NAMICon 2020
A Virtual Event • July 13-14
Together Toward Tomorrow
CBT for Psychosis-Informed Caregiving: Bringing Evidence-Based Strategies to Family and Caregivers

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Recovery by Enabling Adult Carers at Home
Agenda for this Research Update

- Describe the **Psychosis REACH** (Recovery by Enabling Adult Carers at Home) model and its rationale.
- Share Psychosis REACH pilot data from Washington State.
- Present a sneak peak of what’s next for **Psychosis REACH**.
With Tremendous Gratitude to the UW Psychosis REACH Implementation Team
And our trainers and intervention co-developers!

Douglas Turkington, MD

Kate Hardy, Clin.Psy.D.

Stanford University

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Recovery from psychosis is the default. Expect recovery.

Schizophrenia and Psychosis
Treatment Guidelines

- Evidence-Based Psychotherapy
- Case Management
- Family & Community/Social Support
- Evidence-Based Pharmacotherapy
- Educational/Vocational Services
- Peer Support

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Implementation of Practice Guidelines in 2020

- Fewer than half of all Americans with a SMI have access to care\(^1\)
- 2% are offered evidence-based therapeutic approach\(^2\)
- Poor access to care and social factors are driving poor outcomes\(^3\)

1 Folson et al. (2005)
2 ISMICC (2019)
3 Cloutier et al. (2016)
What if we treated psychosis the way we treat other chronic health conditions?

Source: https://www.chop.edu/pages/help-families-newly-diagnosed-diabetes
Caregivers have a positive impact on recovery

- Better treatment outcomes (Glick, Stekoll, Hays, 2011)
- Fewer hospital admissions (Pitschel-Walz, Leucht, Bauml, Kissling & Engel, 2001)
- Shorter inpatient stays (Pfammatter, Junghan, & Brenner, 2006)
- Overall improvement in quality of life (Evert et al., 2003)
- Better work and role performance (Brekke & Mathiesen, 1995)
- Reduced substance use (Clark, 2001)
- Potentially reduced mortality (Revier et al., 2015)
Need to Buck the Status Quo

- Collaboration between supports & mental health providers is uncommon.

- Most mental health providers (psychiatrists, psychologists, and social workers) reported no contact with the families of their patients.¹

- Carers can spend the equivalent of a full-time job in caregiving activities and provide high levels of unpaid care.²

² Flyckt, Lothman, Jorgensen, Rylander, & Koernig (2013)
Caregivers are impacted by caregiving

- Caregivers experience overall work impairment and indirect costs\(^1\)

- Clinical levels of depression identified in caregivers\(^2\)

- Burnout and emotional exhaustion, at equivalent levels to those reported by paid psychiatric staff\(^3\)

1 Schizophrenia Commission (2012)
2 Lowenstein et al. (2010)
3 Angermeyer, Bull, Bernert, Dietrich, & Kopf (2006)
Empirically-Supported Family Interventions for psychosis:
- Psychoeducational Family Approach (Anderson, Hogarty, & Reiss, 1986)
- Psychoeducational Multi-Family Group (MacFarlane, 1994)
- Family Support Service (Somerset Partnership NHS and Social Care Trust; Burbach & Stanbridge, 1998)
- NAMI Family to Family (Dixon, 2001)
- Recovery-Oriented Decisions for Relative’s support (REORDER; Cohen et al., 2013)
- Online (Glynn et al., 2010; Duckworth & Halpern, 2014)

Poor uptake by providers (Kavanagh et al, 1993; Burbach & Stanbridge, 2006)
Incorporating Families within Psychotherapeutic Interventions

- Within the context of individual treatment
  - Guided by clinical formulation and client comfort
- As a separate cognitive behavioral family intervention
- As a supplement to CBTp treatment, families learn CBTp-informed skills
- Families whose loved ones will not engage with treatment can learn CBTp-informed skills
Psychosis REACH

A Cognitive Behavioral Therapy-Informed Training for Families and Caregivers
Psychosis REACH Training

1. Recovery-oriented psychoeducation

2. Applicability of cognitive behavioral theory and therapy to psychosis and caregiver experience

3. Coaching in CBT for psychosis-informed skills and concepts (FIRST skills)
The FIRST Skills: An Overview

- Fall back on your relationship
- Inquire Curiously
- Review the information and put it together
- Skill development
- Try out the skill and get feedback
The FIRST Skills: An Overview

• Fall back on your relationship
  • Highlight strengths/shared interests
  • Develop shared goals
  • Normalize experiences
The FIRST Skills: An Overview

- Inquire Curiously
  - Asking questions about their experiences & symptoms
  - Dropping assumptions
The FIRST Skills: An Overview

- Review the information and put it together
  - Orient to role of stress & stress management strategies
  - Make sense of experiences through shared understanding
  - Orient to cognitive triangle & maintenance formulation
The FIRST Skills: An Overview

- Skill Development
  - Cognitive skills
  - Behavioral skills
  - Problem-solving
Try out the skill and get feedback

- Encourage the individual to practice the skill independently and provide feedback on how it worked.
p-REACH Implementation Model

Outreach to CBTp, PACT, FEP Provider Networks

Foundational Training
(N = 183)

3-Day Intensive (skills) Workshop
(N = 29)

12 Monthly Calls (N=29)

Family & Caregiver Advisory Board

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Psychosis REACH Project Timeline
Registration: February – May 2019
Event: May 14th – 17th, 2019
Data Collection: May - September 2019

<table>
<thead>
<tr>
<th>Action</th>
<th>Count</th>
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<tbody>
<tr>
<td>Registered for Psychosis REACH</td>
<td>298</td>
</tr>
<tr>
<td>Family &amp; caregivers enrolled</td>
<td>183</td>
</tr>
<tr>
<td>Consented to surveys</td>
<td>170</td>
</tr>
<tr>
<td>Completed pre-training survey</td>
<td>168</td>
</tr>
<tr>
<td>Completed post-training surveys</td>
<td>134</td>
</tr>
<tr>
<td>Completed follow-up surveys</td>
<td>121</td>
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What did we find?
# Psychosis REACH Trainee Demographics

## Family & Caregiver Demographics

<table>
<thead>
<tr>
<th></th>
<th>REACH N = 168</th>
<th>Intensive Trainees N = 29</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>56.2 (14.7)</td>
<td>57.9 (11.9)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>123 (73.2)</td>
<td>23 (82.1)</td>
</tr>
<tr>
<td>Male</td>
<td>42 (25.0)</td>
<td>5 (17.9)</td>
</tr>
<tr>
<td>Non-binary or Transgender</td>
<td>2 (1.8)</td>
<td>-</td>
</tr>
<tr>
<td><strong>Education Level</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some high school/HS graduate or GED</td>
<td>4 (2.4)</td>
<td>1 (3.4)</td>
</tr>
<tr>
<td>Business or tech training, incl. military</td>
<td>6 (3.6)</td>
<td>-</td>
</tr>
<tr>
<td>Some college</td>
<td>14 (8.3)</td>
<td>-</td>
</tr>
<tr>
<td>Associates degree</td>
<td>11 (6.5)</td>
<td>2 (6.9)</td>
</tr>
<tr>
<td>Bachelors degree</td>
<td>65 (38.7)</td>
<td>13 (44.8)</td>
</tr>
<tr>
<td>Some graduate or Masters/Doctoral degree</td>
<td>68 (40.4)</td>
<td>13 (44.8)</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>26 (15.5)</td>
<td>4 (13.8)</td>
</tr>
<tr>
<td>Married</td>
<td>105 (62.5)</td>
<td>19 (65.5)</td>
</tr>
<tr>
<td>Separated</td>
<td>2 (1.2)</td>
<td>-</td>
</tr>
<tr>
<td>Divorced</td>
<td>25 (14.9)</td>
<td>4 (13.8)</td>
</tr>
<tr>
<td>Widowed</td>
<td>2 (1.2)</td>
<td>-</td>
</tr>
<tr>
<td>Other</td>
<td>8 (4.8)</td>
<td>2 (6.9)</td>
</tr>
</tbody>
</table>

## Race

- Caucasian/White: 90.4%
- African American: 5.4%
- Asian American: 5.4%
- Latino/Hispanic: 1.2%
- Native American, Alaskan Native: -
- Native Hawaiian or Other Pacific Islander: -
**PRIMARY RELATION OF LOVED ONE**

- Child: 76%
- Sibling: 10%
- Friend: 3%
- Spouse: 3%
- Significant Other: 1%
- Other relation: 6%

**Average # of hospitalizations**: 4.67

**Average # years since first diagnosis**: 5

**PRIMARY DIAGNOSIS**

- Schizophrenia spectrum disorder: 69%
- Mood disorder with psychotic features: 21%
- Neurodevelopmental disorder: 8%
- Personality disorder: 1%
- Unknown: 1%
- Other: 1%
Caregivers’ Experiences

Experience of Caregiving Inventory (Szmukler et al., 1996)

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Range</th>
<th>Pre Score (Mean [SD])</th>
<th>F/u Score (Mean [SD])</th>
<th>T-score</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficult Behaviors</td>
<td>0-32</td>
<td>17.93 (6.91)</td>
<td>15.01 (6.72)</td>
<td>5.68</td>
<td>p&lt;.001</td>
</tr>
<tr>
<td>Negative Symptoms</td>
<td>0-24</td>
<td>14.01 (5.42)</td>
<td>12.36 (5.26)</td>
<td>3.99</td>
<td>p&lt;.001</td>
</tr>
<tr>
<td>Stigma</td>
<td>0-20</td>
<td>8.46 (4.42)</td>
<td>7.58 (3.90)</td>
<td>3.29</td>
<td>p&lt;.001</td>
</tr>
<tr>
<td>Services</td>
<td>0-32</td>
<td>15.06 (7.12)</td>
<td>13.64 (6.49)</td>
<td>2.56</td>
<td>p&lt;.05</td>
</tr>
<tr>
<td>Family</td>
<td>0-28</td>
<td>12.84 (5.40)</td>
<td>11.25 (5.17)</td>
<td>4.14</td>
<td>p&lt;.001</td>
</tr>
<tr>
<td>Backup</td>
<td>0-24</td>
<td>14.15 (4.45)</td>
<td>12.25 (4.26)</td>
<td>5.54</td>
<td>p&lt;.001</td>
</tr>
<tr>
<td>Dependency</td>
<td>0-20</td>
<td>11.81 (3.98)</td>
<td>10.26 (4.00)</td>
<td>5.61</td>
<td>p&lt;.001</td>
</tr>
<tr>
<td>Loss</td>
<td>0-28</td>
<td>13.96 (4.59)</td>
<td>11.56 (4.70)</td>
<td>7.67</td>
<td>p&lt;.001</td>
</tr>
<tr>
<td>TOTAL NEGATIVE SCORE</td>
<td>0-208</td>
<td>108.28 (30.19)</td>
<td>93.92 (30.53)</td>
<td>7.25</td>
<td>p&lt;.001</td>
</tr>
<tr>
<td>Good aspects of relationship</td>
<td>0-24</td>
<td>12.21 (4.10)</td>
<td>12.71 (3.89)</td>
<td>-1.73</td>
<td>p=.11</td>
</tr>
<tr>
<td>Positive personal experiences</td>
<td>0-32</td>
<td>17.27 (4.81)</td>
<td>17.85 (4.46)</td>
<td>-1.60</td>
<td>p=.08</td>
</tr>
<tr>
<td>TOTAL POSITIVE SCORE</td>
<td>0-56</td>
<td>29.45 (7.42)</td>
<td>30.46 (6.78)</td>
<td>-1.89</td>
<td>p=.06</td>
</tr>
</tbody>
</table>

Graph:
- **p<.001**
- *p<.05*
Caregivers’ Experiences

ECI TOTAL NEGATIVE SCORE

PRE FOLLOW UP

ECI NEGATIVE SYMPTOMS SCALE

PRE FOLLOW UP

ECI NEED FOR BACK UP SCALE

PRE FOLLOW UP

ECI LOSS SCALE

PRE FOLLOW UP
Attitudes Towards Psychosis

Psychosis Attitude Scale (Sivec et al., 2020)

- Evaluated on a 1 (Strongly Disagree) to 7 (Strongly Agree) scale

PAS Total: Statistically significant changes over time \(F(1.852, 201.832) = 118.660, p < .0001, \text{ partial } \eta^2 = 0.521\)

- Pre -> Post: +16.07 pts (p < .0001)
- Post -> F/u: -2.25 pts (p < .05)
- Pre -> F/u: +13.81 pts (p < .0001)

Subscales: All demonstrated statistically significant changes over time, with the following observations:

- **Empathy & Adequacy:**
  - Statistically significant increase from Pre->Post
  - No statistically significant change observed from Post->Follow-up
  - Relationship of Pre->F/u is a statistically significant increase

- **Optimism:**
  - Yielded statistically significant increase from Pre-Post
  - Statistically significant decrease Post->F/u
  - Relationship of Pre->F/u is a statistically significant increase
Attitudes Towards Psychosis

**PAS TOTAL SCORE**

**OPTIMISM SUBSCALE**

**ADEQUACY SUBSCALE**

- One-Day Only
- Intensive Training
Caregiver Depression & Anxiety

Hospital Anxiety & Depression Scale (HADS)

- **Anxiety**
  - Statistically significant reduction between Pre->Post (-1.09 score) which persisted through F/u (-1.10 score; \( p = .002 \))
  - No statistically significant change between Post->F/u \( (p=.792) \)
  - No difference between groups

- **Depression**
  - Statistically significant reduction between Pre->Post (-0.52 score, \( p = .007 \)) and Pre->F/u (-0.61 score; \( p = .04 \))
  - No statistically significant change between Post->F/u \( (p=.882) \)
  - No difference between groups

![Graph showing depression and anxiety scores](image-url)
Family Attitude Scale

- On a scale of “Every Day” (4) to “Never” (0)
- Scores range from 0-120; higher scores indicate higher levels of burden or criticism
- Statistically significant change in scores over time [$F(2, 214) = 32.969, p < .0001$, partial $\eta^2 = 0.236$]
- Statistically significant Pre->Post (-7.21 points, $p = .0001$) and Pre->F/u (-7.99 points, $p = .0001$)
- No statistically significant change in points between Post->F/u ($p=.664$)
- No differences between groups

Cutoff: ≥ 50 (Kavanaugh et al., 1997)
Self-Rated Mastery of CBT-Informed Skills

**FIRST Skills**
- Rated on a 1 (Minimal/Not Familiar) to 5 (Expert/Advanced) scale across five dimensions
  - Forming a Relationship
  - Inquire Curiously
  - Review the Information
  - Skill Build
  - Try Out the Skill
- Repeated Measures ANOVA conducted to determine differences across time

### Graph Description
- **Total**, **F Scale**, **I Scale**, **R Scale**, **S Scale**, and **T Scale**
- Pre, Post, Follow Up
- **p<.05**, **p<.001**
Self-Rated Mastery of CBT-Informed Skills

- FIRST Skills

“TRY OUT THE SKILL”

- One-Day Only
- Intensive Training
Doug, Sarah, Maria, and Kate were the first to tell me there was hope with our son. After many different Social Workers, LMHC and Psychiatrists telling us that there is nothing you can do for schizophrenia (but over medicate) - we were given HOPE! I do not say this lightly - **This program saved our family!** Our life is so much calmer/peaceful now. Through education and CBTp Skills we have our son back. Through befriending and curiosity, as parents we are no longer the enemy. These are simple skills - not easy - but once incorporated peace is back in the house. And after sharing these skills I have learned with other parents I know I am not the only one that it helps. Many parents have said once they use the curiosity questioning their loved one in psychosis becomes calmer. Our gratitude for this program is overwhelming. Thank you does not begin to cover it. It works if you work it!
Next Steps for Psychosis REACH
Expand Psychosis REACH
Next Psychosis REACH Foundational Training

- Next p-REACH training is scheduled for October 15-16, 2020 in WA
  - Bring together ~150 family members
  - 7 hours, including experiential and interactive exercises (+ networking time)
  - Broken into two days, 3-4 hours each
  - Includes supplemental materials
  - Leverage interactive app and webinars
Psychosis REACH Family Ambassadors

- Attend training; serve as Ambassadors; Identify who they are on the app and where they’re located
- Lend new families their hope
- After October training, start up monthly p-REACH Ambassador calls with UW training team, focused on helping new family members, developing comfort with training slides, connection to one another
Psychosis REACH Hub & Spoke Model in WA State
Psychosis REACH Nationally

- The virtual model is highly scalable.
- But, must be mindful of the limitations:
  - No CBTp Provider Network
  - No Family Ambassadors
  - Questionable capacity for follow-up skills training
- While we know that a 1-day training is helpful, more is better.
Thank you!

Contact:
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