How do Some People with Schizophrenia Thrive?

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Presentation Outline

• Recovery Movement and Definitions

• Successful Community Adaptation Project
  – Background
  – Methods
  – Sample characteristics & psychiatric profile
  – Qualitative findings
  – Challenges & next steps
A recovery paradigm is still necessary
Recovery has been conceptualized as having objective (i.e. symptom and community functioning) and subjective (i.e. strengthening attitudes of hope, self-efficacy, empowerment, etc.) components.
Most believe those with schizophrenia don’t recover

- DSM-III’s conceptualization (1980):
  - “a complete return to premorbid levels of functioning in individuals diagnosed with schizophrenia is so rare as to cast doubt upon the accuracy of the diagnosis.”

- DSM-IV-TR’s conceptualization (2000):
  - “Complete remission (i.e., a return to full premorbid functioning) is probably not common in this disorder.”

- Clinician’s Illusion:
  - recovering patients are seen infrequently or not at all, causing the majority of a clinician’s caseload to be those with the most severe illnesses*

# Recovery: it’s possible

<table>
<thead>
<tr>
<th>Study</th>
<th>N</th>
<th>Yrs followed</th>
<th>% Recovered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bleuler (1974) Switzerland</td>
<td>208</td>
<td>23</td>
<td>53-68%</td>
</tr>
<tr>
<td>Hinterhuber (1973) Austria</td>
<td>157</td>
<td>30</td>
<td>75%</td>
</tr>
<tr>
<td>Ciompi &amp; Muller (1976) Switzerland</td>
<td>289</td>
<td>37</td>
<td>53%</td>
</tr>
<tr>
<td>Kreditor (1977) Lithuania</td>
<td>115</td>
<td>20</td>
<td>84%</td>
</tr>
<tr>
<td>Tsuang et al. (1979) Iowa</td>
<td>200</td>
<td>35</td>
<td>46%</td>
</tr>
<tr>
<td>Huber et al (1979) Germany</td>
<td>502</td>
<td>22</td>
<td>57%</td>
</tr>
<tr>
<td>Marinow (1986) Bulgaia</td>
<td>280</td>
<td>20</td>
<td>75%</td>
</tr>
<tr>
<td>Harding et al. (1987b,c) Vermont</td>
<td>269</td>
<td>32</td>
<td>62-68%</td>
</tr>
<tr>
<td>Ogawa et al (1987) Japan</td>
<td>140</td>
<td>22.5</td>
<td>56%</td>
</tr>
<tr>
<td>DeSisto et al (1995a) Maine (matched to Vermont)</td>
<td>269</td>
<td>35</td>
<td>49%</td>
</tr>
</tbody>
</table>
Operationalizing recovery*

- **Symptom remission**: $\leq 4$ on + & - Sx items on the BPRS for 2 yrs
- **Vocational functioning**: $\geq 2$ yrs of $\frac{1}{2}$ time competitive employment
- **Independent Living**: living on their own without supervision for major life tasks
- **Peer relationships**: social interaction $\geq$ once per week

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Recovery refers to the process in which people are able to live, work, learn, and participate fully in their communities. For some individuals, recovery is the ability to live a fulfilling and productive life despite a disability. For others, recovery implies the reduction or complete remission of symptoms. Science has shown that having hope plays an integral role in an individual’s recovery.
Consensus Conference on Mental Health Recovery (Dec ’04)

Mental health recovery is a journey of healing and transformation for a person with a mental health disability to be able to live a meaningful life in communities of his or her choice while striving to achieve full human potential or “personhood.” Recovery is a multi-faceted concept based on these 10 fundamental elements and guiding principles:

1. Self-Direction
2. Individualized and Person-Centered
3. Empowerment
4. Holistic
5. Non-Linear
6. Strengths-Based
7. Peer Support
8. Respect
9. Responsibility
10. Hope
Common recovery elements

• Hope
• Redefining self
• Incorporating illness
• Meaningful activities
• Overcome stigma
• Assuming control over illness

• Becoming empowered in life
• Managing symptoms
• Getting support from others

*Davidson et al 2005
Successful Community Adaptation Study Goals

- Understand the characteristics of individuals with schizophrenia who could be considered “high functioning” in terms of occupational status- objective recovery
- Understand the strategies that Successful Community Adaptation individuals use to negotiate their daily lives
Study Research Team

Stephen Marder, MD
Elyn Saks, JD
Amy N. Cohen, PhD
Alison Hamilton, PhD
Shirley Glynn, PhD
Doug Hollan, PhD
John Brekke, PhD

University of California, Los Angeles
VA Desert Pacific Mental Illness, Research, Education, and Clinical Center
University of Southern California
Project History

- Assembled multi-disciplinary team
- Submitted a rapid-cycle R03, did not get scored
  - Would not be able to find such high-functioning individuals
- Received funding from Larsen & Greenwall Foundations at USC
  - Recommended confirmation of diagnosis with SCID
Inclusion Criteria

– 21 years or older
– Diagnosis of schizophrenia, some active symptoms in past 6 months
– “High functioning” defined as employment in a professional, technical, or managerial occupation or high-level functionality as a stay-at-home caretaker or full-time student (http://www.occupationalinfo.org/cat_div1_0.html)
– Employed continuously for past 6 months
– Available for in-person interviews and consent to be audiotaped
Methods

- Diagnosis, Symptoms, Demographics
  - SCID (confirmation of Dx only)
  - PANSS (selected items)
  - BASIS-24
  - First 4 items from the Scale to Assess Unawareness of Mental Disorders (SUMD)
  - Brief background survey

- Person-Centered Interviews
Procedures

- Recruitment: flyers posted; word-of-mouth; calls to local psychiatrists; Elyn’s book tour
- Screen: by telephone
- Session 1: informed consent, SCID, PANSS
- Session 2: background survey, BASIS, person-centered interview part 1
- Session 3: person-centered interview part 2
- Participants are paid $100 per hour
- Analyzed with Altas II
21 individuals were enrolled;
Of the 27 who called but did not enroll:
  15 Not eligible b/c not did not meet successful community adaptation criteria (by study definition),
  4 were not eligible b/c of diagnosis (Bipolar I with psychotic features or Schizoaffective by subject's report),
  2 were not eligible b/c lived too far and did not have transportation,
  2 refused when they heard the methods,
  and 4 called initially, call was returned (multiple times), and they never called again.
Study Subjects

21 individuals with schizophrenia
  – avg age = 41.9 years old (range 25-67)
  – 11 female, 10 male
  – 8 Caucasian, 6 African-American, 4 Hispanic, 2 Asian, 1 Persian
  – 12 never married, 3 married, 1 living together unmarried, 4 divorced, 1 separated
  – 6 have children
### Highest Degree

<table>
<thead>
<tr>
<th>Degree</th>
<th>#</th>
<th>%</th>
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</thead>
<tbody>
<tr>
<td>HS Diploma</td>
<td>3</td>
<td>14.3</td>
</tr>
<tr>
<td>Some college or prof degree, not finished Diploma (BA, BS)</td>
<td>1</td>
<td>4.8</td>
</tr>
<tr>
<td>Master's degree</td>
<td>7</td>
<td>33.3</td>
</tr>
<tr>
<td>Doctoral Degree</td>
<td>5</td>
<td>23.8</td>
</tr>
</tbody>
</table>
PANSS items (past week)

<table>
<thead>
<tr>
<th>PANSS item</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delusions</td>
<td>3.2</td>
<td>1.6</td>
</tr>
<tr>
<td>Conceptual Disorganization</td>
<td>1.9</td>
<td>1.0</td>
</tr>
<tr>
<td>Hallucinatory Behavior</td>
<td>3.2</td>
<td>1.8</td>
</tr>
<tr>
<td>Blunted Affect</td>
<td>2.1</td>
<td>1.3</td>
</tr>
<tr>
<td>Passive/Apathetic Social Withdrawal</td>
<td>2.7</td>
<td>1.6</td>
</tr>
<tr>
<td>Lack of Spontaneous Conversation</td>
<td>1.6</td>
<td>0.9</td>
</tr>
<tr>
<td>Mannerisms</td>
<td>1.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Unusual Thought Content</td>
<td>2.1</td>
<td>1.3</td>
</tr>
</tbody>
</table>
# Illness and Hospitalization

<table>
<thead>
<tr>
<th></th>
<th>Average</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td># of years ill</td>
<td>20.2</td>
<td>13.2</td>
<td>1-43</td>
</tr>
<tr>
<td>Age at 1st psych symptom</td>
<td>19.5</td>
<td>7.7</td>
<td>5-35</td>
</tr>
<tr>
<td>Age at 1st psych med</td>
<td>22.7</td>
<td>7.5</td>
<td>4-35</td>
</tr>
<tr>
<td>Age at 1st psych hospitalization</td>
<td>23.8</td>
<td>7.0</td>
<td>13-40</td>
</tr>
<tr>
<td>Total # of hospitalizations</td>
<td>5.1</td>
<td>4.4</td>
<td>2-20</td>
</tr>
</tbody>
</table>

**NOTE:**

- 4 individuals have never been hospitalized
- 1 individual is not on any psych meds currently
**Ever had psychotherapy?**

<table>
<thead>
<tr>
<th></th>
<th>#</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>1</td>
<td>4.8</td>
</tr>
<tr>
<td>Yes, previously but not currently</td>
<td>7</td>
<td>33.3</td>
</tr>
<tr>
<td>Yes, currently</td>
<td>13</td>
<td>61.9</td>
</tr>
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</table>
Self-report of Coping (BASIS-R)

During the past week, how much difficulty did you have:
Managing your day to day life?

<table>
<thead>
<tr>
<th>Difficulty</th>
<th>#</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No difficulty</td>
<td>5</td>
<td>23.8</td>
</tr>
<tr>
<td>A little difficulty</td>
<td>10</td>
<td>47.6</td>
</tr>
<tr>
<td>Moderate difficulty</td>
<td>6</td>
<td>28.6</td>
</tr>
<tr>
<td>Quite a bit of difficulty</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Extreme difficulty</td>
<td>0</td>
<td>0.0</td>
</tr>
</tbody>
</table>
Self-report of Coping (BASIS-R)

During the past week, how much difficulty did you have: Coping with problems in your life?

<table>
<thead>
<tr>
<th>Difficulty</th>
<th>#</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No difficulty</td>
<td>7</td>
<td>33.3</td>
</tr>
<tr>
<td>A little difficulty</td>
<td>7</td>
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<td>28.6</td>
</tr>
<tr>
<td>Quite a bit of difficulty</td>
<td>1</td>
<td>4.8</td>
</tr>
<tr>
<td>Extreme difficulty</td>
<td>0</td>
<td>0.0</td>
</tr>
</tbody>
</table>
Qualitative findings:

Some common behavioral coping strategies

- Taking medications as prescribed
- Staying healthy: getting exercise, getting sufficient sleep, eating healthy foods

“I know this is kinda boring but I think it’s important to take the medication, avoid drugs and alcohol, and get a good night’s sleep.”

- Going to church or being engaged in spiritual activities
- Having pets and/or not living alone
- Controlling the amount of stimulation in the environment

“I have to kinda prep my environment around me to be able to be the way I am because I don’t like to go be alone in my bedroom when I’m symptomatic.”

- For some, being involved in the mental health recovery movement
Some common avoidances

- Illicit drugs and alcohol
- Traveling
- Crowded social situations
- Isolation
Attitude of perseverance

• Several participants talked about “pushing through” their illness, e.g., persevering through symptoms

• They often ascribed this perseverant attitude to their parents

“[Does your family ever talk about [your illness]?]?

My parents just kind of [say], “Move forward, move on”…It’s kind of how I was raised I guess. I think that’s kind of the mentality…of everyone, it’s just kind of like, “Keep going, keep at it”…

American Psychological Association
Vigilance about preventing manifestation or exacerbation of symptoms

I think there’s a lot of ways I try and maintain symptoms. Ultimately though, I think it’s out of my control...It’s just gonna happen, because at the same point of when I became psychotic, I couldn’t prevent myself from becoming psychotic...but, I feel like there’s some things that I do. [Like?] Well I guess it goes back to coping. Like, if I have a thought that somebody’s following me then I need to do two things immediately, even if I think they’re following me, I need to consider it’s a symptom, and tell somebody...

I think my fear stands out more, and kinda protects me more than anything else, ‘cause I’m so scared that I’m gonna get psychotic, that anything could set it off, or something like that. So I really am careful.
Vigilance about preventing manifestation or exacerbation of symptoms

Now symptoms get triggered in ways that I’m not really aware of. I think the most that I do is function with symptoms. I just function with symptoms and if they’re really strong, I have to slow down. I cancel [things at work] when I can cancel.

Recovery is identifying triggers and processing them and preventing a fuller blown experience of symptoms than you would have if you didn’t process and you weren’t aware. But when they’re strong, it has to do with depersonalizing, it has to do with the brain chemically being hard-wired physiologically or structurally…but I know what it feels like when I feel well.
Summary of findings to date

- Individuals with schizophrenia can develop strategies for functioning even with substantial symptom burden.
- Although some of these strategies may be idiosyncratic, they may be of use to other individuals who have been less successful in managing their symptoms.
- In-depth information from individuals who are high-functioning with schizophrenia can strengthen our understanding of what it means to “recover” from serious mental illness.
Challenges

- Defining “high functioning”
  - Occupation versus other characteristics
  - Feedback from subjects
- Finding individuals (though we were able to reach our target sample size of 20)
Next Steps

- Continuing to enroll subjects
- Analyzing & presenting data
- Considering more structured survey for sample of “mid to high functioning”
- Developing interventions based on coping behaviors and attitudes identified
Interventions should be based on an individual’s strengths and personal goals

“When I was examined for readmission to Yale Law School, the psychiatrist suggested I might spend a year working at a low-level job, perhaps in fast food, which would allow me to consolidate my gains so that I could do better when I was readmitted.”

Interventions should be based on an individual’s strengths and personal goals

“Yet for me, being a student was far less stressful than being a cashier would have been. I had learned to be a student before I became ill…My time was flexible. I could do the work without significant interaction with others (I need time to myself).”

“…a menial job would have been far more stressful.”

For more information:

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