What You need to Know about the Evidence Base for Mental Health Recovery

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What I hope to cover:

- Brief history of recovery movement
- Long-term outcome research on ‘clinical recovery’ (role of “clinician’s illusion”)
- Political reality, and nature, of ‘personal recovery’
- Evidence-based practices that are recovery-oriented
- Recovery-oriented practices that are becoming evidence-based
- Future research directions
“One cannot ignore a striking analogy in nature’s ways when one compares the attacks of intermittent insanity with the violent symptoms of an acute illness. It would in either case be a mistake to measure the gravity of the danger by the extent of trouble and derangement of the vital functions. In both cases a serious condition may forecast recovery, provided one practices prudent management” – Philippe Pinel in “Memoir on Madness: A contribution to the natural history of man” presented to the Society for Natural History, Paris, France, 1794
Pinel’s Insights into Recovery

First sentence of 1801 edition:

“Few subjects in medicine are so intimately connected with the history and philosophy of the human mind as insanity. There are still fewer, where there are so many errors to rectify, and so many prejudices to remove.”
What “errors” and “prejudices”? 

- Incomprehensibility 
- Total pervasiveness of the illness 
- Incurability
Pinel’s Corrections

• “To consider madness as a usually incurable illness is to assert a vague proposition that is constantly refuted by the most authentic facts.”

• “The idea of madness should by no means imply a total abolition of the mental faculties. On the contrary, the disorder usually attacks only one partial faculty such as the perception of ideas, judgment, reasoning, imagination, memory, or psychologic sensitivity… A total upheaval of the rational faculty … is quite rare.”
The Eclipsing of Recovery

1800

Philippe Pinel
Mental illness is an illness. It rarely takes over the entirety of the person, and recovery is not only possible, but likely.

1900

Emile Kraepelin
Schizophrenia is a progressive, degenerative disease, from which recovery is impossible.

England
People with mental illnesses are like wayward children, who need to be brought back to reason through moral discipline.
100 years of Institutionalization

- Incomprehensible person
- Pervasive illness
- Incurable condition
- Abuses and neglect ("snake pit")
The (more recent) Recovery Movement

Three primary sources:

- Institutionalization leading to Consumer/Survivor Movement
- Addiction Self-Help/12 Step Community
- Longitudinal Clinical Research beginning in the 1970s and consistently since (over 30 studies in over 30 countries for over 30 years; cf. Davidson L, Harding C, & Spaniol L, Recovery from severe mental illnesses: Research Evidence and Implications for Practice, 2005)
<table>
<thead>
<tr>
<th>Study</th>
<th>Sample Size</th>
<th>Average Length In Years</th>
<th>Subjects Recovered and/or Improved Significantly*</th>
</tr>
</thead>
<tbody>
<tr>
<td>M. Bleuler (1972 a and b) Burghölzli, Zurich</td>
<td>208</td>
<td>23</td>
<td>53%-68%</td>
</tr>
<tr>
<td>Huber et al. (1975) Germany</td>
<td>502</td>
<td>22</td>
<td>57%</td>
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<tr>
<td>Ciompi &amp; Müller (1976) Lausanne Investigations</td>
<td>289</td>
<td>37</td>
<td>53%</td>
</tr>
<tr>
<td>Tsuang et al. (1979) Iowa 500</td>
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<td>35</td>
<td>46%</td>
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<tr>
<td>Harding et al. (1987 a &amp; b) Vermont</td>
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<td>32</td>
<td>62-68%</td>
</tr>
<tr>
<td>Ogawa et al. (1987) Japan</td>
<td>140</td>
<td>22.5</td>
<td>57%</td>
</tr>
<tr>
<td>DeSisto et al. (1995 a &amp; b) Maine</td>
<td>269</td>
<td>35</td>
<td>49%</td>
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</table>

*For schizophrenia subsamples
# MORE STUDIES USING WIDER DIAGNOSTIC CRITERIA

<table>
<thead>
<tr>
<th>STUDY</th>
<th>Year &amp; Place</th>
<th># of Ss</th>
<th>Av. Years in length</th>
<th>% improvement or recovery</th>
</tr>
</thead>
<tbody>
<tr>
<td>HINTERHUBER</td>
<td>(1973 AUSTRIA)</td>
<td>157</td>
<td>30</td>
<td>75%</td>
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<tr>
<td>KREDITOR</td>
<td>(1977 LITHUANIA)</td>
<td>115</td>
<td>20.2</td>
<td>84%</td>
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<tr>
<td>MARINOW</td>
<td>(1986 BULGARIA)</td>
<td>280</td>
<td>20</td>
<td>75%</td>
</tr>
</tbody>
</table>
Longitudinal Clinical Research shows Broad Heterogeneity in Clinical Outcome

- Approximately 33% of individuals diagnosed with a serious mental illness will recover *from* the disorder fully over time.

- Approximately another 33% will experience significant improvements in their condition over time, with domains of functioning only “loosely linked” (Strauss & Carpenter, 1977).

- 10% will suicide and approximately 25% will continue to have a ‘chronic’ illness.
Implications for “Recovery”

- Many people with serious mental illnesses will recover *from* the disorder over time (but it may take years)

- Many other people will learn how to manage and lead a safe, dignified, and gratifying life *with* the disorder

- Learning how to live with the disorder is important when the illness will not go away and may contribute to it remitting
Two Different Forms of “Recovery” in relation to Serious Mental Illnesses

- Clinical, Symptomatic, or Functional Recovery (or remission)

- Human and Disability Rights, Independent Living Movement (self-determination)
How Recovery becomes a political force and possible for everyone

- A person can be “in recovery” regardless of the duration and severity of the disability.
- This is the right of every citizen.
- People do not have to wait to recover from the disorder in order to reclaim citizenship.
- Rather, reclaiming citizenship promotes recovery.
The right of **Social Inclusion**: People with mental illness are entitled to a life in the community *first*, as the foundation for recovery—not as its reward. For example,

It is very hard to recover if you don’t have a place to live (a home). Housing cannot be contingent on compliance or improvement in one’s condition ("**Housing First**" 80% success).
While work may, in fact, be stressful for some people with some mental illnesses some of the time …

Another Example

Being out of work and poor is sure to be stressful for most people with most mental illnesses most of the time (And working decreases symptoms)
While some people with some serious mental illnesses pose some risks some of the time . . .

most people with most mental illnesses—like most people in general—pose no risks most of the time

(and also make no worse decisions than anyone else)
What are the implications for practice?

• Persons with serious mental illnesses have the same right to evidence-based medicine as anyone else.

• Persons with on-going mental illnesses, like others with disabilities, have the right to environmental modifications and supports to optimize access to community life.
Recovery-oriented practice as evidence-based medicine

Evidence-based medicine is a combination of 1) the available scientific evidence with 2) the practitioner’s clinical experience and judgment and 3) the patient’s choice.

At its most basic level, the recovery movement argues that people with serious mental illnesses be offered evidence-based medicine just like everyone else. That, in most instances, they be treated in the same way that all other individuals are treated. In this case, that they have the same freedom to choose, and right to consent to or decline any given intervention that we might suggest.

This is because the recovery movement argues that people with serious mental illnesses have been, are, and remain people just like everyone else, with the same rights and responsibilities as everyone else—even that their crises should be managed like everyone else’s.
Another source of confusion

Evidence-based medicine is not the same as “evidence-based practices”

The term has been defined as the integration of at least three main elements: “best research evidence with clinical expertise and patient values” (Sackett, 2000).
An Important Confusion

Somewhere along the way, “evidence-based practice” (i.e., what doctors do) became confused with evidence-based practices (those interventions which have been shown to be effective).

This had led some to suggest broad-scale and indiscriminate adoption of evidence-based practices for everyone with a select condition (regardless of the other evidence and other relevant factors, including patient choice).
Response to Criticism

According to Sackett, *BMJ* 1996;312:71-72: “Evidence based medicine is not ‘cookbook’ medicine. Because it requires a bottom up approach that integrates the best external evidence with individual clinical expertise and patients' choice, it cannot result in slavish, cookbook approaches to individual patient care.”
Add to this local circumstances, as Bob Drake writes:

“Evidence-based medicine assumes that scientific evidence is only one important component of decision-making. A second involves including the patient’s values, goals, preferences, and participation in shared decision-making. A third is the sum of local circumstances: the availability of hospitals, specialists, programs, insurance, supports, and other resources that affect health care decisions. All of these must be considered to make optimal decisions.

Patient preferences, local conditions, or societal decisions about resources often override the scientific evidence, especially in situations where the evidence is weak. Consider a few brief examples. One patient understands the evidence that surgery for an aneurysm is the most effective treatment but decides to decline surgery (as Albert Einstein did). Unless competence to make the decision is at issue, the patient’s preference always overrides the scientific evidence…”
One last clarification: Principles of Recovery-Oriented Practice

- “Recovery” is the responsibility of the individual with the mental illness, it is not something we can do to or for him or her.

- We can offer recovery-oriented care, which assists the person to live the best and fullest life he or she can given his or her illness and life circumstances.

- People “in recovery” will be key partners in developing new knowledge and practices to promote this kind of care. (expertise by experience)
Interventions we can offer that are evidence-based as long as they are offered collaboratively

- Medication (with specific behavioral targets)
- Cognitive behavioral psychotherapy
- In vivo community supports (supported housing, supported employment, supported education, and other supported activities, e.g., parenting) through ACT or other means
Recovery-oriented interventions that are accumulating an evidence base

- Peer support in a variety of forms (e.g., recovery mentoring, recovery coaching, peer specialists, peer bridgers, health navigators)
- Person-centered care or recovery planning
- Wellness Action Recovery Planning (WRAP)
- Pathways to Recovery (self-help)
- Whole Health Action Management (WHAM)
Peer Support

has been found to:

• reduce readmissions by 42%
• reduce days in hospital by 48%
• Improve relationship with providers
• increase engagement with care
• decrease substance use
• decrease depression
• Increase hopefulness
• increase activation and self-care
• increase sense of well-being

Recent review by Chinman et al in psych services
WRAP and WHAM

- WRAP was found to significantly decrease symptoms and increase hopefulness, enhance quality of life, and lead people to be more likely to engage in self-advocacy with their service providers.

- WHAM was associated with significantly greater increases in patient activation and engagement in primary care.
Culturally-Responsive Person-Centered Care for Psychosis
(NIMH #R01-MH067687)

Demographics:

278 participants
  143 Hispanic origin
  135 African origin

Mean age 44
Average education level 11 years
15% employed
57% male (n = 88)
43% female (n = 46)

Conditions

IMR = 84
IMR & Peer Advocate = 94
IMR & Peer Advocate & Connector = 100
6-Month Process and Outcome Data

Peer-Run Community Integration Program
- ↓ Psychotic Symptoms but ↑ Distress from Symptoms
- ↑ Satisfaction with Family Life, Positive Feelings about Self & Life, Sense of Belonging, & Social Support
- ↑ Engagement in Managing Illness & Use of Humor as Coping Strategy

Peer-Facilitated Person-Centered Care Planning
- ↑ Sense of Responsiveness & Inclusion of Non-Treatment Issues in Care Planning
- ↓ in Spiritual Coping
- ↑ Sense of Control in Life & Power of Anger to Impact Change
- ↓ Satisfaction with Work Status

Illness Management & Recovery
- ↓ Paranoid Ideation & Medical Problems
- ↑ Social Affiliation & Satisfaction with Finances
- ↑ Coping & Sense of Participation
- ↓ Sense of Activism

Medication, Monitoring & Case Management

Psychosis
African and/or Hispanic Origin
Poverty
The central shift that creates recovery-oriented practices

- From treatment/service/care plan (primarily for practitioners) to culturally-responsive, person-centered, individualized recovery plan (primarily for person, subsuming treatment as one set of recovery/resiliency tools)

- From focusing on deficit/dysfunction/problem to identifying and building on internal and external strengths and resources to accomplish personally meaningful and desired goals
Shifts that create Recovery-Oriented Research

- Include persons in recovery in all phases and aspects of the research/evaluation process; value lived experience and the perspective it brings to the research/evaluation enterprise.

- Consider recovery to refer to both a clinical outcome and an ongoing personal process; be clear about which meaning of recovery is focal at any given time.

- Use measures, questions, and tools that have been informed by lived experience with mental illness and recovery.

- Focus on strengths and social roles as well as impairments and needs, and considers person in environment as well as his or her ‘functioning’ (i.e., person-environment fit).

- Assess services and supports in terms of the degree to which they support people in living the lives of their choice.
Some Potential Directions for Future R & D

- Decision support, supported decision-making
- Supported parenting and other supported pursuits (spirituality, recreation/leisure)
- Employment supports that are not as individual-based (e.g., social cooperatives)
- Alternatives to hospitalization (e.g., respite)
- Targeted and time-limited use of medications
Discussion