

Engaging Youth at Clinical High Risk (CHR) for Developing Psychosis

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Overview

- ▶ **Brief overview of how to identify youth at clinical high risk for developing (CHR) psychosis**
- ▶ **Case examples**
- ▶ **Factors that facilitate and impede engagement with services**
- ▶ **Strategies to engage this population with services**

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Overview

- ▶ **Brief overview of how to identify youth at CHR for psychosis**

Psychosis

- ▶ A period of loss of contact with reality, with disruptions in the way one thinks, feels, perceives, and behaves (NAMI, 2019)

DSM-5 Key Features of Schizophrenia Spectrum Disorders (American Psychiatric Association, 2013)

- ▶ Positive symptoms
 - Delusions
 - Hallucinations
 - Disorganized thinking
 - Disorganized behavior

DSM-5 Key features of Schizophrenia Spectrum Disorders (American Psychiatric Association, 2013)

- ▶ Negative symptoms
 - Diminished emotional expression-expression-little display of emotions, body gestures, eye contact, speech
 - Avolition - lack of motivation
 - Anhedonia - decreased ability to experience pleasure
 - Alogia - diminished speech output
 - Asociality - lack of interest in other people

Positive vs. Negative Symptoms

- ▶ **Positive symptoms**
 - Added onto every day experiences
- ▶ **Negative symptoms**
 - Loss of every day experiences
 - Most common in Schizophrenia

Clinical High Risk for Developing Psychosis

- ▶ **CHR for psychosis develops during late adolescence / young adulthood**
- ▶ **Attenuated positive symptoms**
 - Subthreshold delusions (e.g. unusual thought content, grandiosity, suspiciousness)
 - Subthreshold hallucinations (perceptual disturbances)
 - Subthreshold thought disorder (e.g. disorganized communication)
- ▶ **Negative symptoms**
 - Inability to experience pleasure
 - Withdrawing from others
 - Losing interest in every day activities
- ▶ **Functional decline (e.g. school/work)**

Feeling broken:

“Maybe in my head something did not develop properly or there is something missing.”

(Ben-David, et al. 2014)

Going crazy:

“The anxiety about being crazy was worse than forgetting a meal.”

(Ben-David, et al. 2014)

Problems communicating:

“I want to communicate to other people, but sometimes I feel like I’m just mumbling over some kind of mountain. I’m trying to make myself understood, but they just can’t hear me, no matter how hard they try.”

(Ben-David, et al. 2014)

Family history:

“There is such a history in my family of thought disorders and I have pretty much known my whole life that I had a higher chance of going nuts than other people.”

(Ben-David, et al. 2014)

Attenuated Positive Syndrome (APS) in DSM-5

(American Psychiatric Association, 2013)

- ▶ Conditions for further study in the DSM-5
- ▶ Debate within the community
- ▶ Attenuated delusions, hallucinations, disorganised speech (insight is relatively maintained)
- ▶ Onset begun or worsened in the last 12 months
- ▶ Frequency/duration - at least once per week in last month
- ▶ Degree of distress
- ▶ Interference with life leads to help-seeking
- ▶ Criteria for psychotic disorder has never been met

Structured Interview for Prodromal Syndromes and the Scale of Prodromal Symptoms (SIPS/SOPS)

- ▶ Certification training of SIPS/SOPS through the PRIME clinic at Yale University
- ▶ Trainer comes to your site for two-day training
- ▶ For more information:
- ▶ Contact Dr. Barbara C. Walsh at barbara.walsh@yale.edu or by calling 203-974-7052
- ▶ https://medicine.yale.edu/psychiatry/research/programs/clinical_people/prodome.aspx?organizationId=109519?organizationId=109519

Overview

- ▶ **Case examples**

Vignette 1

- ▶ 17-year-old Charlie first accessed services for problems with concentration at school, and chronic headaches
 - ▶ He failed several classes and recently stopped attending school
 - ▶ Has problems with sleep, playing video games all night and falling asleep by 5 am, sleeping late into the day
 - ▶ He avoids classmates and worries that they have been talking about him behind his back because he hasn't been pulling his share of work
 - ▶ He admitted to his counselor that he fears that some of his classmates might be out to harm him
 - ▶ When questioned further by the counselor, he stated that he does not believe that his friends are going to actually harm him but feels the need to remain on guard “just in case”.
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- ▶ Discussion (e.g. CHR, First episode)

Vignette 2

- ▶ Jess is a 20-year-old bartender and student
- ▶ Family history of schizophrenia (mother)
- ▶ Problems taking care of herself and recently fired from job because of the number of days missing work
- ▶ Spends most of her time watching Netflix and daydreaming
- ▶ Has been fighting more often with significant other
- ▶ She believes that psychic powers run in family and is getting messages from the TV show Sabrina that she has can read minds
- ▶ When probed by therapist, she stated that these experiences feel real and has begun to sell some of her belongings to pay for online spells
- ▶ She feels worried that she may have inherited her mothers mental illness, and has been feeling “down in the dumps”

- ▶ Discussion (e.g. CHR, First episode)

Overview

- ▶ **Factors that facilitate and impede engagement with services**

Significance

- ▶ Increased rates of suicide, school drop-out, comorbid mental health problems
- ▶ Predictive validity - 20-40% of young adults at risk for developing psychosis develop a psychotic disorder (Larson et al., 2010)
- ▶ Delays in treatment for psychosis lead to worse outcomes (Harris et al., 2005)

Importance of Early Intervention

Mental Health Service Use

- ▶ High rates of underutilization of mental health services
- ▶ Have the capability to: a) recognize that they have a problem, and b) make decisions about seeking mental health services (Boydell et al. 2013)
- ▶ Shortage of mental health service use research among young adults at CHR:
 - Decision-making
 - First-person perspectives

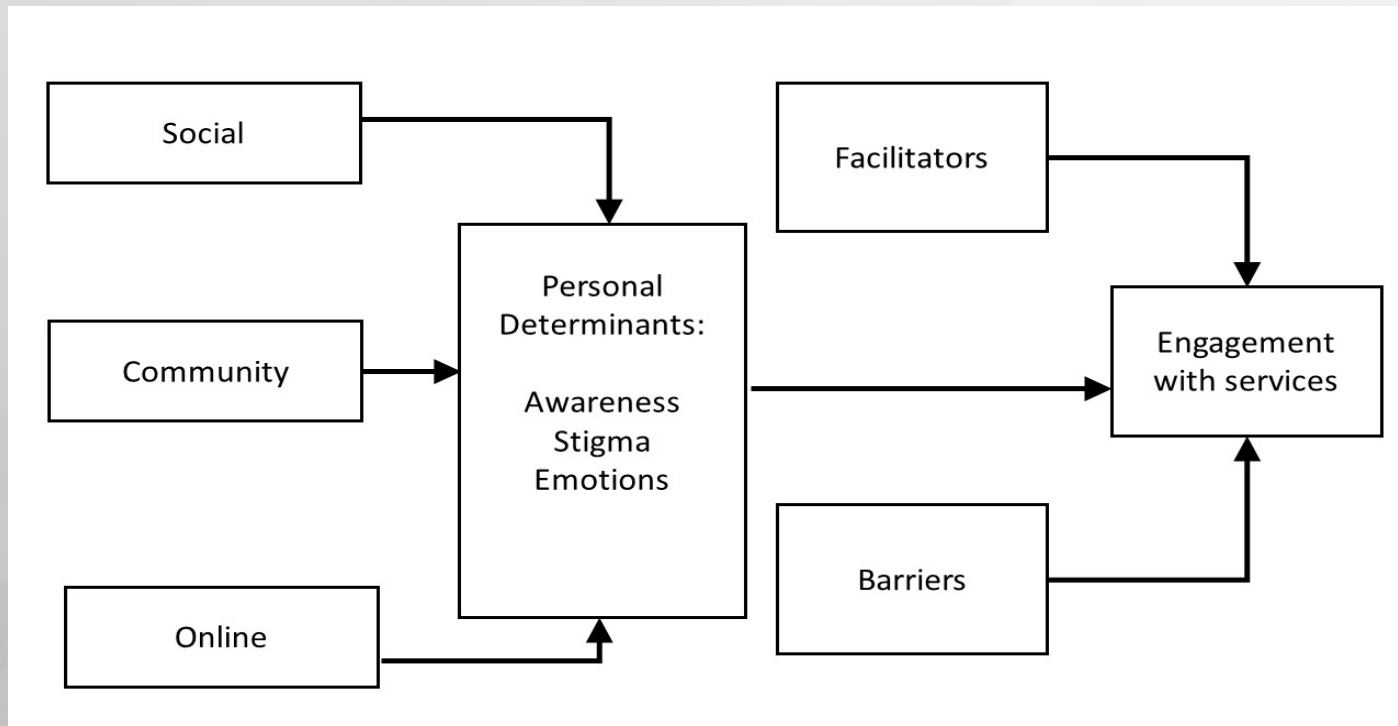
Specific Aim

- ▶ Aim #1: Ben-David et al. (2019): Understand the perspectives of young adults (aged 18-30) at risk for developing psychosis on what keeps them engaged (not engaged) with services at the Center of Prevention and Evaluation (COPE) clinic.
- ▶ Aim #2: Ben-David et al. (2018): Understand the decision-making process that young people make when seeking services at COPE by applying the Unified Theory of Behavior (Jaccard et al., 2002).

Sample Characteristics

- ▶ Sample size: 30
- ▶ Age 23 (SD = 3.41); 60% male
- ▶ Race/ethnicity: White 34%, Black 23%., Hispanic 20%, Bi-Racial 20%, Asian 3%
- ▶ Type of engagement with services at COPE: 54% receiving clinical services, 46% research only

Conceptual Model of Mental Health Service Use



Ben-David et al., 2019

Overview

- ▶ **Strategies to engage this population with services**

Networks: Communities

Negative (barrier) messages from specific racial/ethnic communities (African American, Eastern European, Dominican)

“I would say that from my experience there’s a lot of stigma about getting mental health services in the Black community. There has been several instances where people tell me you don’t need to seek help you just need a good friend or family or person to talk to.”

Networks: Family/Friends

Positive, negative and mixed messages from social networks

From a parent, “the resources at the clinic is helping you”

From friends, “because every time I tell them what I am dealing with they [friends] say you are going to get worse [at the clinic]”

Networks: Online

Positive messages

“I was reading a forum for schizophrenic people and I made a post saying that this is how I feel... they told me there might be a place in the city where I could go and talk to people for free.”

More research needs to be done in this area

Engagement Strategies

- ▶ Including family members as part of the treatment
- ▶ Psychoeducation to communities and families about CHR state:
 - Reduce stigma
 - Increase buy-in to services
 - Work in collaboration with community leaders (e.g. churches, community centres)
- ▶ Online mental health apps and communities

Hierarchical Stigma

Psychotic symptoms are viewed as the most stigmatized symptoms compared to other mental illness

“Psychotic symptoms are especially something that you're supposed to not talk about or keep hidden and people are afraid of people who have experienced psychotic symptoms...that's like definitely the one kind of symptom that people really don't understand if they've never been mentally ill.”

Public and Internalized Stigma

Highly endorsed public stigma
Stigma leads to secrecy

Public: “It’s always talked about like in the media...people with schizophrenia are scary or are the people who shoot other people in schools.”

Internalized: “It’s kind of terrifying but I am glad it was sort of spotted...there is that feeling of being distraught, like am I that crazy”

Disclosure

Partial disclosure

“I’m not going to tell people I’m seeing a psychiatrist and therapist that’s silly. I can’t do that because they will begin to question me”

Engagement Strategies

- ▶ Positive images of the type of young people that seek MHS (interested in getting help, brave, in distress and want alternative ways to cope)
- ▶ Universality of experiences- there are many young people that share these same experiences
- ▶ Stigma free environment
- ▶ Clinicians checking their own biases

Emotions

- ▶ Positive, negative, and mixed emotions

E.g. Shame, fear, confusion, happy, hopeful, relief

“I was really excited at first and I still love it here but I was so confused”

Engagement Strategies

- ▶ Paying close attention to emotional reactions to services
- ▶ Normalizing emotions
- ▶ Providing young people with skills to regulate emotions
- ▶ Mindfulness

Facilitators: Expertise of Services

- ▶ One of the most endorsed facilitators
- ▶ Really important that clinicians have some knowledge about the CHR stage

“Knowing that the people here know what they are doing and have experience is what keeps me going here”

Facilitators: Efficacy of Services

- ▶ Important to the youth that the service help alleviate symptoms and improve functioning

“We used CBT to tackle most of my fears and anxieties”

“Helps you get out of the funk”

“Learning how to have better interpersonal relationships”

Facilitators: Clinical Factors

- ▶ Tailoring therapy towards needs
- ▶ Therapeutic alliance
- ▶ Treatment can help

“He is the first therapist that I have had that I actually felt can help me”

Facilitators: Social Connection

- ▶ Importance of connections with therapist and staff at the clinic

“You have these deep connections with people who want to help you.”

Facilitators: Access

- ▶ Free therapy
- ▶ Services all in one place

“All of these options in one place”

Engagement Strategies

- ▶ Practitioners can focus engagement interventions on:
 - Attitudes towards services
 - service improves symptoms/functioning
 - clinicians have expertise
 - Relationship building
 - social support embedded within clinic from the staff to the therapist
 - therapeutic alliance
 - Clinicians gaining confidence in working with the population

Barriers: Lack of Access

- ▶ Transportation, temporary nature of the clinic, lack of access to therapist

“It’s a pain in the neck to get here sometimes”

Barriers: Physical Environment

- ▶ Directions to get to the clinic within building confusing, feels like a hospital, stigma associated with psychiatric hospital

“The clinical setting itself feels impersonal”

Barriers:

Clinical Barriers

- ▶ Problems with scheduling, not feeling understood or respected by clinicians, issues not aligning with clinicians agenda, clinicians mannerisms (e.g. impersonal)

“Frustrated not able to reschedule same week”

Barriers: Services Lead to Negative Emotions

- ▶ Seeking services at the clinic leads to the experience of negative emotions (anxiety, worried, bummed out, fear of developing schizophrenia)

“The reason I didn’t want to see a therapist is because I would be worried that it would send me into a negative spiral.”

Engagement Strategies

- ▶ Practitioners can reduce barriers to services:
 - Providing psychoeducation to youth about expectations about services at clinic, and what to expect in therapy (e.g. how to manage negative emotions)
 - Trauma informed approach
 - Environments that are youth-friendly
 - If in large hospital or center- provide user friendly directions
 - How can you make your space more inviting and youth friendly?
 - Consider having peer navigators at the clinic

Implications

- ▶ Speciality clinics for young people at CHR to psychosis are limited in the USA
- ▶ Not all young people will get access to these clinics, especially youth that are low-income, minority and live in low resourced neighborhoods
- ▶ Be able to identify CHR youth
- ▶ Increase assessment of this state in community mental health clinics
- ▶ Reduce stigma at clinics, within families, and communities
- ▶ Know where to refer these youth to get more specialized care in USA

Resources

- ▶ Center of Prevention and Evaluation (COPE) at NYSPI Columbia University <https://www.columbiapsychiatry.org/research-clinics/prodromal-clinic-center-prevention-and-evaluation-cope>
- ▶ EASA Center for Excellence <https://www.nasmhpd.org/sites/default/files/2015%20Program%20Directory.pdf>
- ▶ Taylor, E. (2016). Program Directory of Early Psychosis Intervention Programs. Portland, OR: EASA Center for Excellence. http://www.easacommunity.org/files/Early_Psychosis_Intervention_Program_Directory.pdf
- ▶ OnTrackNY <https://www.ontrackny.org/>

OnTrackNY is an innovative treatment program for adolescents and young adults who recently have had unusual thoughts and behaviors or who have started hearing or seeing things that others don't.

Goal

OnTrackNY helps people achieve their goals for school, work, and relationships.

Eligibility

The program is for adolescents and young adults between the ages of 16 and 30 who have recently begun experiencing psychotic symptoms, such as hallucinations, unusual thoughts or beliefs, or disorganized thinking, for more than a week but less than 2 years.

OnTrackNY teams provide services to all referred individuals meeting clinical admission criteria, without wait lists and regardless of their insurance status or ability to pay.

Q&A

Thank you!

Please send me an email with any further content questions:

shelly.ben-david@ubc.ca

For CTAC questions, email ctac.info@nyu.edu

www.ctacny.org

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