Helping People with Schizophrenia

- The Medical Model vs. a Rehabilitation Model
- Non-Pharmacological Approaches
- Applications to the Here & Now

Greg Jurenec, Ph.D.
Associate Professor of Clinical psychology
Wisconsin School of Professional Psychology

Today's Game Plan

- What Schizophrenia is and is not, and the spectrum of schizophrenia
- A little about Etiology
- The medical model: assumptions and implications
- A rehabilitation model
- Non-Pharmacological models:
  - Soteria
  - Open Dialogue
- Applications

But 1st...How I got here....

- Grad School
- MHC.....then and now
- Robert Whitaker – Anatomy of an Epidemic
- Doctoral Students
  - Melinda Somogyi, Psy.D.
  - Amanda Dowling, M.A.
  - Emily Jirikowic, M.A.

What Schizophrenia is....

- Schizophrenia is a Brain Disorder, which generally affects functions of:
  - Thinking
  - Feeling
  - Perceiving
- Affects around 1% of the population, world wide
- Starts in teens to early 20s**
- As of today, it cannot be cured, but often can be effectively managed.
- The picture varies enormously in regard to:
  - Symptom expression
  - Severity
  - Outcomes (will discuss this more later)

What Schizophrenia is not...

- “Split Personality”
- A response to trauma or stress
- “Burned out on drugs”
  - Is exacerbated by marijuana and cocaine
  - Exception: Methamphetamine seems to be quite capable of causing unremitting psychosis.
- A result of bad parenting
The Spectrum as a Continuum (per DSM-V)

- Paranoid, Schizoid, Schizotypal Personality Disorders
- Brief Psychotic Episode
- Delusional Disorder
- Schizophreniform Disorder
- Schizophrenias

Clusters of Symptoms

- Feeling:
  - Blunted, flat, unemotional
  - OR, “affect” is “inappropriate” to the situation
  - Can be easily overwhelmed by emotions

- Thinking:
  - Concrete: The “chickens” story.
  - Loose associations: make connections to irrelevant aspects. Example with “Proverbs”
  - Tangential: Can’t stay on topic
  - “Neologisms” (“brush on plaque”)
  - Slowed, impaired information processing

- Perceiving:
  - Hallucinations
  - Delusions

- NOTE: Everyone does not have all of the symptoms.

Information Processing

- Frontal Lobe Activation
- Attention/Concentration
- Difficulty screening out irrelevant stimuli
- Stimulus Overload
  - Equipotentiality of all stimuli
  - Emotions as stimuli
  - Expressed Emotion

Schizophrenia has a Profound Effect

- The condition has a profound effect on a person’s psychosocial world:
  - Consider what is happening in life when it begins
  - Effects on education, employment and SES
  - Social Stigma

- Persons with a diagnosis of schizophrenia can expect a life expectancy of 15 years less than the non-ill population.
- Lifetime Risk of suicide = about 5.6%

Some Videos to Watch

- John Nash
  - https://www.youtube.com/watch?v=5ZkInO0b0J8&list=PL83EB4759EDD816F
  - http://www.youtube.com/watch?v=BUO0kQ5wvJ1s&list=PLF39AFFCD95C4CD17D
- A Beautiful Mind
- The Soloist (but, the book is far better)

The Brain and Biology

- Structural Findings
- Neurotransmitters
- Genetics
- Environmental Factors
Biological Evidence

Genetic
- 1% incidence in general population
- 48% if identical twin has schizophrenia
- 46% if both parents have schizophrenia
- 16% if one parent has schizophrenia
- 9% if one sibling has schizophrenia
- 6% if a half sibling has schizophrenia
- 2% if an uncle or aunt has schizophrenia

Structural Brain Imaging Findings
- Progressive loss of brain tissue
- Begins in adolescence, and continues progressively
- Majority of loss is in the frontal and temporal areas
- Larger amounts of loss associated with:
  - Poor outcome
  - Negative Symptoms
- Does not relate to the history of medication dosing
- Similar pattern seen in healthy full siblings

More Biological Evidence

Functional Imaging Studies
- Routinely find differences in patterns of cortical activation
  - Using glucose metabolism
  - Measures of blood flow
- Failure of frontal lobes to “activate” with onset of a task.
- Andreasen (2008) found reduced blood flow to anterior cingulate gyrus and posterior hippocampus on a social reasoning task.

The Effect of Antipsychotic Medications
- Produces a reduction of positive symptoms in at least 80%
- Potency related to the effectiveness in blocking specific dopamine receptors
- New drug being tested targets glutamate

However...none of these alone is diagnostic

Traditional Picture of Course
- RELAPSE:
- 80% of treated patients relapse at least once within 5 years of the initial episode.
- 12.2% = One episode only, no further impairment
- 14.6% = Several episodes, with minimal impairment
- 17.1% = Some continuing impairment after the 1st episode, with some additional episodes.
- 33% = Repeated episodes with increasing impairment & negative symptoms.
- 11% = Symptoms and impairment persist after the 1st episode without significant remission.

The Medical Model of Treatment: Assumptions
- Schizophrenia is a physical sickness, a physical state which is improper, and needs to be medically corrected.
- If this underlying medical/physical condition can be corrected, the person will be “well”.
- Social factors are seen as peripheral

The Standard of Care in the US
- Follows from this Medical or Disease Model
- The primary focus of intervention is the use of antipsychotic medication to correct the impaired physical state
- Therefore, the key to a good outcome is medication compliance
- Social support, therapy, education, vocational experience are usually secondary.
- The take away message is that you have a chronic illness.

Implications of the “take away message”
- I’m sick, and I’ll have “this” for the rest of my life.
- I won’t be able to go to school, pursue a career, etc.
- My goals will be out of my reach.

WHO WOULD WANT TO ACCEPT THIS MESSAGE?
What happens when a young person is diagnosed with schizophrenia?

- Family/caregivers frightened
- Seek medical care: Labeled as "sick"
- Lowered expectations
- Subjective experience:
  - Their experience is a function of this "sickness"
  - Isn’t real, "...all in your head."
- Medical Care
- Social alienation begins

Implications for a person experiencing schizophrenia

- Invalidation of their experience, which is seen as just a symptom of a sickness
- Withdrawal and social isolation
- Development of an unhelpful personal understanding/interpretation of their experience.
- “Squashed goals”
- Adversarial relationships with:
  - Providers
  - Family

Why Not Take Meds?

- 75% of patients discontinue their medication within 18 months. Why??
- Unwilling to accept that they have the disorder
- Symptoms are seen as positive, and so do not want them treated:
  - Talking to God is a good thing
  - The voices are funny, are my friends, they keep me company
- Expectation meds won’t work:
  - “How can a pill stop the devil?”
  - “How can pills do anything about the corporate conspiracy that’s ruining my life?”
- 2nd hand experience with relatives, etc.
- Negative Expectations:
  - The “drooling zombie” image
  - “I don’t want to be controlled by drugs”
  - “I don’t want to be dependent on drugs”

More reasons patients don’t take meds...

- Perception that the medication does not help
  - They do not see the changes others see
  - They may not see that the symptoms were a problem, so their absence is not a benefit.
- A realistic cost-benefit appraisal, including experience and concern about side effects.

What we DON’T hear about…

- In fact, many people get better with little or no medication use.
  - Vermont Studies
  - Rappaport
- WHO has reported outcomes for people with schizophrenia in non-industrialized countries are better than those in the US and the UK.
- “Clinician’s Illusion”

Has Modern Treatment Helped?

Global recovery rates, based on a meta-analysis of 320 studies across a span of 100 years. From Mueser & Jeste, 2011 (p. 100)

<table>
<thead>
<tr>
<th>Year</th>
<th>Recovery Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>1895-1955</td>
<td>35%</td>
</tr>
<tr>
<td>1956-1985</td>
<td>49%</td>
</tr>
<tr>
<td>1986-1992</td>
<td>36%</td>
</tr>
</tbody>
</table>
Vermont Longitudinal Study
(Harding et al., 1987)
- 269 persons Dx with schizophrenia in mid 1950’s (using DSM-I)
  • Chronically ill for an average of 16 years, disabled 10 years
  • Had received phenothiazines for about 2½ years
  • These people were retrospectively re-diagnosed with DSM-III criteria using hospital records:
    - 118 retained as meeting DSM-III criteria.
    - Of these, 82 could be located and were interviewed 20-25 years after the index hospitalization.

Vermont Longitudinal Study: Findings at Follow-Up
- 68% had no signs of schizophrenia
- 45% showed no psychiatric symptoms at all
- 23% shifted to a probable affective or organic disorder
- Medication Use:
  - 84% were prescribed psych medications
  - 25% reliably took the medications
  - 25% self-medicated only when having symptoms
  - 50% were functionally medication free
  - 34% did not take the prescribed medications
  - 16% not prescribed any medication

Harrow & Jobe, 2007
Chicago Follow-Up study
- 64 patients Dx schizophrenia on DSM-III from Illinois public and state hospitals, and 81 non-schizophrenic patients.
- FU at average of 2, 4.5, 7.5, 10 and 15 years.
  - 76% interviewed at all 5 FU points
  - Another 16% at 4 of the 5 points
- Looked at:
  - Med Use
  - Symptoms
  - Employment and social adjustment

Long Term Outcomes (Torrey, 1986)
10 Years After 1st Professional Contact
<table>
<thead>
<tr>
<th>%</th>
<th>25%</th>
<th>25%</th>
<th>25%</th>
<th>15%</th>
<th>10%</th>
</tr>
</thead>
<tbody>
<tr>
<td>%</td>
<td>Completely recovered</td>
<td>Much improved</td>
<td>Relatively independent</td>
<td>Improved, but requires extensive support</td>
<td>Hospitalized, unimproved</td>
</tr>
</tbody>
</table>

30 Years After 1st Professional Contact
<table>
<thead>
<tr>
<th>%</th>
<th>25%</th>
<th>25%</th>
<th>25%</th>
<th>15%</th>
<th>10%</th>
</tr>
</thead>
<tbody>
<tr>
<td>%</td>
<td>Completely recovered</td>
<td>Much improved</td>
<td>Relatively independent</td>
<td>Improved, but requires extensive support</td>
<td>Hospitalized, unimproved</td>
</tr>
</tbody>
</table>

Some conclusions
- The course of schizophrenia is not necessarily as dismal as it is portrayed.
  - Even by Torey’s standards, 60% are ultimately “completely recovered” or “relatively independent.”
  - Vermont Study suggests almost 70%
- Many succeed with little or no medication, even without specialized help
An Alternative: A “Rehabilitation Model”

Analogy to a stroke
- It is a physical condition that produces mental (and sometimes physical) changes
  - Speech
  - Memory
  - Motor & Sensory function
- Treatment Strategy?

Things that are DONE
- Provide hope
- Practice and develop lost skills
- Compensatory strategies
- Engage family
- Begin treatment immediately

Things that are NOT DONE
- Invalidate experience
- Sedate with medication
- Isolate from social network
- Wait to treat until the person is forced to engage.

Alternative Treatments
Let’s think OUTSIDE the box

“Never, never, think outside the box!!”

Non-Pharmacological Approaches to Treatment

Soteria House & Emanon House
- Locations:
  - San Francisco, 1971-1976
  - Emanon House 1976-1982
  - Soteria House-Alaska (2008)
  - Soteria, Berne, Switzerland
- Purpose: To provide a choice/alternative to the standard treatment which relied on antipsychotic medication.

Description of Soteria & Emanon House
- Community setting in the San Francisco Bay area
- Homelike setting for 6-8 individuals. Quiet, supportive, protective, tolerant social environment.
- 24-hour day application of interpersonal phenomenologic interventions performed by nonprofessional staff
- No neuroleptics for at least 6 weeks.
- Nonintrusive, noncontrolling, empathetic
- Being with the person
- Staff to develop a shared experience with the patient.
- Goal is to share, understand, and communicate these disorganized states of psychosis and their relationship with the life events which precipitated these mental states.
- Self-Determination

Soteria Principles
- No medication without agreement
- Used non-medical staff, without preconceptions about the treatment of psychosis.
- Key components
  - Acceptance, understanding, and validation of the experience.
  - Soteria as a mutually supporting community or social network. Members stay in touch & involved after discharge
  - Self-Determination
The NIMH Funded Study

- Young, unmarried, 1st or 2nd episode.
- Care at Soteria House compared to “treatment as usual”: hospitalization, medication, outpatient
- Individuals presenting for admission at the local hospital who met criteria were randomly assigned to either Soteria or the CMHS.

Outcomes

6 Weeks
Both groups showed significant improvement in symptoms
But, those at Soteria received little or no meds.
Average LOS about 6 weeks at Soteria compared 30 days at CMHS

2 Years: Soteria patients:
- Similar levels of symptoms
- Had a lower frequency of rehospitalization. (Even though only 10% of the Soteria patients received any medication.)
- More often living independently
- Higher levels of occupational functioning

Conclusions from Soteria

- People treated psychosocially had no worse symptoms at 6 weeks and 2 year follow-up than those treated with meds.
- However:
  - They FUNCTIONED better in the community.
  - And so, had fewer relapses
  - Typical LOS was much longer

Open Dialogue

- Developed in Finland, beginning in 1980s.
- In response to a national mandate to develop alternatives to hospitalization.
- Influenced by principles of systems and communications theories (such as family therapy).
- Replicated in Sweden, Latvia, Lithuania, Norway

Key Components

- Early Identification, and rapid response (within 24 hours)
- Delivery of care primarily in the community, typically the person’s home
- All staff meet with client, family members, relevant social network (friends, neighbors, teachers, employers)
- No separate meetings for clinicians
- Medication use is NOT “Plan A”

Treatment Team – Family Meetings

- Multidisciplinary, all trained in family therapy.
- All discussions and decisions are made within these meetings
- Eliminates disease model:
  - No hierarchy – no one person is viewed as being more important.
  - Subject not viewed as sick, but as someone to be understood.
- Generates dialogue that leads to a common understanding, which becomes the basis of care.
- The purpose is not to eradicate symptoms but, rather, to take a understand and find meaning to them.
Goals and Principles:
- Living through the crisis together
- As clients are supported and gain a stronger voice, this leads to empowerment and meaningful participation in decision making and goals regarding their lives.
- Recovery from psychosis occurs between people, resulting in much less reliance on meds and hospitalization.

Open Dialogue: Outcomes
Seikkula, et al., 2006
- Five-year Study:
  - 83% of patients returned to jobs or school or were looking for a job
  - 77% patient did not exhibit residual symptoms
  - This surpassed outcomes for those who received conventional treatment (hospitalization, medication, and outpatient follow-up).
- Regarding the catchment area:
  - 50% decrease in need for inpatient treatment
  - 40-60% decrease in patients with psychotic symptoms
- Claim: There is no longer any chronic mental illness in the catchment area.

Applications of Open Dialogue in the US
- Burlington, Vermont (scheduled to open this year)
- Institute of Dialogic Practice: Training institute for Open Dialogue
- Parachute, NYC: Pilot project to provide in-home care as an alternative to hospitalization in New York City.

Soteria & Open Dialogue: Common Elements
- Conceptualization of schizophrenia as a valid experience to be shared and understood, rather than an illness to be fixed.
- Maintain or develop the person’s engagement in their social network.
- Empowerment
- Emphasis on adaptive functioning
- Early Identification
- Subordination of psychotropic medication in the program of care

Take Away Concepts We Can Apply Now
- It’s all about the relationship:
  - Listening
  - Understanding
- Finding some adaptive meaning to the experience:
  - Most delusions DO mean something
- Purpose, Meaning, and interpersonal connection are key factors (A Beautiful Mind)
- It’s really about functioning NOT “symptoms”

Examples/Illustrations
- Social isolation due to stigma and fear lead to maladaptive interpretations of symptoms.
- Working with delusions:
  - Grandiose: Compensatory: Richard, Michael (& father), Phil
  - Persecutory: Grains of truth
  - Religious: Father was a evangelical minister
  - Go with the delusion: “Brush on plaque”
Role Models: Patricia Deegan, Ph.D.

- Who she is.
  - YouTube video: [http://www.youtube.com/watch?v=OVYOfuKdJ YE&feature=BFa&list=PL3EB470E0D881D5F](http://www.youtube.com/watch?v=OVYOfuKdJ YE&feature=BFa&list=PL3EB470E0D881D5F)
  - She also has a YouTube channel devoted to Recovery. [http://www.youtube.com/user/patdeegan?feature=results_main](http://www.youtube.com/user/patdeegan?feature=results_main)