Not Broken

Empowering Young Adults with a Mental Health Diagnosis

Who I am and Why I Care About This

Disclaimer

- Please understand that what follows is a perspective gained from

  - Personal Observations in Clinical Work
  - Lived Experience
  - A little bit of Research

  - ❖ My goal is not to give advice but to share a perspective ☺

Recovery-Oriented Cognitive Therapy

Traditional CBT	Recovery-Oriented Cognitive Therapy
Focuses on challenging unhelpful thoughts	Focus on Meaningful Reintegration
Focuses on changing thoughts to change emotions and behaviors	Focus on purpose/meaning out of experience of mental health condition
Look for patterns in what may seem random	Acknowledge patterns/meaning in what might be dismissed otherwise
Typically focused on the individual	Support and Community Connection Key in Recovery

Psychosis

Psychosis

- Positive Symptoms
  - Hallucinations
  - Delusions
- Negative Symptoms
  - Loss of Motivation
  - Emotional Disconnection
  - Social Withdrawl
- Cognitive Symptoms
  - Focus Difficulties
  - Disorganized Thoughts/Speech
- Mood Symptoms

The Trajectory of a Psychotic Disorder

Clinical High Risk

Concentration Difficulties

Changes in Organization/Thought Process

Sub-Threshold Psychotic Symptoms

Withdrawal

Loss of Motivation

Cognitive and Negative Symptoms Take Effect Before Other Symptoms

Often Onsets in Adolescence

- Family History Increases Risk
- Watchful Waiting, Psychoeducation, Intervention for other mental health or Substance abuse issues

Early Psychosis

Early Psychosis/First Episode of Psychosis
Some clear psychotic symptoms
First 18 months-5 Years after psychotic symptoms onset
Insight Higher
Could be intermittent/Episodic

Subsequent Episodes
The longer psychosis goes untreated, often the more difficult
Recovery is

Early Intervention Improves Outcomes

▶ A meta-analysis of 17 studies showed that early intervention in psychosis improved multiple dimensions of outcomes including increased likelihood of engagement in work/school and lower 'symptom severity' (Correll et al, 2018)

▶ Research suggests that a longer duration of untreated psychosis likely negatively correlates with functional connectivity in brain regions (Maximo et al, 2020)

▶ Some have suggested the first episode of psychosis (first 18 mo-2 years of illness) to be a 'critical period for intervention effectiveness similar to critical periods of intervention in other phenomena (Chang et al, 2022)

Some have suggested that the weighted benefits of receiving assistance within the first two years of onset of psychotic symptoms is similar to the importance of receiving treatment in the first fifteen minutes of a stroke

Stigma Even Before Diagnosis

-A systemic review found that stigmatizing beliefs concerning individuals with mental health challenges were common in primary care providers and that attitudes toward individuals living with Schizophrenia trended worse than toward those with depression (Vistorte, 2018)

-Research shows that families at times in fear of the effects of a label are less likely seek out help for their family member in the initial stages of psychosis (Franz et al, 2010)
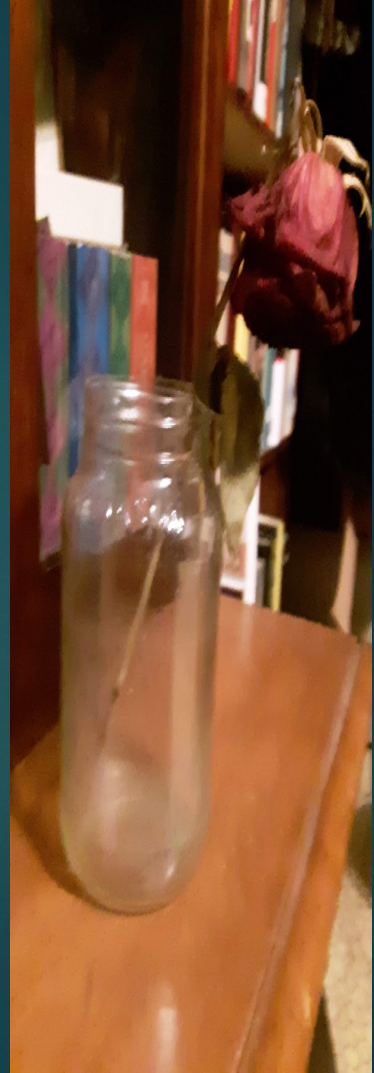
How do you think this affects who gets help and when?

Research shows that on average 142 WEEKS (Almost 3 YEARS) Go By Before Intervention in Early Psychosis

I went through a lot of physical tests. I wanted something physically to be wrong so it wasn't my fault. I thought having a mental illness meant I was bad, weak and less than.

How do you think blame affects willingness for people to seek help?

And…..young adults with serious mental illness are notoriously difficult to engage

▶ An systemic review found that on average 30% of individuals referred to first episode psychosis specific specialty care disengage for treatment

▶ Why?

What were you doing at 22?

The Music of Youth and Young Adulthood

- ▶ Identity Development

- ▶ Securing Relationships for the Rest of Life

- ▶ Rapid Growth

- ▶ Friendships Especially Important

How does psychosis affect the music of youth and young adulthood?

Medical Model………..

- Historically getting better meant the disease (the person) was subdued

- Oftentimes (and sometimes still the case) the response of treatment was to gain control of the person "for their own good"---Paternalism

A natural response to this can be **fighting off help/others (in DBT Speak----Willfulness)** or **giving up**

Common Responses for Youth and Families

- Fear

- Overwhelm

- Wanting things to Go Back to Normal

- Difficulty Accepting the Diagnosis

- All made worse by **stigma** and **pessimism**

Normalization; "I'm not crazy......."

▶ 1 in 4 people live with a mental health condition

▶ All People have Mental Health, Moods, 'Anxiety', False Beliefs

▶ We all have perceptions and our perceptions can be tricked

▶ Many people recover or live a good life with these challenges

▶ Meaning can be found

How is this different from CBTp?

- Recovery oriented cognitive therapy integrates many of the principles from CBT for Psychosis (CBTp) such as behavior experiments, socratic questioning and the like--- but focuses on the meaning of difficulties and aspirations over symptoms----the objective is to improve quality of life rather than make the symptoms go away

- Recovery-Oriented Cognitive Therapy was originally designed for psychosis spectrum disorders however since has been applied to a variety of challenges ranging from mood disorders to coping with chronic illness

- Recovery-Oriented Cognitive Therapy and CBTp are both evidence based practices for the treatment of Serious Mental Illness

When I was struggling most, I felt out of control, my mind had always been my jurisdiction

HOW CAN CLINICIANS EMPOWER A YOUNG ADULT WHO FEELS THEY ARE LOSING CONTROL?

Spiraling

▶ As challenges progress, particularly with significant mental health conditions, people may lose control of other things such as

  ▶ Housing

  ▶ Involvement in the legal system

  ▶ Substance Use

  ▶ Relationships

  ▶ Employment

  ▶ Choices
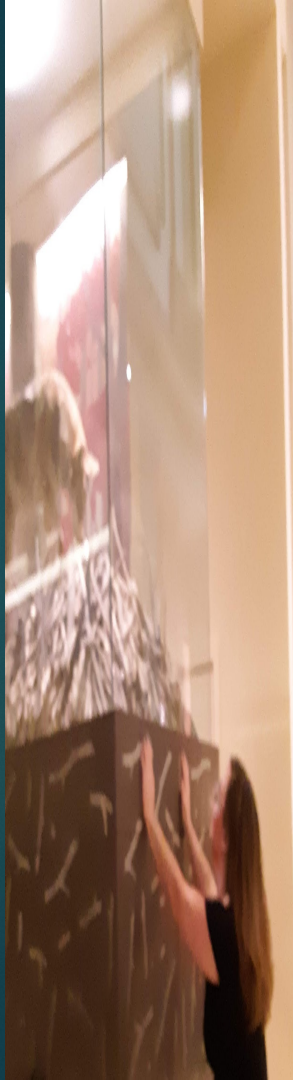
Schooling….

▶ Stigma in secondary school and on college campuses is in pervasive at all levels

▶ A Study of 114 students in a first episode psychosis program found that 82% had some interruption in their studies due to their experience (although many were able to return to school) (Shinn et al, 2020)

▶ Many colleges have policies calling for compulsory leave of absence when students present with certain mental health related challenges particularly when self-harm or suicidal ideation are present (Xu, 2022)

How do people regain a sense of agency, when it keeps getting taken away?

Treatment Can Be Traumatic

▶ Hospitalizations

▶ Seclusion, Restraint, and Sedation: A focus group found that among 8 service users all found these experiences upsetting citing miscommunication as a common reason for their application. In addition many considered the experience to be more punishing than theraputic (Mayers et al, 2010)

▶ An meta-analysis of research targeting the self-reports experiencing a first episode of psychosis report being discredited, treated as incapable/less than, dehumanized and otherwise harmed in the name of treatment (Grifffiths, 2019)

In my first year of seeing a psychiatrist I thought I was going to the hospital every visit. And sometimes I did.

HOW DO YOU EMPOWER CLIENTS IN A SYSTEM THAT OFTEN USES COERCIVE MEANS? OR IS BUILT TO FOCUS ON COMPLIANCE?

The Importance of Hope

A study of college students living with mental health challenges found that many endorsed experience of microaggressions both in and outside of treatment settings including being treated as second class citizen, shaming, treated as inferior, fear, and invalidation (Gonzalas et al, 2015)

A study of individualized hospitalized during the initial stages of a psychosis found that most had the same life goals as most people---education, work, housing, love (Ramsey et al, 2011)
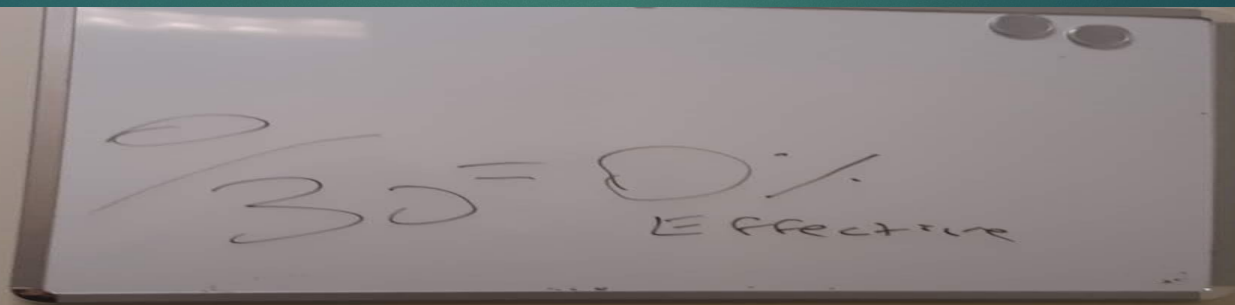
"When asked at first what I most wanted to change about my experience I would say to not have appointments anymore or take meds."

How would you respond to this?

Engagement After the Referral

- Level of trust with practitioners as well as the quality of therapeutic relationship may predict engagement (Kim et al, 2019)

- Engagement in work or school is also a positive predictor of engagement in services (Kim et al, 2019)

- Lastly, a belief of mental health challenges as being caused through social stress also may positively correlate with engagement (Casey et al, 2018)

What would make mental health intervention worthwhile to you if you were an young adult experiencing a serious mental health issues?

Youth are most likely to engage when they find services RELEVANT to THEIR GOALS, EMPOWERING, and WHEN THERE IS AN ALLIANCE

Building Alliance

Appreciation for Individual Perceptions and Validation

Shared Activities, May Look Different than a Therapy Room

Are clinical terms such as "delusion" or "hallucination" by definition invalidating?

Normalization, All Brains Can Be Tricked

Normalizing psychosis as a human experience.

Access to peer support and human conversation ☺

Even in Psychosis, a person's experiences are real to them

Research has shown access to peer support to have a positive impact on social connection, self-efficacy and quality of life in individuals experiencing first episode psychosis (Casteline, 2008)

Chosen Language

Recognition the person's choice in the language they wish to use and whether or not they wish to identify as a 'person with a mental health condition' or with any diagnosis

Acceptance of Diagnosis is Not Necessary for Recovery

Acknowledge that diagnoses often change.

People kept wanting me to accept that I had a psychotic disorder….then it was Bipolar….then depression…OCD…..ODD….Those words did not help me.

Phases of Recovery-Oriented Cognitive Therapy

▶ Energizing the Adaptive Mode (Bringing out a person's best mind state often through activities, music and non-traditional therapeutic discussions)

▶ Developing Aspirations

▶ Enriching Motivation Surrounding Aspirations

▶ Actualizing Aspirations

▶ Empowerment and Building Resilience
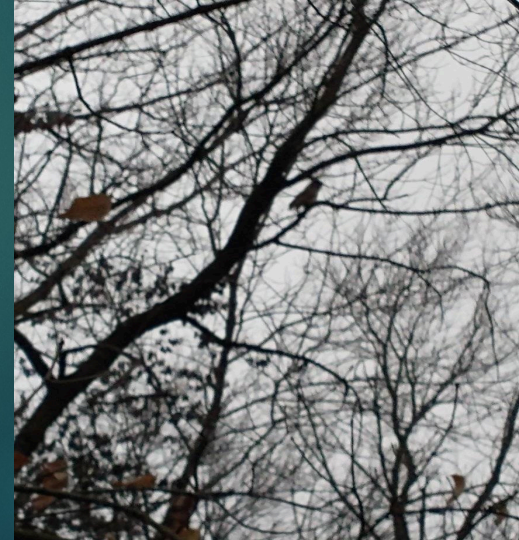
In Recovery-Oriented Cognitive Therapy, Good Therapy Might Not Look Like "Therapy"

The Adaptive Mode

When are you at your best?

Where are we.......

Non-Adaptive Mode

- "I can't connect anymore."
- "Things don't work out for me."
- Inertia
- Isolation
- Great friends with Negative Symptoms

Adaptive Mode

- "I can."
- "I still enjoy…."
- Moving toward values (even in small ways)
- Finding meaning
- When a person is doing what they love

Energizing the adaptive mode

- ► Music

- ► Activity

- ► Fun Conversation

- ► Asking Advice

Developing Aspirations

- Ask: "What are your dreams?" "What do you hope to do?" Listen

- Watch for Smiles

- We aren't in the business of shooting down dreams…..even if we think a dream might be unrealistic. Who are we to tell the future? If a person chooses a huge aspiration ask "what would be the best part of that---focus on those values

Treatment Compliance is Rarely an Life Goal

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Focus on individual chosen values/quality of life goals as opposed to compulsive treatment and overarching goal of 'compliance' or symptom reduction

- Recovery: Meaning many things to many people

Some of the most harmful things treatment providers did for me were made comments like "you will need to know when you need to go to the hospital for th rest of your life." Encouraging me to apply for disability. And letting me know I would need to just deal with terrible side effects. I painted a picture of my future as a career patient and I didn't want it.

Shared Decision Making.....

Use of shared decision making including shared decision making tools, minimum use of coercion

Research shows that shared decision making may improve engagement and retention among young adults presenting with a first episode of psychosis (Hamilton, 2019)

While clinicians may be tempted to work on severe symptoms like paranoia, mania, or hearing voices, initially, oftentimes individuals feel more comfortable with more universally relatable challenges such as sleep, anxiety and depression---which all affect psychotic and major mood symptoms!

When I first entered treatment, focus was on compliance. I was non-compliant. My psychiatrist today focuses on my goals and all decisions are shared. I am much more compliant.

A Turning Point in My Recovery Was Access to a Peer-Led Recovery Group

WHY WOULD ENCOUNTERS WITH OTHERS WITH LIVED EXPERIENCE BE IMPORTANT TO A YOUNG ADULT EXPERIENCING MENTAL HEALTH CHALLENGES?

Enriching Motivation Surrounding Aspirations

- Stepping Stones toward Meaningful Goals

- May Not Lead to the Original Goal but the purpose behind it

- WHY does this matter to you?

- Dreaming

Some of the most helpful things treatment providers did for me were helping me apply to college, talking to me about the future like any other kid. I painted a life of a future as a therapist, speaker and writer. I have been free of the hospital for 19 years and counting!

Encouraging the Fire

▶ Clinician advocacy in systems where individuals given a mental health diagnosis may experience stigma or oppression such as the education system, medical systems, education system

▶ Focus on the meaning behind the goal, ask "what is the best part?"

▶ Send a message of hope

▶ You can take a step toward a value/meaning everyday!

I remember being in a special school and advocating to go back to mainstream school. They were going to put me in a self-contained classroom. I remember the social worker stood up for me. I didn't get what I wanted but that meant something to me. As I completed applications for college the following year, I felt hopeful.

Actualizing Aspirations

- ▶ Celebrate Every Step

- ▶ More than Behavior Activation

- ▶ If All Targets are Not Hit That's OK!

At 13, after my first psychiatric hospitalization, I remember visiting the library to learn about 'psychosis.' I found all sorts of books written for young adults on depression, anxiety, Anorexia, and even Bipolar Disorder. But only one on 'Schizophrenia' and it was not teen-friendly! I thought to myself "is this condition so bad that people with it can't read." This year, I am happy to announce that I have been able to change that through release of my workbook "The Psychosis and Mental Health Recovery Workbook: Activities for Young Adults from ACT, DBT, and Recovery-Oriented Cognitive Therapy."
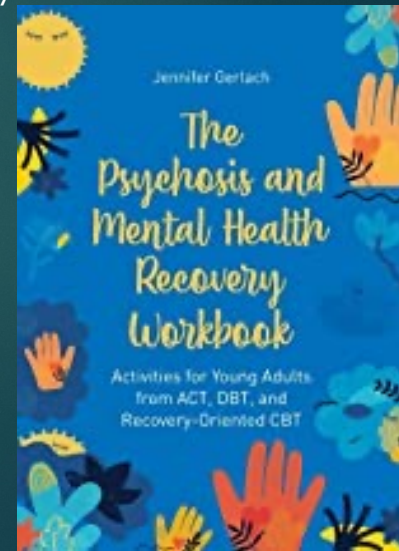
"Non-traditional" Social Interventions including peer support, dog-assisted recovery programs, supported volunteering, and mutual engagement in Social Activities can be exceptionally helpful in fighting loneliness but are not often offered

HOW WILLING ARE YOU TO BE A REBEL?

Questions?
☺

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