs^{1, 4}, Zarina R. Bilgrami¹, Emily Kline⁵, Anne Brodsky³, Rachel Jespersen^{1, 4}, Yulia Landa^{1, 4}, Cheryl Corcoran^{1, 4}, and Jason Schiffman^{3, 6}

“Now I have a word for it...It does worry me a little bit, but it doesn't keep me awake at night. ... I worry that people will see me in the ‘crazy category’ and how far people will take it. The people I have told are nice and fond of me so I don't think they will run from me or from it. They are more concerned than anything.” (Woodberry et al., 2021)

Public/societal level

- Significant help-seeking delays (Gronholm et al., 2017; Oluwoye et al., 2021).
- At its root, stigma is a societal problem (Evans-Lacko et al., 2012).
- Education & contact can help reduce psychosis-risk stigma (Parrish et al. 2018, Yang et al., 2013)

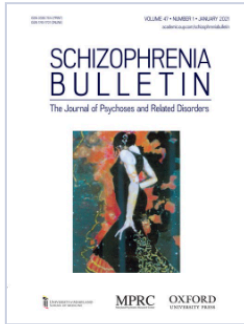


Brief Reports

Public Stigma Associated With Psychosis Risk Syndrome in a College Population: Implications for Peer Intervention

“The psychiatrist explained that being at high risk of psychosis means that the person has not yet developed a full psychotic disorder but has some symptoms that might lead to a future psychotic disorder. However, the psychiatrist said only 35% of these individuals will go on to exhibit psychosis within 2.5 years of identification” (p. 285)

Yang et al., 2013



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January 2021

Article Contents

JOURNAL ARTICLE

Reducing Stigma Toward Individuals With Schizophrenia Using a Brief Video: A Randomized Controlled Trial of Young Adults

Doron Amsalem , Lawrence H Yang, Samantha Jankowski, Sarah A Lieff, John C Markowitz, Lisa B Dixon

Schizophrenia Bulletin, Volume 47, Issue 1, January 2021, Pages 7–14,

<https://doi.org/10.1093/schbul/sbaa114>

Published: 15 August 2020

ALL FEP CENTERS ARE ACCEPTING NEW PARTICIPANTS AS WELL AS CONTINUING TO OFFER SERVICES THAT FOLLOW CDC GUIDELINES

 Penn Medicine

HeadsUp 

For Me 

For Friends & Family 

For Clinicians 

For

Changing Minds, Empowering Lives

Support for Me

Support for Friends & Family

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Structural level (Anglin et al., 2021; 2022)

- Provider training
 - to enhance early identification & treatment efforts
- Research funding priorities and program development
- Working “upstream”, and addressing various social determinants and racial disparities

Summary

- Psychosis-risk experiences are not uncommon.
- Stigma is widespread, on the rise in some ways, and detrimental to young people.
- This stigma should be targeted on multiple levels.
 - Specific ways to combat psychosis-risk stigma are emerging.
- Cultural factors and broader identity factors must be considered.
 - Developmental and intersectional lenses
- Early treatment can save lives and recovery is possible! Check out the resources to find local resources in your community.
- *I encourage you to consider one thing you can do this week to better understand psychosis-risk and/or combat mental health stigma!*

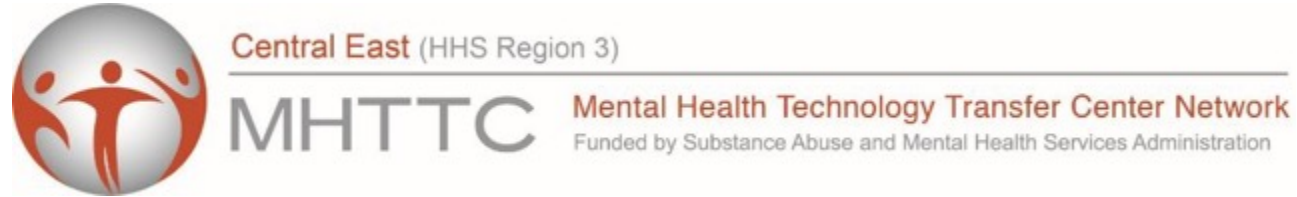
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MHTTC

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