Building a Population-Based System of Care for Psychosis: The STEP Program

Vinod H. Srihari, M.D.
P.I. and Director
www.step.yale.edu

Yale University  Connecticut Mental Health Center
I. The Problem

A. Psychotic disorders are common, distressing and disabling:

- Affects between 0.55 and 1 percent of people during their lives (McGrath et al., 2008);
- With routine care, less than a fifth of patients achieve full recovery after a first episode of psychosis (Menezes et al., 2006).

B. Psychotic disorders are expensive:

- Schizophrenia leads annual U.S. mental illness expenditure ($62.7 billion, 2002 dollars) attributable mostly to acute hospitalizations in early course and vocational losses in longer term (Wu et al., 2005).
### The Persistent and Heavy Burden of Psychotic Illnesses

Leading causes of Years Lived with Disability (YLD) worldwide

(Source: Global Burden of Disease, 2010 Lancet. 2012;380(9859):2163–2196)
The Critical Period: Rationale for Early Intervention for the Schizophrenia(s)

Phase of illness

Premorbid    Prodrome    Acute    Plateau / Chronic

Most of the clinical and psychosocial deterioration occurs in first 5 years (Lieberman et al., 2001)

De-synchrony of symptoms and functioning: phases are different

Prognostically important period: Symptom duration in first 2 years is strongest predictor of outcome (Harrison et al., 2001); Highest Suicide risk; Onset of substance misuse; Longer DUP associated with poorer outcomes (Marshall, 2006)

adapted from Srihari et al. Psych Clin of N America, 2012
II. EI can improve outcomes

A. Early Detection (ED)
   – Intervening earlier (even without enriching care) appears to have durable effects on functional outcome (Larsen et al, 2011)

B. First Episode Services (FES)
   – Intervening comprehensively after the onset of psychosis improves outcomes over usual care (OPUS Trial, Lambeth Trial) at 2+ years (reviewed in Srihari et al, Psych Clinics N America 2012)
ED can improve outcomes

**TIPS** (Norway/Denmark): **DUP reduction** 114 weeks mean (26 weeks median) --> 25 weeks mean (5 weeks median)

- Reduced distress and disability at presentation for care
- Improved *negative symptoms* at 5 years
- Doubled chance for recovery at 10 years (31% vs. 15%) (Velden WT et al., 2012)
Comprehensive (First-Episode Services) improve outcomes & costs

- 3 Randomized Controlled Trials (RCTs) of FES in U.K., Denmark and Norway had established significant improvements in
  - relapse,
  - re-admission,
  - suicidality,
  - social and vocational functioning and quality of life (Craig:2004, Petersen, 2005)

- Health economic analysis in the U.K. and Denmark have also supported cost effectiveness of these intensive ACT based models of care (Mihalopoulos et al, 2009).
Knowledge Translation: State of the Art for EI in 2006

- Efficacy (can it work?) ✔

- Effectiveness (does it work?) ? in U.S.

- Costs (is it worth it?) ? in U.S.

- Dissemination (is it portable?) ? in U.S.
III. STEP 1.0
(NIH RC1 MH088971)

Can a feasible and cost-effective model of FES be delivered in a ‘real-world’ U.S. setting?
The Clinic for Specialized Treatment Early in Psychosis (STEP) est. 2006

- Pragmatic RCT (2007-'13)
  - Broad recruitment
  - Feasible interventions
  - Relevant outcomes

- Based in public sector
  DMHAS-Yale partnership

- Addressed barriers to access
  - Insurance status
  - Catchment of residence
  - Adolescent-Adult agencies
The STEP Trial
2007–’13
ClinicalTrials.gov NCT00309452
NIH MH088971-01

Age: 16-45 yo
Duration of illness: ≤12 wks lifetime antipsychotic Rx AND <5yrs illness
Exclusion: sub-induced psychotic d/o
Exclusion: DDS (DMR) eligibility

TAU
Referral to private or public-sector care

STEP Care
Based within CMHC ambulatory services

Referrals from:
CMHC triage
YNHH Hospital/ER
Area Clinics
College counseling
# STEP: A Diverse Population

<table>
<thead>
<tr>
<th>Demographics</th>
<th>STEP participants (n=149)</th>
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<tbody>
<tr>
<td>Age, mean (SD) years</td>
<td>22.9 (4.8)</td>
</tr>
<tr>
<td>Gender, male, n (%)</td>
<td>121 (80%)</td>
</tr>
<tr>
<td>Race/Ethnicity, n (%)</td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>63 (42%)</td>
</tr>
<tr>
<td>White</td>
<td>58 (39%)</td>
</tr>
<tr>
<td>Latino/a</td>
<td>21 (14%)</td>
</tr>
<tr>
<td>Asian</td>
<td>3 (2%)</td>
</tr>
<tr>
<td>Multi-racial</td>
<td>4 (3%)</td>
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<tr>
<td>Immigrant (First Gen.)</td>
<td>43 (29%)</td>
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High Clinical Distress At Entry

- Co-morbid Sub Use Disorders: 45%
- Previously hospitalized: 89%
- Previous suicide attempt(s): 9%
- Unemployed: 61%
- mean DUP in months (+/- sd): 10 (+/-12)
  - >50% with DUP > 3 mos.
  - >40% with DUP > 6mos
  - Interquartile range: 12 mos.
1. NNT of 5 for Hospitalization over first year
2. Fewer in STEP had ‘dropped’ out of labor force 8% vs. 33%
Components of STEP care

• Evaluation: for rare secondary causes (e.g. epilepsy, fronto-temporal dementia) and more common taxonomic categories (acute intermittent psychoses, bipolar disorder, MDD with psychosis, borderline PD)
• Family Education / Support: individual and group
• Social cognition and skills: individual and group
• Individual Psychotherapy
• Pharmacologic Treatment
• Rehabilitation (Support for employment and/or education)

Integration within a team that phases and prioritizes goals based on explicit principles of care
What is STEP care? Phase-specific

1. ACUTE
Engage around ‘interrupted’ narratives: work, school, relationships
Safety: self-harm & impulsive aggression
Symptoms: remission of ‘positive’ symptoms, mood/anxiety
Cognitive losses, stigma, substance use

2. STABILIZATION
Maintain symptomatic remission
Prevent relapse
Support rehabilitation
Work/school, relationships

3. RECOVERY
Prevent relapse
Maintain functioning
Cardiovascular risk
1. The Problem
- Psychotic illnesses are disabling and costly
- Effective models of First-Episode Services have been in existence >10yrs around the world

2. STEP 1.0 models a U.S. solution
STEP care is a feasible and effective model of early intervention:
- Reduced frequency and duration of hospital use
- Improved school & employment engagement
- Improved range of measures of symptoms, social functioning and quality of life
- Reduced direct costs of expensive hospital care by implementing non-intensive, office-based FES
IV. STEP 2.0: Adding Early Detection to specialized care

The STEP+ED trial
(NIH R01 MH103831)
Early Intervention (EI) services in New Haven & Boston

Phase of illness

Premorbid  Prodrome  Acute  Plateau / Chronic

Critical Period

Onset of illness
First episode

PRIME/CEDAR  DUP  STEP/PREP

Age (years)

5  10  15  20  25  30  35  40  45  50  55  60

Adapted from Srihari et al. Psych Clin of N America, 2012
1. **Primary**: To determine whether an early detection intervention can reduce DUP in the US vs. usual detection.
   
   Goal: 50% reduction of DUP

2. **Secondary**: To determine whether DUP reduction can augment the outcomes of FES
   
   Goal: >75% will be vocationally engaged at one year
TIPS, Norway & Denmark

Expected number of included patients with first-onset psychosis over 4 years: 300

(Melle I et al. Arch Gen Psych 2004)
BOW-H-HAVENS
Population: 323,285
Area: 365 km²
Estimated incident cases of psychosis: 70-100/yr

Metropolitan Boston
Population: 646,000
Area: 232.1 km²

STEP-ED catchments

Rogaland
Population: 473,600
Land Area: 8,590 km² (3,320 sq mi)
The STEP Program: Developmental History

- **2006**: founded within a public-academic collaboration (CMHC-Yale) (Srihari et al., Psych Services 2009)
- **2007-2013**:STEP 1.0 RCT establishes real-world effectiveness (Srihari et al., Psych Services 2015)
- **2013**: STEP receives CT-DMHAS funding to stabilize clinical service
- **2014**: Development of Early Detection campaign
- Additional SAMHSA set aside funding supports staffing...
- **2015**: ED campaign launches….
“Everything you read in newspapers is absolutely true, except for that rare story of which you happen to have first-hand knowledge.” -Erwin Knoll

**Developing a DUP reduction campaign**

*Media + Professional Outreach + Performance Improvement*
Theories of Health Behavior Change

Macro or Mass (vs. Individual) Behavior Change Models

1. Social Marketing: “a program-planning process that applies commercial marketing concepts and techniques to promote voluntary behavior change” Grier & Bryant, 2005

Better conceived of as a set of tools/strategies rather than a theory of behavior change

Education vs. Law vs. SM “…marketing influences behavior by offering alternative choices that invite voluntary exchange. Marketing alters the environment to make the recommended health behavior more advantageous than the unhealthy behavior it is designed to replace and then communicates the more favorable cost-benefit relationship to the target audience.”
Addressing Pathways To and Through Care

Figure 1: Heuristic model for DUP in STEP’s catchment

- **Community Agencies**
  - Police/Jail diversion
  - Church/mosque

- **Acute Clinical Settings**
  - Emergency Rooms
  - CMHC* Triage
  - Inpatient units

- **Non-acute clinical settings**
  - Community mental health centers
  - College counseling centers
  - School based clinics
  - Primary care (Internist, Pediatrician)

- **Components of DUP**
  - ‘Demand’
  - ‘Supply’

- **STEP**

- **Patient and/or Caregiver**
Theories of Health Behavior Change

Macro or Mass (vs. Individual) Behavior Change Models

2. Social-Ecological Model: addressed multiple different levels e.g. individual, interpersonal, institutional/organizational, community, and social structure/policy/systems (McLeroy et al., 1988) and uses multiple individual change theories

STEP-ED will employ an Ecological approach that utilizes Social Marketing strategies....
STEP-ED: Theory of the campaign

1. Modified *Goldberg-Huxley* model: Levels and Filters; Non-clinical actors/organizations

2. ‘*Demand*’ (onset to identification of illness and initiation of help-seeking) and ‘*Supply*’ (correct identification of diagnosis and referral to FES) components of DUP

3. Entry into care as an iterative/interactive process with the caregiving system (including non-professional actors) vs. a linear progression towards effective help-seeking behavior (e.g. transtheoretical model). Also, a social process (influenced by family/peers/cultural mores)

4. *Ecological* approach or ‘*kitchen-sink*’ campaign: agnostic about relative strength of supply and demand contributors to DUP, broad assessment of impact
#1: Media Campaign (targets Demand)

- *Distinct* messages
  - (i) patients,
  - (ii) friends/peers
  - (iii) family/adult caregiver using a variety of *Channels*

- Multiple *Channels* (social and traditional media, professional and advocacy networks)
  - social vs. mass media
STEP-ED: 3-pronged Early Detection:

1. Media campaign

- 3 Distinct Messages
- Multiple Channels
PSYCHOSES

DEPRESSED
UNMOTIVATED
WITHDRAWN
APATHETIC

DON'T LET THE SYMPTOMS OF PSYCHOSES SET IN.

OVERWHELMING CONFUSION
POOR HYGIENE
THINGS LOOK OR SOUND DIFFERENT

DON'T LET THE SYMPTOMS OF PSYCHOSES SET IN.

mindmap
A CLEAR PATH TO MENTAL HEALTH
WWW.MINDMAPCT.ORG

SAMHSA
PSYCHOSIS
AM I LOSING MY MIND?

IF SOMETHING IS WRONG WITH YOUR CHILD
BE THE FIRST TO GET THEM HELP

PSYCHOSIS
IF YOUR FRIEND WAS HURTING
YOU'D CALL A DOCTOR

DON'T LET THE SYMPTOMS SET IN

WHERE

CHECK IN
#mindcheck quiz here

SHARE

[Icons for YouTube, Pinterest, Facebook, Twitter]
STEP-ED: 3-pronged Early Detection:

# 2: Professional Outreach & Detailing (POD) *(Supply & Demand)*

- PRIMARY CARE
- EDUCATION
- MENTAL HEALTH SERVICES
- CIVIC/RELIGIOUS
- JUDICIAL
- POLICY
- SOCIAL WELFARE
- CONSUMER/YOUTH ORG.
# 3: Rapid Access to STEP care (RAS) (targets Supply & Demand)

- Simple, structured screening to determine eligibility and begin engagement into care
- Relationship management/responsiveness to all 8 POD groups
- In-person eval within 24hrs and on-site of referral if preferred
- ‘Pre-referral’ support for parents/caregivers/friends & POD
- Continuous audit of delay: screening to engagement
The STEP-ED trial: other design elements

**Sampling**
- 16-35yo
- Within 3 yr. of psychosis onset
- Any schizophrenia spectrum disorder
- Living in 8 towns (New Haven/ED site) or usual catchment (Boston/noED site)

**Measures**
- ‘DUP 1’ & ‘DUP 2’
- Pathways to Care
- Neuro/Social Cognition
- Social & Vocational Fx
- QOL
- Symptoms
- Resource utilization

*Srihari et. al (BMC Psychiatry, 2014)*
V. Salience of the STEP-ED project

Envisioning Population Based Systems of care
Population Health

“A goal of achieving measurable improvements in the health of a defined population.” (Kreuter M, Lezin N. 2001)

A middle ground between the traditional focus of the clinic (focused on outcomes of those already in care) and public health (focused on environmental determinants of health) (see Kindig at el., 2008)
Making Population Health Operational

A *Systems-Network-Pathways* perspective

(See Jani A, Gray M in outcomes.BMJ.com)
The STEP program seeks to model a population based system of care for psychotic disorders by engaging a network to transform pathways in a defined geographic area (8 contiguous towns).
Population-based systems of care for Psychosis as a way to reach the Triple Aim: FES as 'integrators’

(Berwick et al., 2008)
“What happens to individuals with psychosis in Connecticut?”

- 169 Towns
- Popn. 3.5 million (63% 18-65yo)
- 4800 sq.miles

‘First-break’ ~500/yr
Identification of illness
Help-seeking
Diagnosis/Referral
Treatment

DUP

169 towns: 5 LMHAs, 3-4 regional healthcare networks, multiple private and public providers…
What happens to individuals with psychosis in Connecticut? building a model

DUP as a measure that can deliver accountability and allow useful comparisons across geographic sectors
The STEP-ED Team

**STEP/Yale/CMHC**
Jessica Pollard, Ph.D.
*Director of Clinical Services*
Scott Woods, M.D.
Thomas McGlashan, M.D.
Cenk Tek, M.D.
Barbara C. Walsh, PhD
Nina Levine, B.A.
Vinod Srihari, M.D. (P.I)

**PREP/Harvard/MMHC**
Larry Seidman, Ph.D. & Matcheri Keshavan, M.D. (site-P.I.s)
Suzannah Zimmet, M.D.
Michelle Friedman-Yakoobian, Ph.D.
Raquelle Mesholam-Gately, Ph.D

**Red Rock (Marketing)**
Glen McDermott
Giulia Gouge
Jeff Kubarych
Mason Rabinowitz
George Vasilopoulos

**TIPS (Norway) - Consultants**
Inge Joa
Svein Friis
Jan Olav Johannessen
The STEP Program

EARLY INTERVENTION FOR PSYCHOSIS
WHO ARE WE LOOKING FOR?

STEP
Recent onset of psychosis (<3 years)
16 - 35 years
Restricted to the following towns:

PRIME
At risk or 'prodromal' for psychosis
12 - 35 years
No geographic restrictions

(203) 589-0388
www.mindmapct.org

If in doubt about eligibility, please call us OR get the patient’s verbal consent to give us their contact information, leave that on our voicemail, and we’ll take it from there.

L to R: Miranda Mast (Vocational Specialist); Anna Fiskin, MD (Resident); Lauren Utter Psy.D (Primary Clinician); Tracey George LCSW (Primary Clinician); *Shannon Imetovski RN (not in picture, Primary Clinician); Al Powers MD, (Resident); Barbara Walsh PhD, (Director of Assessment and Professional Outreach); Nina Levine BA (Research Assistant); Jessica Pollard PhD, (Director of Clinical Services); John Cahill MD (Medical Director); Vinod Srihari (Program Director)