The Role of Self-Tracking in Coming to Terms With and Managing Bipolar Disorder

Mark Matthews, Elizabeth Murnane, Jaime Snyder
Goals for today

- Self-tracking motives of people with mental illness
- Personal data practices, benefits, challenges
- Insights into designing personal informatics tools for a mental health context
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BACKGROUND
Bipolar Disorder (BD)

- One of 10 most debilitating illnesses worldwide
- 60 million people; affects men and women equally
- Chronic — progressively worsens over a lifetime
- Permanent neurological damage with each relapse
Mood is central

Depressive period
- feeling empty, worried
- inactivity
- tired
- changes in sleeping, eating
- suicidal thoughts

Manic period
- very high mood
- irritability
- racing thoughts
- high risk behavior
- sleeping less

Balanced period
Self-assessment is key
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STUDY
Research Questions

1. How and why do individuals with bipolar disorder engage in self-tracking?

2. How does the experience of bipolar disorder influence self-tracking practices?

3. What role does, or could, technology play in supporting the self-tracking needs of individuals with bipolar?
Participants & Procedure

• **N=10**
  - 5 females, 5 males
  - 25-64 years old
  - Confirmed diagnosis of BD, no active suicidal ideation

• Recruited through clinical collaborators

• Semi-structured qualitative interview & 2 surveys
  - $50 for interview, $25 per questionnaire

• Thematic analysis
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FINDINGS
Vignettes

- Personal stories that illustrate participants’ lived experiences of BD and self-tracking
- Foreshadow thematic analysis
- Provide a holistic experiential context
- Pseudonyms used
Rachel

**Background**
- BD Type 1
- First episode ~25 yrs ago
- Masters degree
- Self-reports as highly structured and stable

**Tracking history**
- Started tracking post-diagnosis, on paper, shared with doctors
- Now only shares if problem
- Tracking helps her recognize patterns and make adjustments

**Technology attitudes**
- Self-declared tech enthusiast
- Has tried many apps, but aren’t customizable enough
- Created her own custom digital tracking setup
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How am I doing?

Now is the time to try Your Hardest ~ xox
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<th>Overall</th>
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<th>Spanish</th>
<th>Clean house 30m</th>
<th>Training for 8-day bike ride</th>
<th>Employment Efforts</th>
<th>10:30 Breakfast</th>
<th>2:30 Lunch</th>
<th>3:30 Vitamins (coffee)</th>
<th>Hoop Q. Exercise/Bike</th>
<th>Physical Therapy</th>
<th>7:00 Ion</th>
<th>Shower</th>
<th>7:30-9:30 Meds, Alarm, DVD/new/read</th>
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Average 7-day Score: 0%

Now is the time to try Your Hardest ~ xox

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- Diagnosed 2 years ago
- Helped him make sense of his life

Tracking practices
- Got medication, established structured techniques for coping
- Uses paper-based Social Rhythm Metric clinical instrument
- Issues with forgetting to carry form and/or track

Technology attitudes
- Uses smartphone alarms and digital calendars as reminders to track
- Smart watch for tracking HR, steps, etc
- Desire for pattern detection tools
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Quantifying the Changeable Self

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