

Recovery is in the Eye of the Beholder



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Background

- **Present Life**
- -Family member
- Professor Emerita at UAB
- NAMI (National Alliance on Mental Illness): National Associate Medical Director,
- APA Annual Meeting Scientific Program Committee
- Board Member, AACCP

- **Past Life**
- Family member
- Past Editor-in-Chief: Community Mental Health Journal
- Consultant, federal court monitor for Tutwiler, AL Department of Corrections
- DOJ Consultant to investigate of state hospitals in Georgia
- Ran mental health center and psychiatric hospital at UAB
- Research on genetic liability for schizophrenia, ACT, Dual Diagnosis, and Criminal Justice and Mental Health
- American Association for Community Psychiatry
- Chair, APA Annual Meeting Scientific Program Committee

Quiz

- Do you believe people living with schizophrenia can recover?
- How would you define recovery for someone living with schizophrenia?
- What have been your recovery experiences? What do you think needs to be in place for a person to recover?
- How can our system of care improve, and what can WE do about it?

Recovery in Evolution

Symptom remission/reduction

Skills expansion

Deficit focus

Strength-based

isolation

Social skills

Out of control

Episodic

Non-compliant

Non-adherent

Hopeless

Hopeful

MD control

**Consumer-empowered
partnership**

Professional support

Natural supports

Recovery does not equal Remission

- Remission: “a state in which patients have experienced improvements in core signs and symptoms to the extent that any remaining symptoms are of such low intensity that they no longer interfere significantly with behavior and are below the threshold typically utilized in justifying an initial diagnosis of schizophrenia.”

Andreasen et al. AJP, 2005, 162, 441-449.

Demographics of Recovery

- Older studies have demonstrated that over the 5-10 year period after the first psychiatric hospitalization 10-20% have a good outcome; 50% with a poor outcome
- Newer longitudinal studies have demonstrated a higher rate (>50%, range 20 – 70%) of “good outcomes” including: symptom reduction, improved psychosocial functioning, work, no psychiatric hospitalizations, normal functioning. Outcomes seem to be better in less-developed countries
- Key to recovery was access to continuous and reasonably comprehensive mental health services that are flexible, coordinated, competent, and consumer-oriented, those that are focused on cognitive and social skills training, and that address social determinants of mental health (poverty, housing, social supports, trauma, physical health).

Evolving Concepts of Recovery

- 2 year period with **functioning** in domains of reduced (not necessarily absent) symptomatology, participating in school or work, living independently and maintaining social relationships.
- Includes “**hope, optimism, destigmatization, empowerment, self-acceptance, insight, awareness, collaboration with professionals, connection, sense of autonomy and self-control**”
- Successfully **cope** with life’s challenges, and **build resilience**

SAMHSA

Evolving Concepts of Recovery

- Opportunity for a fulfilling life that includes a job, a home, and meaningful relationships with family and friends
- Choice: shared decision making
- “Recovery means regaining a purpose in life in order to return and resume control over one’s lives” (Deegan)
- Able to maintain wellness and responsibility for self-care

Recovery

- Wellness:

- Know what's needed to prevent symptoms from occurring
- Know how to keep symptoms from disturbing the overall sense of well-being
- Ability to get on with one's life
- Recognizing warning signs, exacerbation signs, crisis signs, and knowing what to do about each
- Having the confidence and responsibility to make the necessary decisions and take action

Mark Ragins

Recovery

- Hope
- Engagement
- Knowledge
- Wellness
- Function
- Choice

What's "Broken"?

- Neurotransmitters
- The concept of self and the concept of the disease process
- Survival skills; resilience
- Social skills (ADLS, engagement)
- Cognitive crispness (illness, substances)
- Vocational skills
- Our philosophy and our systems of care

What Complicates Recovery?

- Limited acceptance of illness/insight
- Co-occurring illness (substance use)
- Stigma
- Overwhelming side effects
- Delayed access to adequate care
- Uncaring/ignorant bureaucracies which put in place barriers to care
- Insufficient social supports
- Inadequately trained health professionals

Traditional Approaches to “Fixing Them”

- Limited outpatient care (brief med checks) focused on symptom reduction with medication
- Response with non-adherence, co-morbidities, relapses, re-hospitalization
- Few linkages to other resources
- Constraints of stigma
- Clinical trials (pharma)..how many of our patients have had their illness for 6-12 weeks?
- Effectiveness trials (Catie, TMAP)

Barriers Created by Traditional Approaches (what us docs do)

- Limit our ability to understand the lives of those living with...
- Limit our capacity to engage in partnerships
- Focus on symptom reduction, counter-transference re: adherence
- Stigma and paucity of resources inhibit improvement, focus on patient-hood not person-hood

What Enhances Recovery?

- Continuity of care in partnerships, shared decision making, hope
- Enhanced access (RAISE programs) Clinics for people with first-episode psychosis (FEP) to decrease duration of untreated psychosis (DUP)
- Enhanced treatment: Includes multi-disciplinary team, recovery-oriented service for those in FEP
 - Psychotherapy
 - Illness/wellness management; Coping skills
 - Low-dose medication
 - Family engagement and education
 - Supported employment and education
 - Case management

Transforming of Our Systems of Care

- Ask yourself:
 - Philosophical: Do you believe in recovery? How do you show that belief?
 - Clinical: Do you understand what your patients want? (“where do you want to be in 5 years, and how can we help you get there?”)
 - Ethical: How do you advocate for your patients? Are you a member of NAMI?
 - Practical: Can you help find resources?
 - Housing, psychiatric emergency services, social and vocational skills training, medical care

Final Words

- Providers and those living with mental illness should define recovery as more than symptom reduction
- People living with mental illness and providers should explore what recovery means to them
- Systems of care should support recovery in a wide variety of ways



References

- Deegan, P. The journey to use medication optimally to support recovery. *Psychiatric Services*. 79, 2020, 401-402.
- Ragins, Mark. *Journeys Beyond the Frontier: A Rebellious Guide to Psychosis and Other Extraordinary Experiences*. 2021 (on Amazon)
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<https://www.samhsa.gov/find-help/recovery>. August, 2020
- Torrey, WC, Drake, R. Practicing shared decision making in the outpatient psychiatric care of adults with severe mental illness: Redesigning care for the future. *Community Mental Health Journal*. 46, 2010, 433-440.