Epidemiology of First-Episode Psychosis in large, integrated healthcare systems

Gregory Simon MD MPH
Kaiser Permanente Washington Health Research Institute
(formerly Group Health Research Institute)

Match 16, 2017

Note: The views, opinions, and content expressed in this presentation do not necessarily reflect the views, opinions, or policies of the Center for Mental Health Services (CMHS), the Substance Abuse and Mental Health Services Administration (SAMHSA), or the U.S. Department of Health and Human Services (HHS).
Outline:

• Description of Mental Health Research Network
• Epidemiology of First-Episode Psychosis in MHRN
  • Incidence and site of first presentation
  • Utilization prior to first diagnosis
  • Follow-up after first diagnosis
• Implications for service planning
• Thoughts about promises and pitfalls of early detection
MHRN Mission:

To improve the understanding and management of mental health conditions through a closer connection between research, practice, and policy.
Membership:

- **13 integrated healthcare systems**
  - Approximately 13 million members/patients in 15 states
  - Diverse membership (including diversity of race/ethnicity, SES, and source of insurance coverage)
  - Diverse organizational structure (traditional “HMO” and mixed)
- **13 affiliated research centers**
  - All members of broader Healthcare Systems Research Network (formerly HMORN)
  - 25 active investigators
  - Experienced programmer/analysts at each site
Federated data structure

The Virtual Data Warehouse:
A method for standardizing and pooling electronic health data for multi-site research

Individual Health Care Systems
Administrative and claims data

Advance Work
Enormous gains in efficiencies and data quality are made through investments in advance work.

Research centers convert relevant local data to VDW format

Research Projects

Lessons learned
MHRN FEP Project Aims

- Describe first presentation with psychotic symptoms
- Examine patterns of care prior to diagnosis
- Examine treatment adherence/continuity after diagnosis
- Mine clinical text to identify possible prodromal “signals”
- Explore provider, patient and family views regarding outreach interventions
MHRN FEP Project Setting

- 5 health systems (Group Health/KPWA, KP Northwest, KP Northern California, KP Southern California, KP Colorado)
- Defined population of approx. 8.5 million members
- All insurance types (including Medicaid and other low-income plans)
- Race/ethnicity representative of service areas
Aim 1: Incidence and site of presentation

- **Sample of “putative” cases:**
  - Age 15 thru 59
  - First-ever recording of any ICD9 psychosis diagnosis in any setting
  - Enrolled for prior 12 mos
  - No other exclusions (i.e. no exclusion for pre-existing mood disorder or co-occurring substance use)

- **Chart reviews to confirm diagnosis:**
  - Confirm presence of any DSM-IV Criterion A symptom
  - Exclude if prior diagnosis of or treatment for psychosis
  - Exclude if definite medical explanation
  - No exclusions related to substance use or mood symptoms

- **Stratified by age and site of presentation**
Putative cases

- 37,843 putative over 7 years (2007 thru 2013)
- **Index Diagnoses:**
  - *Schizophrenia spectrum psychosis:* 7%
  - *Mood disorder with psychosis:* 19%
  - *Other psychotic disorder:* 74%
- **Insurance Coverage at Index:**
  - *Commercial/Group:* 85%
  - *Individual:* 5%
  - *Medicaid/Medicare:* 10%
Chart review confirmation

- Confirmation rate varied by age and site of presentation
  - 84% among younger people (age 15-29) diagnosed in hospital or ED
  - 19% among older people (30-59) diagnosed in primary care or other outpatient

- Most “non-confirmed” cases lacked clear documentation of psychotic symptoms

- Rates of prior diagnosis/treatment were low – except for older people with first diagnosis in primary care

- Only 1% excluded for “medical explanation”
# Incidence by site of initial presentation

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Initial Incidence (per 100k)</th>
<th>% Confirmed</th>
<th>Adjusted Incidence (per 100k)</th>
<th>Est. % of True Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 15-30, ER/Inpatient</td>
<td>27</td>
<td>84%</td>
<td>23</td>
<td>26%</td>
</tr>
<tr>
<td>Age 15-30, Outpatient MH</td>
<td>56</td>
<td>78%</td>
<td>44</td>
<td>51%</td>
</tr>
<tr>
<td>Age 15-30, Prim Care/Other</td>
<td>42</td>
<td>47%</td>
<td>20</td>
<td>23%</td>
</tr>
<tr>
<td>Age 15-30, TOTAL</td>
<td>86</td>
<td></td>
<td></td>
<td>100%</td>
</tr>
<tr>
<td>Age 30-59, ER/Inpatient</td>
<td>25</td>
<td>66%</td>
<td>17</td>
<td>36%</td>
</tr>
<tr>
<td>Age 30-59, Outpatient MH</td>
<td>37</td>
<td>57%</td>
<td>21</td>
<td>46%</td>
</tr>
<tr>
<td>Age 30-59, Prim Care/Other</td>
<td>45</td>
<td>19%</td>
<td>9</td>
<td>19%</td>
</tr>
<tr>
<td>Age 15-30, TOTAL</td>
<td>46</td>
<td></td>
<td></td>
<td>100%</td>
</tr>
</tbody>
</table>
Key findings: Incidence and site of presentation

- Overall incidence at high end of previous estimates
- Half of first presentations after age 30
- 20% present in primary care or general medical settings
- Most initial diagnoses non-specific (appropriately so)
- Most covered by commercial/group insurance
Aim 2: Utilization prior to diagnosis

- Describe use of specialty mental health and general medical services during two years prior to first diagnosis
- Two comparison groups:
  - First diagnosis of unipolar depression
  - First diagnosis of inflammatory bowel disease
- Stratified by race/ethnicity
### Utilization prior to first diagnosis

<table>
<thead>
<tr>
<th>Prior Timeframe</th>
<th>MH IP Admit</th>
<th>MH ER Visit</th>
<th>MH OP Visit</th>
<th>PC w/ MH Dx</th>
<th>Any MH “Signal”</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Prior 6 MOS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychosis</td>
<td>10%</td>
<td>19%</td>
<td>27%</td>
<td>27%</td>
<td>41%</td>
</tr>
<tr>
<td>Depression</td>
<td>4%</td>
<td>10%</td>
<td>31%</td>
<td>28%</td>
<td>43%</td>
</tr>
<tr>
<td>Inflamm Bowel</td>
<td>2%</td>
<td>4%</td>
<td>8%</td>
<td>10%</td>
<td>13%</td>
</tr>
<tr>
<td><strong>Prior 24 MOS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychosis</td>
<td>16%</td>
<td>29%</td>
<td>33%</td>
<td>46%</td>
<td>55%</td>
</tr>
<tr>
<td>Depression</td>
<td>8%</td>
<td>16%</td>
<td>45%</td>
<td>38%</td>
<td>53%</td>
</tr>
<tr>
<td>Inflamm Bowel</td>
<td>4%</td>
<td>9%</td>
<td>17%</td>
<td>23%</td>
<td>29%</td>
</tr>
</tbody>
</table>
### Utilization prior to diagnosis by race/ethnicity

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>PRIOR 6 MOS</th>
<th>PRIOR 24 MOS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>MH IP Admit</td>
<td>MH OP Visit</td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>9%</td>
<td>28%</td>
</tr>
<tr>
<td>African American</td>
<td>9%</td>
<td>18%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>6%</td>
<td>17%</td>
</tr>
<tr>
<td>Asian</td>
<td>4%</td>
<td>9%</td>
</tr>
<tr>
<td></td>
<td>PC w/ MH Dx</td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>30%</td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>26%</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>25%</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>21%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Any MH “Signal”</td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>60%</td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>50%</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>55%</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>35%</td>
<td></td>
</tr>
</tbody>
</table>
Key findings: Utilization prior to first presentation

- Approx. half have recent mental health treatment or diagnosis
  - BUT so do people with new diagnosis of depression (nonspecific)
- Distinguished by recent mental health inpatient/ED care
  - BUT only 30% have that “signal” (not very sensitive)
- Prior use of mental health care lower in racial/ethnic minority groups (especially Asian Americans)
- No magic bullet here, but:
  - Early detection programs would need to include general medical/primary care settings
  - Especially for minority racial/ethnic groups
Aim 3: Utilization after diagnosis

- Describe receipt of mental health services over two years following first diagnosis
- Two comparison groups:
  - First diagnosis of unipolar depression
  - General population
- Distinguish between:
  - Any or cumulative utilization during follow-up
  - “Active” utilization, defined by no gap > 3 months between contacts
Enrollment in MHRN insurance plans after 1\textsuperscript{st} diagnosis
## Utilization after first diagnosis (cumulative)

<table>
<thead>
<tr>
<th></th>
<th>MH Spec Visit</th>
<th>PC Visit w/ MH Dx</th>
<th>Antipsych. Rx</th>
<th>Any MH Rx</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>WITHIN 3 MONTHS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychosis</td>
<td>91%</td>
<td>21%</td>
<td>61%</td>
<td>81%</td>
</tr>
<tr>
<td>Depression</td>
<td>68%</td>
<td>20%</td>
<td>3%</td>
<td>58%</td>
</tr>
<tr>
<td>General Population</td>
<td>9%</td>
<td>3%</td>
<td>&lt;1%</td>
<td>7%</td>
</tr>
<tr>
<td><strong>WITHIN 12 MONTHS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychosis</td>
<td>94%</td>
<td>36%</td>
<td>72%</td>
<td>87%</td>
</tr>
<tr>
<td>Depression</td>
<td>73%</td>
<td>38%</td>
<td>5%</td>
<td>71%</td>
</tr>
<tr>
<td>General Population</td>
<td>22%</td>
<td>8%</td>
<td>&lt;1%</td>
<td>11%</td>
</tr>
</tbody>
</table>
MH specialty visits after 1st diagnosis

Any MH visit by week post-index

- DEP
- PSY
- PSY-12wk
- DEP-12wk
Second-Gen. Antipsychotic use after 1st diagnosis

![Graph showing the use of second-generation antipsychotics after the first diagnosis. The graph includes lines for DEP, PSY, PSY-12wk, and DEP-12wk, with the y-axis representing the percentage and the x-axis representing time in weeks.]
### Utilization after first diagnosis (active)

<table>
<thead>
<tr>
<th></th>
<th>MH Spec Visit</th>
<th>PC Visit w/ MH Dx</th>
<th>Antipsych. Rx</th>
<th>Any MH Rx</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>AT 6 MONTHS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychosis</td>
<td>75%</td>
<td>13%</td>
<td>47%</td>
<td>65%</td>
</tr>
<tr>
<td>Depression</td>
<td>47%</td>
<td>13%</td>
<td>4%</td>
<td>48%</td>
</tr>
<tr>
<td><strong>AT 18 MONTHS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychosis</td>
<td>53%</td>
<td>7%</td>
<td>31%</td>
<td>55%</td>
</tr>
<tr>
<td>Depression</td>
<td>30%</td>
<td>8%</td>
<td>2%</td>
<td>33%</td>
</tr>
</tbody>
</table>
Pilot chart reviews for “lost to follow-up”

<table>
<thead>
<tr>
<th>Description</th>
<th>N=147</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No records available</td>
<td>23</td>
<td>16%</td>
</tr>
<tr>
<td>Documented recovery</td>
<td>29</td>
<td>20%</td>
</tr>
<tr>
<td>Persistent nonpsychotic symptoms</td>
<td>43</td>
<td>29%</td>
</tr>
<tr>
<td>Persistent psychotic symptoms</td>
<td>52</td>
<td>35%</td>
</tr>
</tbody>
</table>

Key findings: Utilization after first presentation

- Most remain enrolled in private-sector health systems
- High rates of initial engagement in mental health care
  - 90% make specialty MH follow-up visit within one month
  - 60% fill outpatient SGA prescription within one month
- High rates of disengagement from mental health care
  - Only 55% remain engaged in OP specialty MH care at one year
  - <40% continue SGA medication beyond one year
- Mixed outcomes after disengagement
  - 20% with good outcome and 16% with no indication of poor outcome
  - 35% with documented poor outcome at last contact
Aim 3: Finding signals in clinical text

**Directed search:**
- Use text “harvested” from chart reviews describing definite and possible symptoms
- Select relevant words or phrases
- Search for same or similar text in notes prior to first diagnosis
- Compare prevalence to comparison group (first diagnosis of depression and general population)

**Undirected search:**
- Extract all clinical text for cases and control groups
- Machine learning to identify any signals which differentiate (whether expected or not)
Examples text for directed search:

- **More obvious**
  - Voices
  - Paranoid
  - Disorganized
  - Confused
- **More subtle**
  - Suspects that
  - FBI
  - Noises
Early findings: Mining clinical text

• More obvious text uncommon, but specific
• Less obvious text more common, but not as specific
• Will some combination be useful? - TBD
Aim 5: Qualitative interviews with patients and family members

- Normalizing – It’s been this way a long time
- Concealment – I wouldn’t have wanted anyone to know. I needed to figure it out on my own first.
- Trusted provider – Maybe if my own doctor had talked to me about it.
Overall summary:

- **Detection**
  - Incidence rate suggests reasonable capture of all new cases in population
  - Half have some prior mental health contact
- **Initiation**
  - >90% with outpatient specialty MH follow-up within 1 month
  - >60% with filled prescription for antipsychotic medication within 1 month
- **Engagement / Continuation**
  - Only 50% still engaged in outpatient specialty MH care by 1 year
  - Of those who disengage: outcome is poor in 1/3 and unknown in 1/3

Familiar story: It’s not a bottleneck, it’s a sieve.
What’s next?

- Continue work on text mining to identify early signals
- Develop/evaluate outreach interventions to prevent disengagement and promote re-engagement
Implications for service planning:

• Potential need exceeds current capacity and usual expectations. In Washington state:
  • 1300 new cases aged 15-29 per year
  • 1350 new cases aged 30-59 per year
• Half of new cases have onset after age 30
• Initial presentation in outpatient sector for 75% and primary care for 20%
• Most people covered by commercial insurance at time of diagnosis, and >80% remain for >1 year
RAISE sample vs. our sample

• RAISE sample
  • Most recruited from specialty treatment settings
  • Up to 6 months of prior treatment with antipsychotic medication
  • Exclude affective psychosis or substance-induced psychosis

• MHRN FEP sample
  • First presentation in any care setting
  • Exclude those with any prior diagnosis or treatment for psychosis
  • No exclusion for substance use or prior mood disorder

• So, MHRN sample certainly excludes larger proportion with milder (and possibly transient) illness.
• But, earlier detection would likely yield a sample more like ours
Threshold for early intervention

• **Question:** Where on the continuum do you draw the line?
  - *Prodromal symptoms*
  - *Transient symptoms (BLIPS)*
  - *Persistent symptoms*

• **Answer:** It depends.
  - *Lower threshold for recovery-oriented and “pro-social” interventions*
  - *Likely higher threshold for pharmacologic interventions*
Threshold for early intervention

Do you wait till the cat is out of the bag?
Examples from cancer screening:

- **Success story:** Colonoscopy/polypectomy to prevent colon cancer
  - Relatively homogeneous natural history
  - Relatively benign pre-emptive intervention

- **Not-so-successful story:** Surgery for PSA-detected prostate “cancer”
  - Heterogeneous natural history
  - Pre-emptive intervention with significant morbidity
Length bias in cancer screening

- **Rapidly Progressive (6 cases)**
  - `Dx` = Time when disease is clinically obvious without testing.

- **Slowly Progressive (6 cases)**
  - `Dx` = Time when disease is clinically obvious without testing.

\[ o = \text{Time of disease onset.} \]

**Legend:**
- `o` = Time of disease onset.
- `Dx` = Time when disease is clinically obvious without testing.
Is DUP the right target or metric?
Yes, if natural history is homogeneous.
Is DUP the right target or metric? Maybe not, if natural history is heterogeneous?
Do we need a “staging” system for psychosis?

- DUP attempts to summarize history and expected prognosis with a single dimension.
- Cancer staging attempts to describe
  - Current state
  - Rate of progression
- To get nerdy, it takes two parameters (point and slope) to describe a line. Neither alone will do.
Questions?

Website: mhresearchnetwork.org
Github repository: github.com/mhresearchnetwork

Note: An archived recording of this webinar will be available in 10 days at www.nasmhpd.org/webinars