Improving Outcomes in Early Psychosis through Data and Collaborative Learning

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Outline

- What is "early psychosis"?
- What is "early intervention" and how does it improve outcomes?
- Using data to improve care through EPI-CAL
- Providing technical assistance through AB1315 to improve access and outcomes across California
- Opportunities & next steps

Symptoms Start Before Diagnosis

Positive symptoms = Hallucinations, delusions, thought disorder

Negative symptoms = Lack of motivation, interest in pleasurable activities, flat affect, paucity of speech



Early Psychosis:

Individuals who have experienced onset of full threshold positive symptoms within last 5 years

"At risk" or "Clinical high risk": Individuals who have experienced onset or worsening of attenuated/subthreshold positive symptoms

Delays in Accessing Care

- Duration of untreated psychosis (DUP) = strong predictor of long-term outcome^[a]
 - Median DUP in US = 18.5 months ^[b]
- A DUP of < 3 Months is Optimal [c]
- "Early" psychosis = first 5 years after onset of symptoms^[c]
 - "Critical period" during which treatment has its biggest impact
 - Focus on MAINTAINING functioning, rather than recovering functioning that was lost

Negative Outcomes

- Life expectancy is 10-20 years below average, increased risk for premature mortality^[a]
 - Medical comorbidities, substance use
 - Rates of death by suicide range from 4% to 13%^[b] Most common during early phase of illness
- Rates of unemployment as high as 90%. High risk for homelessness, poverty, poor quality of life. ^[a,c]
 - How do these experience exacerbate symptoms? How do they complicate treatment and recovery process?
- Annual economic burden of approximately \$155.7 billion \rightarrow \$44,773 annual average cost per individual^[a]
 - \$37.7 billion for direct health care costs (10% for hospitalization, 6% for meds) and 76% indirect costs (high unemployment and caregiver burden)
 - Medicare patients with diagnosed schizophrenia had a cost of care that was approximately 80% higher than the general Medicare population per year in 2010 dollars.
 - For commercial insurance, total claim cost per patient with schizophrenia was more than 4 times the average total claim cost for a demographically adjusted population without schizophrenia.
- 30% of individuals have persistent illness and do not respond to 2+ adequate trials of medication treatment.^[a]
 - Annual costs associated with treatment resistance range from \$66,360 to \$163,795, or 3- to 11-fold higher than the annual cost of patients with schizophrenia who respond to treatment.

a. Wander, C. Am J Manag Care. 2020;26:S62-S68. b. Popovic D, et al. Acta Psychiatr Scand. 2014;130:418-426. c. Volavka J, et al. Int J Clin Pract. 2018;72:e13094. e.

EP Care Standards



- "Standard community treatment" = therapy (individual, group and family), medication management, and case management
- EP programs = team-based approach with rapid access; comprehensive assessment; individual & group psychotherapy; family psychoeducation & support; case management; integrated medication management, and supported education and employment to improve role functioning (Heinssen, Goldstein, Azrin, 2014)
 - Coordinated Specialty Care (CSC)

Testing the Coordinated Speciality Care Model in the Community

- Studies in Europe and Australia showed improved outcomes in schizophrenia with team-based care
- Recovery After an Initial Schizophrenia Episode (RAISE) research initiative – started by NIMH in 2009
- RAISE Early Treatment Program vs usual care in the community
 - Included individuals with diagnoses of schizophrenia, schizoaffective disorder, schizophreniform disorder, brief psychotic disorder and psychosis NOS
 - Excluded mood disorders with psychotic features and clinical high risk
 - Randomized 34 clinics in 21 states

Comprehensive Versus Usual Community Care for First-Episode Psychosis: 2-Year Outcomes From the NIMH RAISE Early Treatment Program

John M. Kane, M.D., Delbert G. Robinson, M.D., Nina R. Schooler, Ph.D., Kim T. Mueser, Ph.D., David L. Penn, Ph.D., Robert A. Rosenheck, M.D., Jean Addington, Ph.D., Mary F. Brunette, M.D., Christoph U. Correll, M.D., Sue E. Estroff, Ph.D., Patricia Marcy, B.S.N., James Robinson, M.Ed., Piper S. Meyer-Kalos, Ph.D., L.P., Jennifer D. Gottlieb, Ph.D., Shirley M. Glynn, Ph.D., David W. Lynde, M.S.W., Ronny Pipes, M.A., L.P.C.-S., Benji T. Kurian, M.D., M.P.H., Alexander L. Miller, M.D., Susan T. Azrin, Ph.D., Amy B. Goldstein, Ph.D., Joanne B. Severe, M.S., Haiqun Lin, M.D., Ph.D., Kyaw J. Sint, M.P.H., Majnu John, Ph.D., Robert K. Heinssen, Ph.D., A.B.P.P.

RAISE-ETP NAVIGATE

- Results demonstrated support for community-based use of CSC Model
- Recipients of NAVIGATE showed:
 - Longer treatment participation
 - Greater reduction in clinical symptoms
 - Greater improvement in quality of life and participation in work/school
- HOWEVER, treatment effects were moderated by Duration of Untreated Psychosis (DUP) → Median = <u>74 weeks (18.5 mths)</u>





mperia

The Rise of Early Psychosis Care in California: An **Overview of Community and University-Based Services**

Tara A. Niendam, Ph.D., Angela Sardo, B.A., Mark Savill, Ph.D., Pooja Patel, B.S., Guibo Xing, Ph.D., Rachel L. Loewy, Ph.D., Carolyn S. Dewa, M.P.H., Ph.D., Joy Melnikow, M.D., M.P.H.

- Influx of state (Prop 63 PEI, AB1315, SB1004) and federal (MH Block Grant) dollars has led to rapid development of early psychosis (EP) programs across California
- Surveyed 30 programs in 24 counties between Oct 2016-May 2016
 - 41% had active programs
 - 21% were developing programs
 - 38% had no program
- Obtained data from 29 programs

Diversity of CA Programs

- Each county developed their own program, some independently and some in collaboration with local UC
- 76% serve first episode psychosis (FEP) AND clinical high risk (CHR)
 - 17% serve FEP only
 - 7% serve CHR only (but SAMHSA Block grant funds have been used to include FEP)
- 86% serve any psychosis spectrum disorder, including schizophrenia spectrum
 - 72% serve mood disorder with psychosis
 - 21% serve mood disorders without psychosis
- Duration of psychosis ranges from 1 year (29%) to indefinite
- 55% serve clients for up to 2 years
 - Range is wide: 17% serve for up to 1 year while 27% go up to 3-4 years or indefinitely

Variability in Treatment Approaches



Treatment Standards

- CSC is appropriate and effective for individuals with schizophrenia spectrum diagnoses who are <u>early</u> in the course of illness
 - Data suggests that combination of treatments may also work for CHR (van der Gaag et al., 2013; Thompson et al 2015)
- Impact of CSC has not been tested in individuals with mood disorders with psychotic features
 - Studies of depression with psychosis show efficacy for pairing medications with CBT (March et al, 2004) or ECT (Rothschild, 2013)
 - Studies in bipolar disorder show efficacy for medication (McClellan et al., 2007), CBT, and family-focused therapy and psychoeducation (review by Young & Fristad, 2015).
- Examining outcomes of CSC for CHR and mood disorders is critical for our field!

EPI-CAL Learning Healthcare Network



Del Norte

- Innovation project funding from 5 counties, with support from One Mind
 - Sonoma and Stanislaus counties in process of joining
- NIMH Grant added 2 counties, 4 UC programs and Stanford – enable participation in national evaluation with 3 other networks
- AB1315/EPI-PLUS may add more counties

Goal of EPI-CAL

- Gather high-quality data to understand:
 - what's happening now in EP programs
 - what is promoting client recovery (and what isn't)
 - the needs and priorities of clients, families, communities
 - how data can influence collaborative care decisions in real time
- Contribute to national evaluation of CSC care through NIMHfunded EPI-NET

EPINET: Data Coordinating Center, 8 Hubs, 101 CSC Clinics Across 16 States



Proposed Learning Healthcare Network for CA Mental Health programs



Consumer (and support persons/ family) enter data on relevant survey tools (in threshold languages) in app-based platform at baseline and then regular follow up. Clinician and/or MD can visualize responses on web-based portal for the individual over the course of treatment and share that data with the consumer during session. Program management can visualize summary of responses on portal for:

- All consumers in clinic

- In relation to other CA programs

Administrator level allows access to a limited data set across all clinics on the app for county- or state-level data analysis

Domains In The Core Assessment Battery

CAB Domain

- 1 Cognition
- 2 Demographics & Background
- 3 Diagnosis
- 4 Discharge Planning & Disposition
- 5 DUP & Pathway to Care 🔶
- 6 Education
- 7 Employment
- 8 Family Involvement 🔶
- 9 Functioning
- 10 Health
- 11 Hospitalizations 🔶

CAB Domain

- 12 Legal Involvement 🔶
- 13 Medication Side Effects & Treatment Adherence
- 14 Medications
- 15 Recovery $\bigstar \rightarrow$ Homelessness
- 16 Service Use
- 17 Shared Decision Making
- 18 Stress, Trauma & Adverse Childhood Events
- 19 Substance Use
- 20 Suicidality
- 21 Symptoms

Evaluating EP programs and Improving Care Outcomes Learning Questions and Outcomes

Evaluation

Impact of Statewide

Learning Health Care Network

County Level Data: ID counties with EP and CG programs. Obtain deidentified data on program utilization, ED and hospital utilization and assoc. costs for EP and CG programs

Are there differences in utilization and costs between EP programs and standard care?

How does utilization and cost relate to consumer-level outcomes within EP programs? Program Level Data: Collect detailed outcomes (symptoms, functioning, satisfaction, etc) measures in participating EP programs ("Learning Healthcare Network")

Do California EP programs deliver components of evidence-based care?

What are the program components associated with consumer-level short-and long-term outcomes in particular domains? Qualitative data: Focus groups, stakeholder meetings and qualitative interviews with consumers, families and providers from EP programs to inform outcome selection, present findings, and assess implementation and satisfaction.

> Consumers and families will have input on what outcomes are selected via focus groups and surveys.

What are the barriers and facilitators to implementing a LHCN app?

FEP-FS Treatment Components Scale

- Will evaluate all sites in project, provide feedback, and use data in analysis
- Involves site interviews of key team members, clients & families, chart review
- Example item:

Component	Rating				
	1	2	3	4	5
 3. Services Delivered by Team Qualified professionals deliver services that include the following: 1. Case management/ care coordination; 2. Health services; 3. Psychotherapy; 4. Substance use management; 5. Supported employment; 6. Family education/support; 7. Patient psychoeducation; 8. Pharmacotherapy (Data source: Team Leader. All interviews) 	Team delivers four or fewer of listed items	Team delivers five items including case management/ care coordination	Team delivers six items including case management/ care coordination	Team delivers seven items including case management/ care coordination	Team delivers all items



Vision for California

GOAL: Make high-quality EP care available to all Californians, enabling improved outcomes across the state

- Have ~30 programs in 24 counties
- 59% of counties do not have a program
 - 21% were developing programs
 - 38% had no program

We need a way to support program development <u>and</u> sustainability statewide

AB1315 EP Training & Technical Assistance Center

GOAL: Make high-quality EP care available to all Californians, enabling improved outcomes across the state



- Led by UC Davis, collaboration with UCSF and Stanford to provide TTA to expand and enhance EP services
- Initial AB1315 funding supported 4 counties (Sonoma, Lake, Kern, and Santa Barbara)
- Second round will fund 2 more programs with a focus on 1) county collaborative and 2) targeting diverse communities
- What about the remaining counties with EP programs?
- What about counties without access to EP programs?

Opportunities & Next steps

- EPI-CAL collaboration provides opportunity to enhance EP care while simultaneous learning what is working vs what is not - for clients & families, programs & staff, and the larger state
- AB1315 EP TTA allows us to build a statewode infrastructure to support program development and sustainability with acknowledgement of the needs of our unique communities

Next Steps:

- How to engage the commercial insurance sector?
 - ~26.6 million Californians who do not have access to this care
- How to support statewide identification and access to care?
- How to support access to EP care in counties without a program, including rural and remote counties?
- How to support workforce development so EP knowledge and skills are common and recruitment is easier.

Questions?

