Lessons We Have Learned From Longitudinal Research About What Promotes Recovery From Psychosis

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Disclosure:
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Foundation for Excellence in Mental Health Care
BUT FIRST .....
Lessons Learned from Ancient Greek Sculptures at Harvard’s old Sackler Museum
Statue from the frieze of the Parthenon in Greece
We thought we knew all about them ....
Investigations with ultraviolet, polarized & raking lights, X-ray fluorescence, defraction analysis and infrared spectroscopy

THE NEW VIEW OF WHAT THESE STATUES REALLY LOOKED LIKE
These investigators found the real people in these statues
Psychiatry has been searching for “real illness” by studying genes and now epigenetics, neurotransmitters and neurochemical imbalance, PET Scans, MRI, fMRI, neuropsych testing, as well as publishing bigger diagnostic manuals and producing more pharmaceuticals
The assumptions about people diagnosed with schizophrenia...

- Continue to have episodes of illness
- Achieve only marginal levels of function or go downhill
- Difficulty interacting with others
- Under-educated
- Impoverished & need SSI or SSDI supports
- Trouble using prescriptions
- Susceptible to using drugs and alcohol
- Commit crimes
- Can’t make use of psychotherapy
- Can’t hold a job
- Don’t have community keeping behaviors
For 100+ years, everyone has thought that people with schizophrenia could not improve much nor possibly recover.
We thought we knew ...
but 11 two and three decade studies reported in the last quarter of the 20th century and the beginning of this one, evidence-based practices, practice-based evidence & recovered people have challenged almost everything we thought we knew
Now for a large body of evidence mostly ignored for 60 years

A Brief Overview of the 11 Very Long-term Contemporary Studies of Schizophrenia
<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>
</tr>
<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>
<td>186</td>
<td>35</td>
<td>46%</td>
</tr>
<tr>
<td>Harding et al. (1987 a &amp; b) 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>57%</td>
</tr>
<tr>
<td>DeSisto et al. (1995 a &amp; b) Maine</td>
<td>269</td>
<td>35</td>
<td>49%</td>
</tr>
</tbody>
</table>

*For schizophrenia subsamples
The Chicago Study

- STUDY # Av. Years % recovered. or
Yr. & Place Ss in length improved

M. Harrow 139 20 yrs. 76%*

- 2013
- University of Illinois
- * Figured derived from those with Scz off meds only group
MORE STUDIES BUT USING WIDER DIAGNOSTIC CRITERIA

<table>
<thead>
<tr>
<th>Study</th>
<th># of Ss</th>
<th>Av. Years</th>
<th>% recov/improved</th>
</tr>
</thead>
<tbody>
<tr>
<td>HINTERHUBER</td>
<td>157</td>
<td>30</td>
<td>74.8 %</td>
</tr>
<tr>
<td>1973 AUSTRIA</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>KREDITOR</td>
<td>115</td>
<td>20.2</td>
<td>84 %</td>
</tr>
<tr>
<td>1977 LITHUANIA</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MARINOW</td>
<td>280</td>
<td>20</td>
<td>75 %</td>
</tr>
<tr>
<td>1986 BULGARIA</td>
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</tbody>
</table>
So.... what have we learned so far getting a few signals out of the noise?
The Major Finding of the Eleven Contemporary Long-term Studies

- Almost half to two thirds of every sample with serious psychiatric disorders such as schizophrenia have significantly improved or recovered when studied as intact groups across 2-3 decades of follow along studies.
More on #1 Finding

• Even higher percentage for Affective Disorders

• Not talking about “just remission” or a “cure”

• Perhaps thinking about the natural healing capacities in people building on neuroplasticity
WHAT ELSE HAVE ALL THESE STUDIES TAUGHT US?

• #2) DIAGNOSIS AND TIME
  • Only a cross-sectional “working hypothesis”
  • Probably does not really qualify as a lifetime label for most people
  • Unable to predict outcome
  • (e.g. Harding, 1987; Insel, 2013)
Tom Insel, the Director of the NIMH, wrote on Oct. 2012

• **On diagnosis:**

  "Terms like 'depression' or 'schizophrenia' or 'autism' have achieved a reality that far outstrips their scientific value. Each refers to a cluster of symptoms, similar to 'fever' or 'headache.' ...**What is missing is validity**.....the field has imbued these symptom clusters with biological meaning .. in the absence of biomarkers or diagnostic tests."
#3) About SYMPTOM COURSE

• Ever widening heterogeneity with early fluctuations and later decrease of virulence for most but not all people.

• (e.g. Bleuler, 1972; Huber et al 1975; Ciompi & Müller, 1976; Harding et al, 1987)
4) PREDICTORS OF LONG-TERM OUTCOME

• **ALL CLASSIC ONES WEAKEN OVER TIME** (e.g. type of onset, age of onset, even gender).

• Being stronger before a problem seems to help for many but not all

• Since we can’t predict who will become completely well, who will be almost well, and who will not, we must treat everyone as if they will be well ... optimizes the chances

  • (e.g. Carpenter & Strauss, 1972; Vaillant, 1975 &
    • DSM 5, 2013)
Social functioning and schizophrenia literature is replete with descriptions of poor premorbid adjustment, deterioration, isolation, estrangement, bizarre behavior and speech blunted affect - all of which increase social isolation. BUT....

5) SOCIAL FUNCTIONING CAN AND DOES RECONSTITUTE AND DEVELOP FURTHER FOR 46 TO 77% OF PEOPLE (e.g. Harding and Keller, 1998)
6) BEING ABLE TO WORK

Not predicted by s/s or diagnosis or hospitalization

Need opportunities (assessment, training, placement in a job-person match, & continued work supports)

Helping people to finish education can lead to careers

(see Anthony et al, 2002)
7) PSYCHOPHARMACOLOGY NOT NECESSARILY LIFELONG

• May be helpful for some in the short haul but actually may make outcome poorer over the long haul for many people

• (e.g. Harding et al, 1987; Harrow et al, 2013, Healy, 2008; Insel, 2013; Whittaker, 2010, Wunderink, 2013)
“Recently, results from several studies have suggested that these medications may be less effective for outcomes that matter most to people with serious mental illness: a full return to well-being and a productive place in society.”

- Tom Insel, Director, Aug. 28th, 2013
Perhaps, now we need to expand the biological perspective and look further into the richness developed in other areas of investigation to find the "real person" underneath the problems.
“Stated simply, the regulation of gene expression by social factors makes all bodily functions, including all functions of the brain, susceptible to social influences”.

Eric Kandel, 1998
Another Preeminent Neuroscientist, Nancy Andreasen

- First wrote the book “The Broken Brain” in 1984
- Underwrote more pessimism and a focus on brain science
- Later changed her mind about neuroplasticity in 2001 in “The Brave New Brain”
The essence of psychotherapy [and rehabilitation and self-help] is to help people make changes in their feelings, thoughts and behavior. This appears to occur through a multiplicity of ...techniques...

N. Andreasen, 2001 p.31
THE BRAIN IN INTERACTION WITH THE MIND

• .. which can lead to changes in a plastic brain which learns new ways to respond and adapt that are then translated into changes in how a person feels, thinks, and behaves. It, in its own way, is [or they, in their own ways, are] as biological as the use of drugs.”

• N. Andreasen, 2001 p.31
The Secrets of Rehabilitation

- Starts on Day 1 focuses on feeling safe and accepted
- Does not wait until the symptoms subside
- Builds on strengths not psychopathology
- Does not need insight except remembering old dreams to reclaim
- Targets environmental re-engineering as well
Secrets of Rehabilitation #2

- The model of rehabilitation, self-sufficiency, and community integration worked in combination to help achieve the best results for 68% of the most seriously impaired people in Vermont State Hospital.
- Focuses first on a home, a job, friends, and a date for Saturday night.
By 2008

• All 50 States declared recovery missions and visions
• Canada
• 11 European Countries
• Australia and New Zealand
• 9 Asian Countries including China
The Dilemma

• The mission/vision from the 11 Long-term studies and active peer groups has spread around the globe
• Pockets of Excellence have endured
• BUT the generalized “on the ground” implementation has not yet occurred
• As many as 178 Evidence-based & Practice-based Evidence Approaches have evolved but rarely implemented as a whole menu from which to select
We want to keep finding and understanding the real person underneath the dysfunction, the disability, and the despair to help them get their life back!
Thank you for the opportunity for this Yalie to come home