

Wisconsin Public Psychiatry Network Teleconference (WPPNT)

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## HELPING PEOPLE WITH SCHIZOPHRENIA

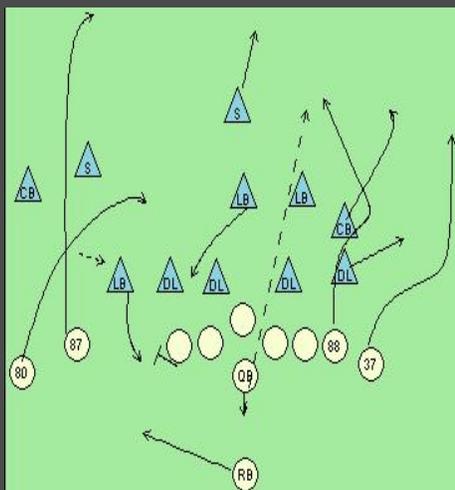
- ❖ The Medical Model vs. a Rehabilitation Model
- ❖ Non-Pharmacological Approaches
- ❖ Applications to the Here & Now

**Greg Jurenc, Ph.D.**

**Associate Professor of Clinical psychology  
Wisconsin School of Professional Psychology**

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## 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

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## *But 1<sup>st</sup> ...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.

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## 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)

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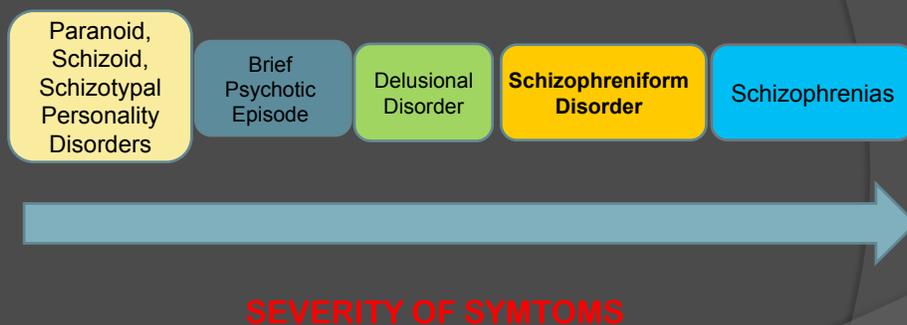
## What Schizophrenia is

### **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

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## The Spectrum as a Continuum (per DSM-V)



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## 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.

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## 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=SizS1nOOeJg&list=PL83EB4759EDD815F1>
- <http://www.youtube.com/watch?v=0UOOKS6vJ1s&list=PLF9AFFCD95C4CD17D>

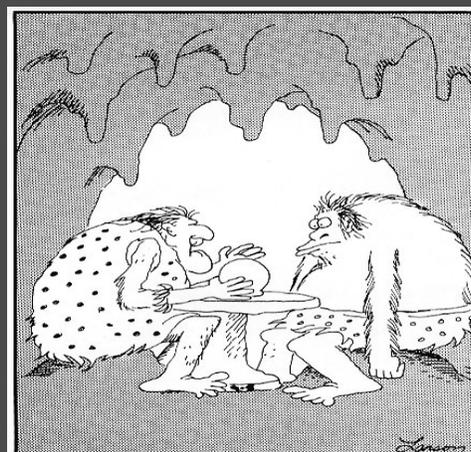
- A Beautiful Mind

- The Soloist (but, the book is far better)

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## The Brain and Biology

Structural Findings  
Neurotransmitters  
Genetics  
Environmental Factors



"I see your little, petrified skull ...  
labeled and resting on a shelf somewhere."

## 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 1<sup>st</sup> episode, with some additional episodes.
- ⦿ 33 % = Repeated episodes with increasing impairment & negative symptoms.
- ⦿ 11 % = Symptoms and impairment persist after the 1<sup>st</sup> episode without significant remission.

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## 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

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## 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*.

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## 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?**

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## 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

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## 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

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## 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?"
  - 2<sup>nd</sup> 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"

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## 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.

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## 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”

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## 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)**

1895-1955	1956-1985	1986-1992
35%	49%	36%

## 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 2 ½ 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

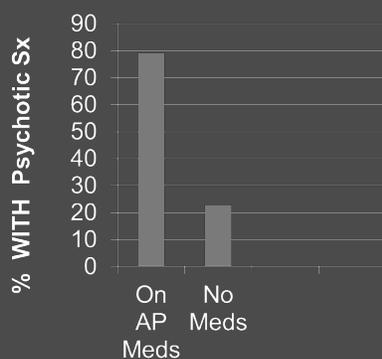
- **68% had no signs of schizophrenia**
- **45% showed no psychiatric symptoms at all**
- 23% shifted to a probable affective or organic disorder
- **Medication Use:**
  - 84% were prescribed psych medications
  - 25% reliably took the medications
  - 25% self-medicated only when having symptoms
  -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

## Harrow & Jobe, 2007

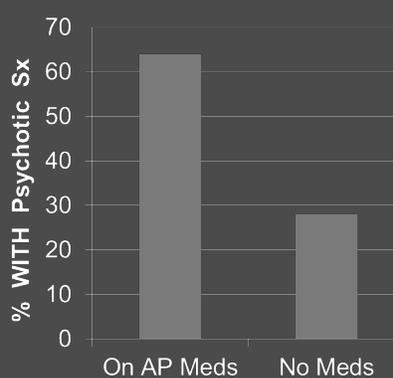
### Chicago Follow-Up study

- 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

## Psychotic Sx at 10 & 15 Year Follow Up (Harrow & Jobe, 2007)



10 Year Follow-Up



15 Year Follow-Up

## Long Term Outcomes (Torrey, 106)

### 10 Years After 1<sup>st</sup> Professional Contact

25%	25%	25%	15%	10%
Completely recovered	Much improved, relatively independent	Improved, but requires extensive support network	Hospitalized, unimproved	Deceased

### 30 Years After 1<sup>st</sup> Professional Contact

25%	35%	15%	10%	15%
Completely recovered	Much improved, relatively independent	Improved, but requires extensive support network	Hospitalized, unimproved	Deceased

## 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.

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## Alternative Treatments Let's think OUTSIDE the box



**"Never, never, think outside the box!!"**

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# Non- Pharmacological Approaches to Treatment

Soteria House  
Open Dialogue

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## 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.

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## 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.**
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## 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, 1<sup>st</sup> or 2<sup>nd</sup> 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.

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## 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

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## 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

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## 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"

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## 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.**

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## 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

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## 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.**

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## Applications of Open Dialogue in the US

- ◉ Burlington, Vermont (scheduled to open this year)
- ◉ Collaborative Pathways, Framingham, MA.: Open Dialogue Pilot Project.
- ◉ 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.

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## 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

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## 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"

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## 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"

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## Role Models: Patricia Deegan, Ph.D.

- ◉ Who she is.

- YouTube video:  
<http://www.youtube.com/watch?v=DVIhfuKDjYE&feature=BFa&list=PL83EB4759EDD815F1>

- 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)

