

Building Community with Psychosis REACH

Victoria Shepard, BS

Karen Schilde, MA

SPIRIT Lab, University of Washington

NAMI WA Conference 2023

Who we are



Psychosis REACH Program Coordinator
Research Coordinator at the SPIRIT Lab



Family Ambassador, Family to Family
State Trainer, Teacher, Support group
facilitator



With tremendous gratitude to
Psychosis REACH
colleagues and families...

Let's do a quick poll!



1. Heard about p-REACH?
2. Attended training?
3. Already connected with a Family Ambassador?

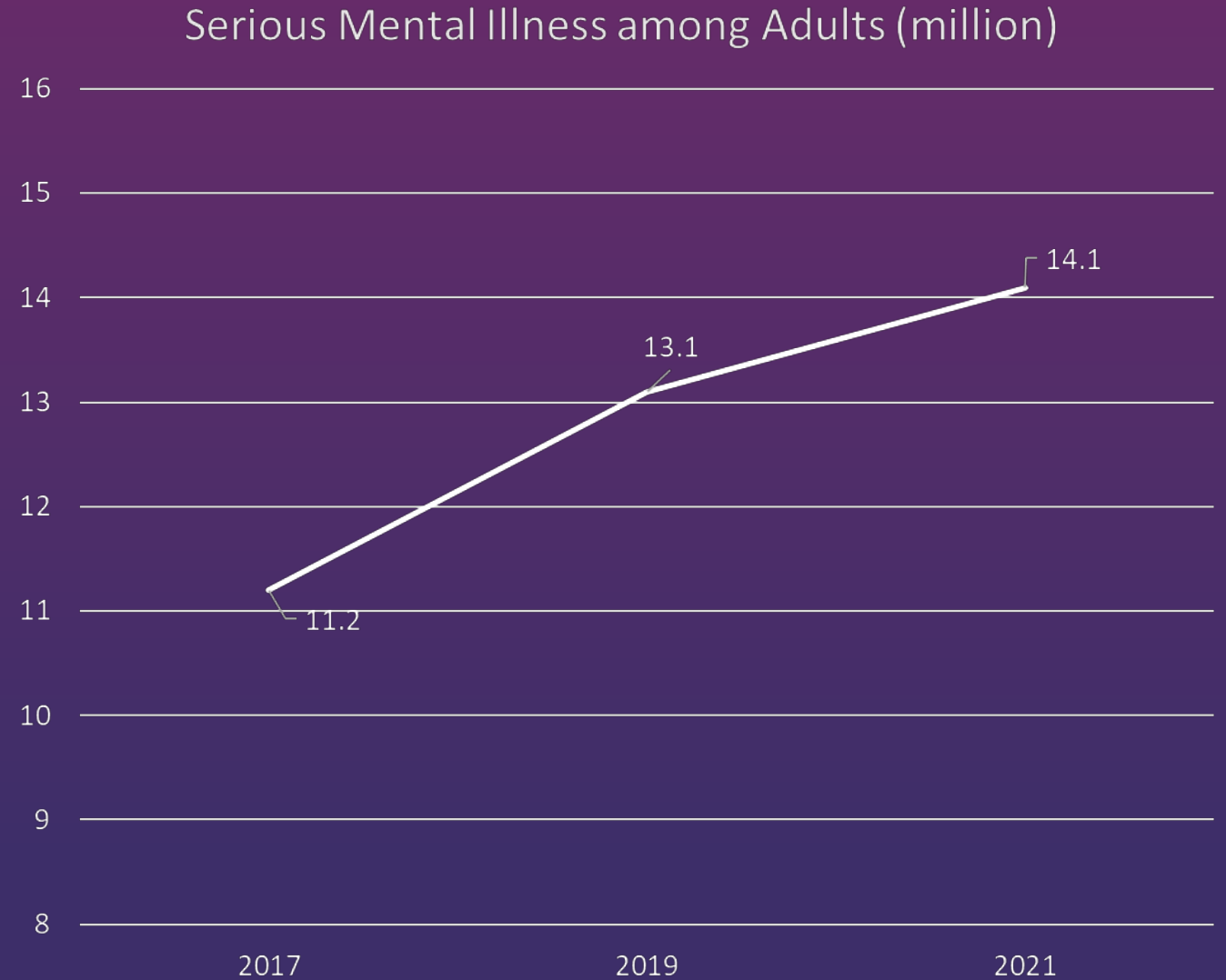
Primary objectives for today

- ✓ Introduce the Psychosis REACH (p-REACH) and the hybrid model
- ✓ Understand the role of p-REACH Family Ambassadors
- ✓ Discuss p-REACH cultural adaptations of a pilot study in Lahore, Pakistan

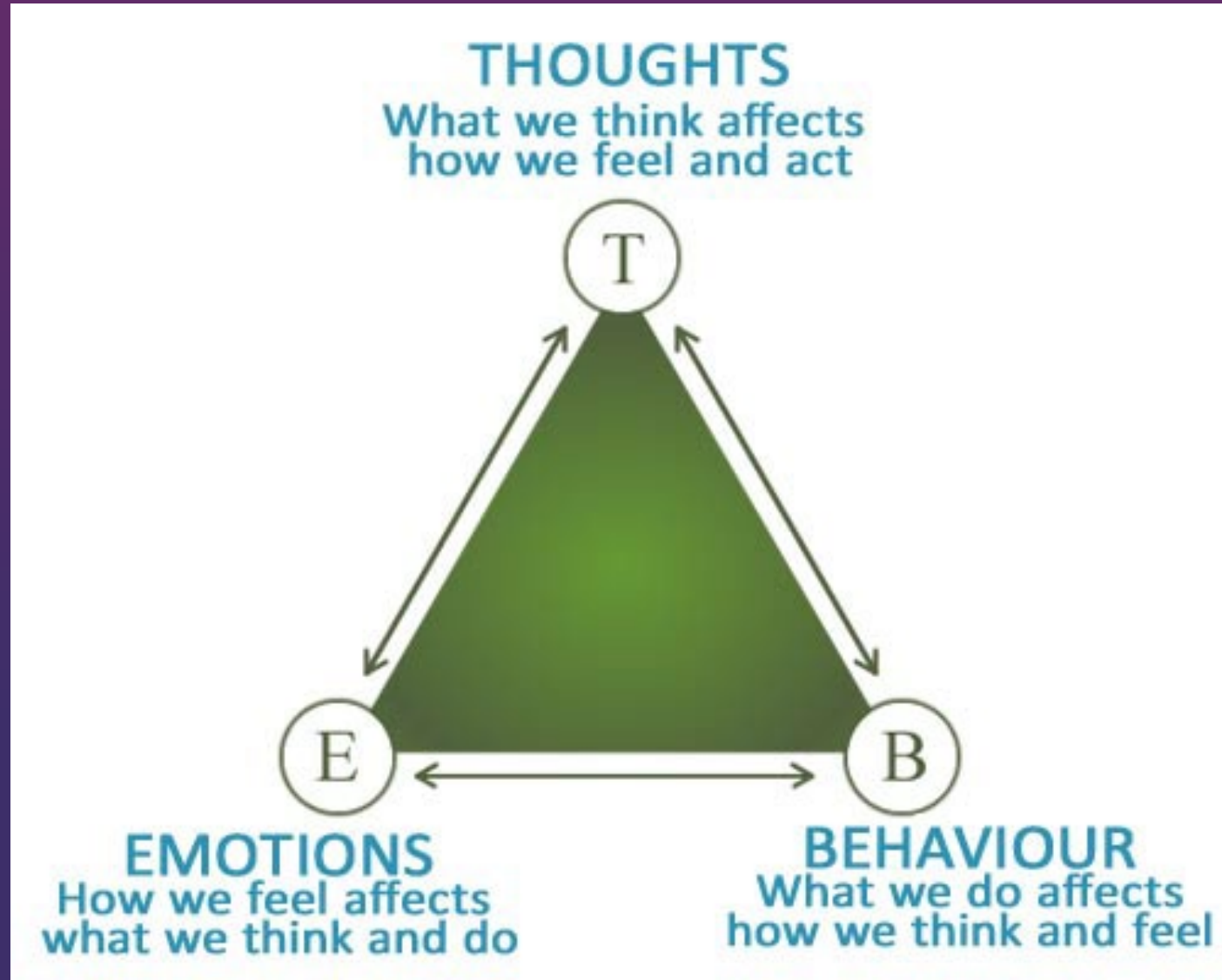
Terms

- **Caregiver** : family member, significant other, or other close support to someone experiencing psychosis
- **Loved one** : will be used to refer to the person experiencing psychosis
- **Psychosis** : a collection of mental health symptoms involving disruptions in the experience of reality. Can include:
 - Hallucinations
 - Delusions
 - Disorganized thinking/behavior

- Among adults aged 18 or older in 2021, 5.5% (14.1 million people) experienced SMI in the past year.
- Only 2% of people with SMI receive evidence-based treatments (Kopelovich et al., 2021)



Cognitive Behavioral Therapy for psychosis



CBTp around the world

- The UK's National Institute for Health and Care Excellence (NICE), guidelines recommends that **ALL people with schizophrenia or other forms of psychosis be offered CBT within 7 days** of a psychotic disorder diagnosis (NICE, 2014)
- **35%** of individuals seeking therapy in the UK for psychotic symptoms will receive CBTp (Kopelovich, 2021)
- The National Audit of Schizophrenia in the UK (NAS2; Royal College of Psychiatrists, 2014), estimated that **39%** of service users had been offered CBT

CBTp still remains inaccessible

Fewer than half of Americans with SMI have access to standard care practices

Less than 1% receive CBTp

Routine implementation of CBTp has proved difficult in North America

Social determinants of health impact access for underserved communities

Why do family interventions matter?

- Up to 90% of individuals with psychosis remain in close contact with caregivers
- Caregivers are often the sole source of emotional, financial and social support
- International treatment guidelines for the schizophrenia-spectrum disorders include the delivery of family interventions (NICE, 2002, 2014)



Caregivers have a positive impact on recovery

- Better treatment outcomes (Glick, Stekoll, Hays, 2011)
- Fewer hospital admissions and reduced relapse rates (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)

Caregiving affects caregivers

1. Caregivers experience overall work impairment and indirect costs
2. Clinical levels of depression
3. Studies comparing family caregivers to inpatient psychiatric staff show both groups experienced equal levels of burnout and emotional exhaustion

What is Psychosis REACH?

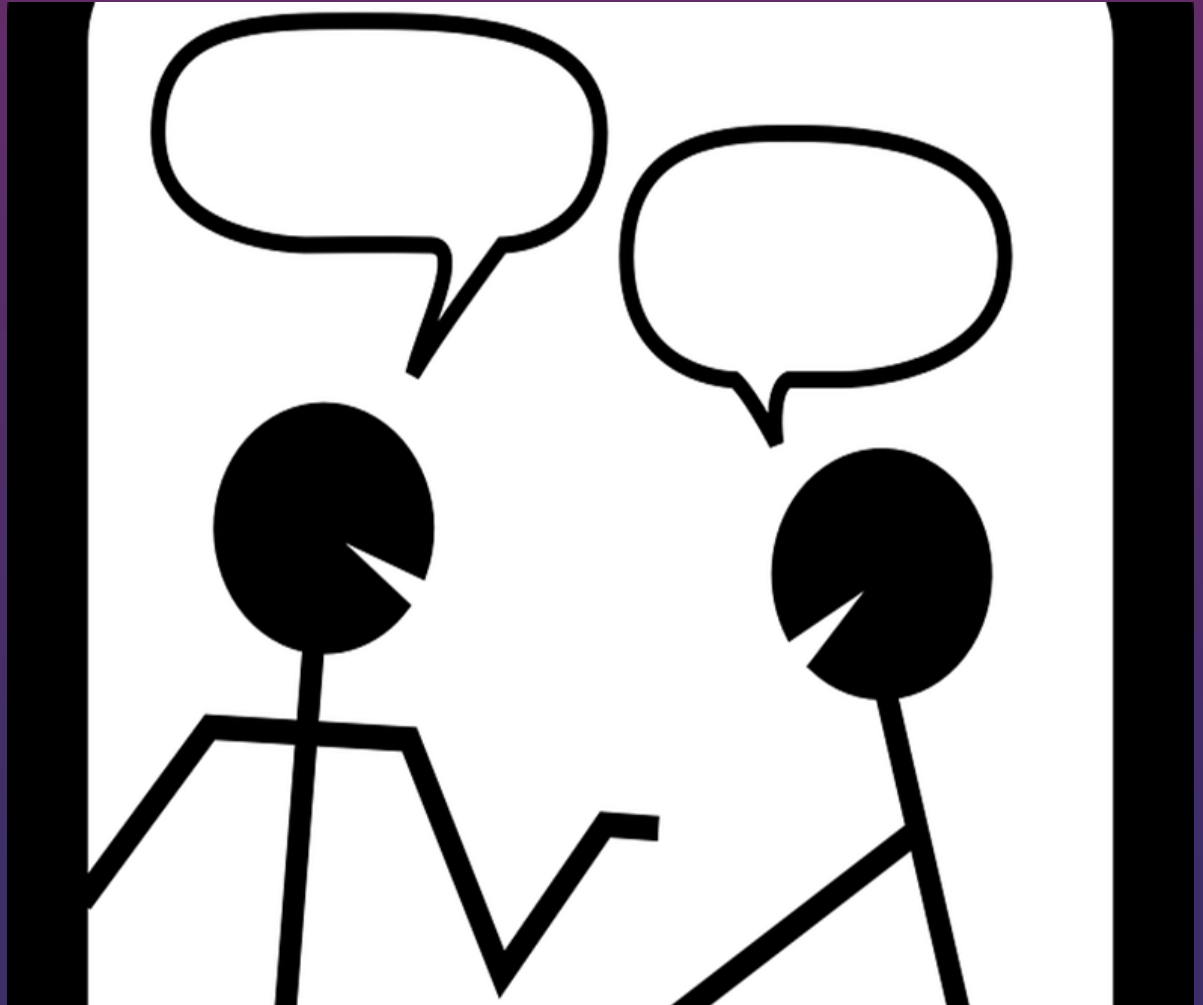
Psychoeducation

Caregiver Self-Care

FIRST Skills

FIRST Skills

- Fall back on your relationship
- Inquire Curiously
- Review the information and put it together
- Skill development
- Try out the skill and get feedback



Hardy et al. (2020)

Qualitative Feedback from Family Participant

"I do not say this lightly - This program saved our family! Our life is so much calmer...peaceful now. Through education and CBT 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. And after sharing these skills with other parents I know I am not the only one that it helps.

Our gratitude for this program is overwhelming...It works if you work it!

Original Training Approach

1-Day Core Training: Global Overview

+

3 Days of Intensive Training: Rehearsal of
FIRST skills

Outcomes for caregivers

- Reduced burnout
- Reduced expressed emotion
- Reduced anxiety and depression
- More prosocial attitudes toward psychosis
- Adoption of a recovery orientation

<https://ps.psychiatryonline.org/doi/10.1176/appi.ps.202000740>

Psychosis REACH: Effects of a Brief CBT-Informed Training for Family and Caregivers of Individuals With Psychosis

Sarah L. Kopelovich, Ph.D., Bryan Stiles, B.A., Maria Monroe-DeVita, Ph.D., Kate Hardy, Clin.Psych.D., Kevin Hallgren, Ph.D., Douglas Turkington, M.D.

Objective: Psychosis Recovery by Enabling Adult Carers at Home (Psychosis REACH) is a training for families of individuals with psychosis that consists of recovery-oriented information, support, and skills training. This study assessed the effects of a 1-day training on the natural supports (i.e., family and other caregivers) of individuals with psychotic disorders.

Methods: Attendees of a 1-day (N=168) and a 4-day (N=29) Psychosis REACH training were surveyed at three timepoints: pretraining, posttraining, and 4-month follow-up. Longitudinal changes across the full sample were evaluated by paired-sample t tests or a one-way repeated-measures analysis of variance (ANOVA). Two-way mixed ANOVAs were conducted with training condition, time, and the training condition × time interactions entered into the model.

Results: Reductions were noted in self-perceived depression, anxiety, negative aspects of the caregiving experience, and expressed emotion. Trainees also showed more prosocial attitudes toward psychosis immediately and at 4 months after the training.

Conclusions: This evaluation of the launch of Psychosis REACH in the United States suggests that the training can improve the mental health, attitudinal, and relational outcomes of family and caregivers of individuals with psychosis. Given the dearth of CBTp and family interventions for psychosis in mental health services in the United States, short-term, intensive training that supplements clinical services has intuitive appeal as a means of surmounting the barriers that have plagued family interventions.

Psychiatric Services 2021; 00:1–7; doi: 10.1176/appi.ps.202000740

Limitations of Original Approach



Accessibility



Reach



Cost

Hybridized Approach

1

- Asynchronous 5-hour online course

2

- Synchronous 3-hour live workshop

3

- Connecting with Family Ambassador

Methods

Survey Completed at 3 Time Points
with 3 cohorts

Learner Outcomes Assessed

- Expressed emotion
- Mood
- Attitudes toward psychosis
- Caregiver burnout
- Skill mastery

Prior to enrolling in
online course



Immediately
following live
workshop



4 months after live
workshop

Findings



Increased geographical reach



Improved skill retention and decrease in anxiety and depressive symptoms – learning outcomes still sustained



Participants found model acceptable and feasible

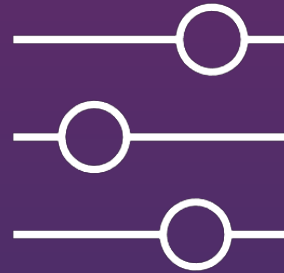
Limitations



Majority of participants white, highly educated mothers of adults with psychotic spectrum disorder

Difficulty engaging diverse participants and communities

Is current ongoing effort – cultural adaptations in non-western communities



Difficult to assess participant engagement with materials



No data collected on experience of loved ones during process

Looking forward!

- Psychosis REACH Training Hubs
- Increasing accessibility/cultural adaptations being further developed
- In development for World Health Organization (WHO) endorsement as a Family Intervention for Psychosis (FIp)

Collaborating with Family Ambassadors — in Delivering Psychosis REACH

Who am I?



- Family Ambassador
- NAMI state trainer for Family to Family
- Mom of son living with schizoaffective disorder
- Fan of Clubhouse international and helped to establish Everett Clubhouse

Objectives

Part 2

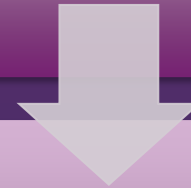
- ✓ Discuss the Psychosis REACH Family Ambassador Program
- ✓ Discuss caregiver self-care
- ✓ Take home coping skills

The importance of caregivers

- Caregivers:
 - Advocate
 - Encourage to engage in and seek treatment
 - Promote medical (including medication) adherence
 - Help identify early signs of relapse
 - Facilitate access to clinical services
 - Facilitate recovery and connection with society

Psychosis REACH Family Ambassador (pRFA) Program

Complete online self-paced course



Attend a Psychosis REACH Live Event



Connect with a pRFA

What a Family Ambassador is

- A family member of a loved one with psychosis who has undergone training to provide support to other family members and caregivers using the psychosis REACH Model (p-REACH)
- A family member who provides three things:
 - Emotional Support
 - Skills Coaching
 - Reviewing of CBT informed FIRST Skills and content

What a Family Ambassador is NOT

- NOT expected to:
 - Be a case manager, therapist, family navigator
 - Be a counselor for the family in de-escalation techniques or address other safety issues
 - Be available on-demand; it is a time limited role.

How do we combat caregiver stigma?

- Caregivers live in the shadows despite being on the frontlines of their loved one's illness
- Psychosis REACH Family Ambassadors aim to encourage:
 1. Psychoeducation for the public
 2. Normalizing the caregiving experience
 3. Community and connection with other carers

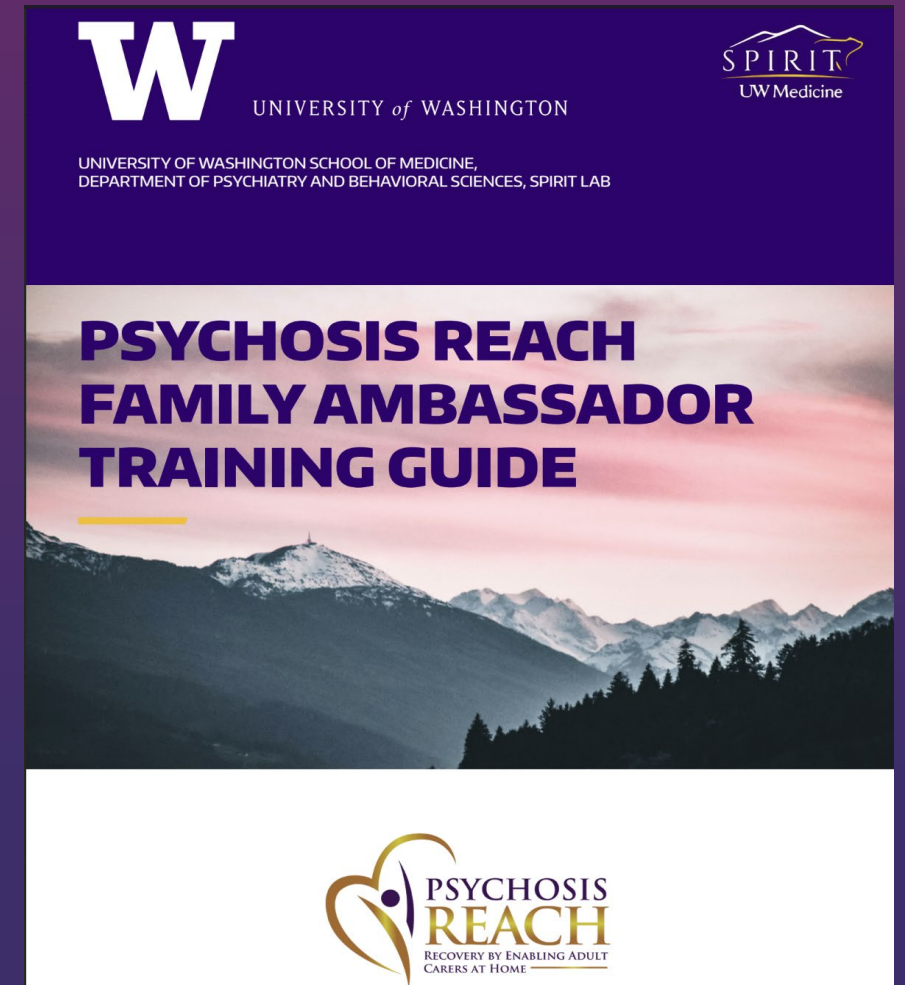
How do pRFAs work with other carers?



- One on one guidance, coaching and/or emotional support
- Mini collaborative teaching sessions with a small group to clarify and expand understanding of CBTp principles and skills
- Small group (4-6) coaching and practice with FIRST Skills
- Workshop style (writing, self-care, etc.)

What does the pRFA training look like?

- Initial attendance at a p-REACH training
- Year long training that involves:
 - Access to curriculum materials
 - “Flipped classroom” approach
 - Monthly “live” Zoom consultation calls



Theme 1

“It changed our family. I mean, I felt like we lived in a war zone prior to attending Psychosis REACH.”

The psychosis REACH program supported the development of hope and recovery for families

Theme 2

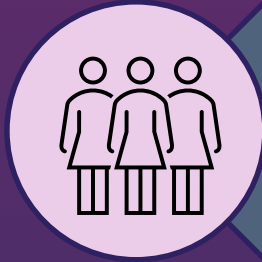
“You're just not going to get it [from professionals]. You get it from people who are suffering through the same things that you are.”

Development
of solidarity networks:
Education and skill-
building in community

Where are we today?



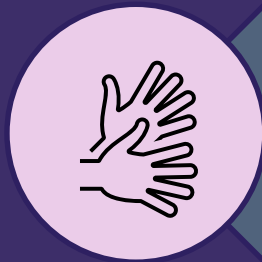
Over 1400 caregivers have registered to attend a Psychosis REACH live training event to date from 7 different countries



23 caregivers have been trained as pRFAs

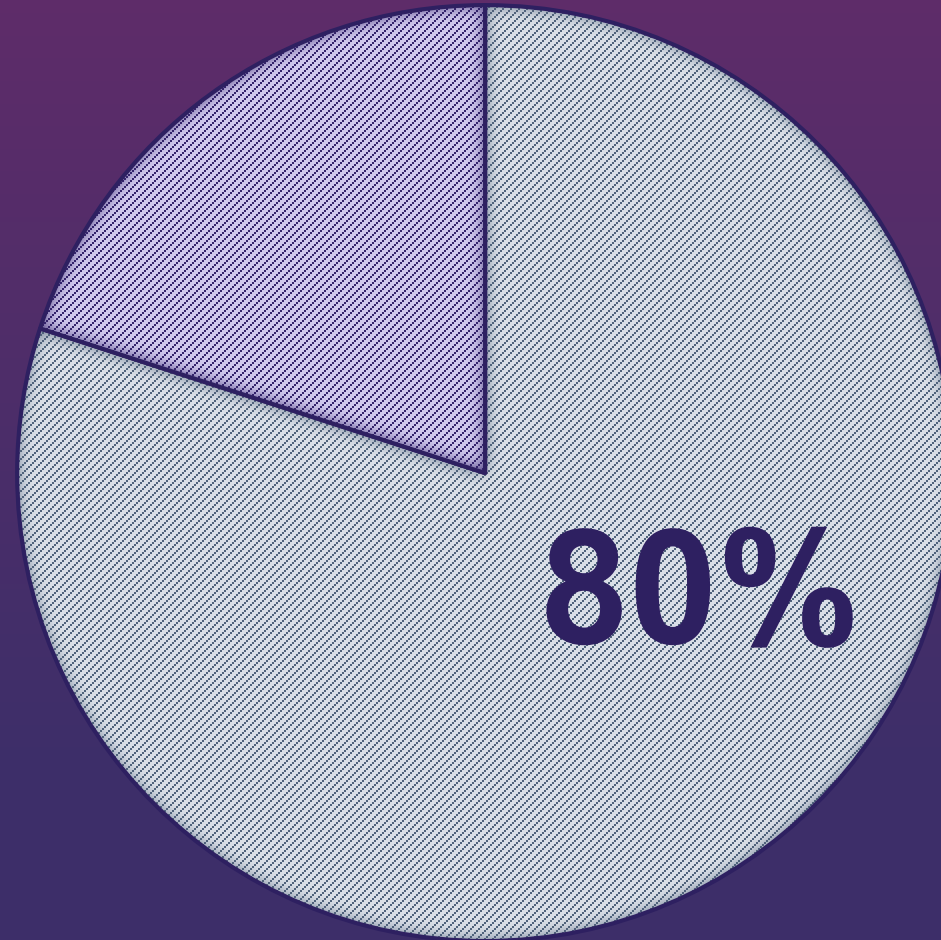


19 caregivers will be trained as a Family Ambassador in 2024



Language expansions for pRFA groups (groups and materials will be in Spanish, Mandarin and Cantonese in 2024)

Percentage of caregivers who show signs of burnout



(Tamizi et al., 2020)







- ☹️ What is psychosis?
- ☹️ Can we make sense of it?
- 😊 Communicating, coping and discovering
- 😊 Activating positive emotions and achievements

BACK TO LIFE, BACK TO NORMALITY

VOLUME 2

*CBT informed recovery for families
with relatives with schizophrenia
and other psychoses*

**Douglas Turkington
and Helen M. Spencer**

Foreword by Aaron T. Beck





HOW AM I DOING TODAY...?

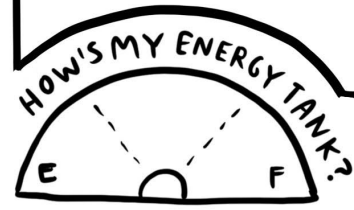
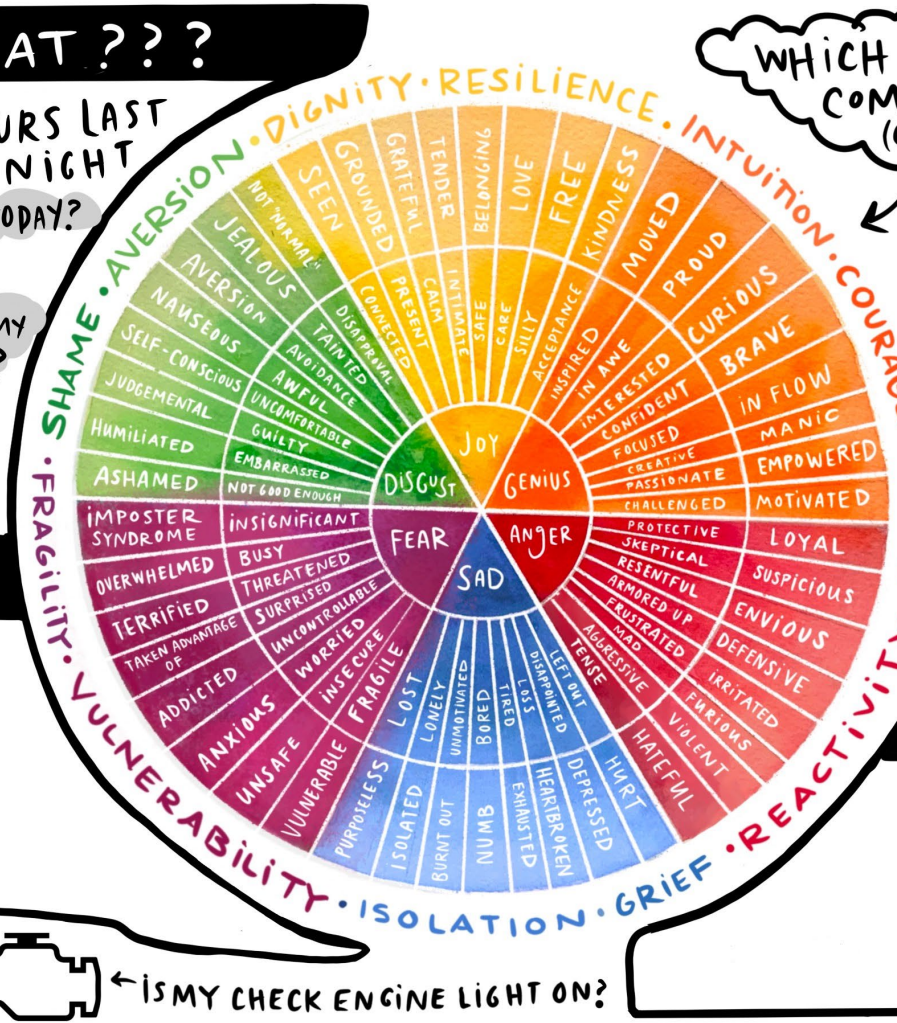
WHERE AM I AT???

Zzz... I SLEPT _____ HOURS LAST NIGHT
WHAT HAVE I EATEN/DRANK TODAY?

HAVE I GONE OUTSIDE? ... MOVED MY BODY?

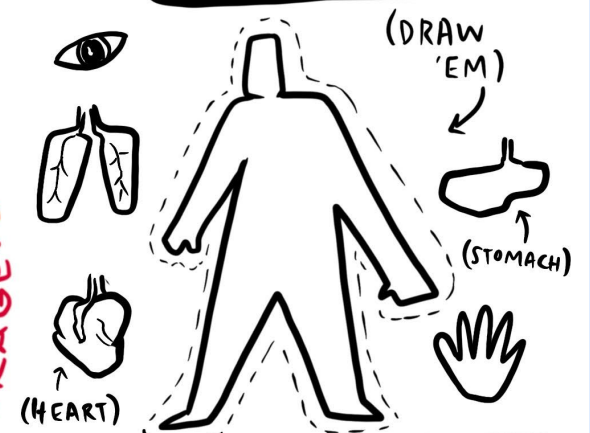
TAKE A NICE BREATH ♡
WHAT'S GOING ON IN MY WORLD?

HOW'S MY ENERGY TANK?
E F

WHICH EMOTIONS ARE COMING UP FOR ME? (CIRCLE 'EM)

WHERE DO I NOTICE THEM IN & AROUND MY BODY?

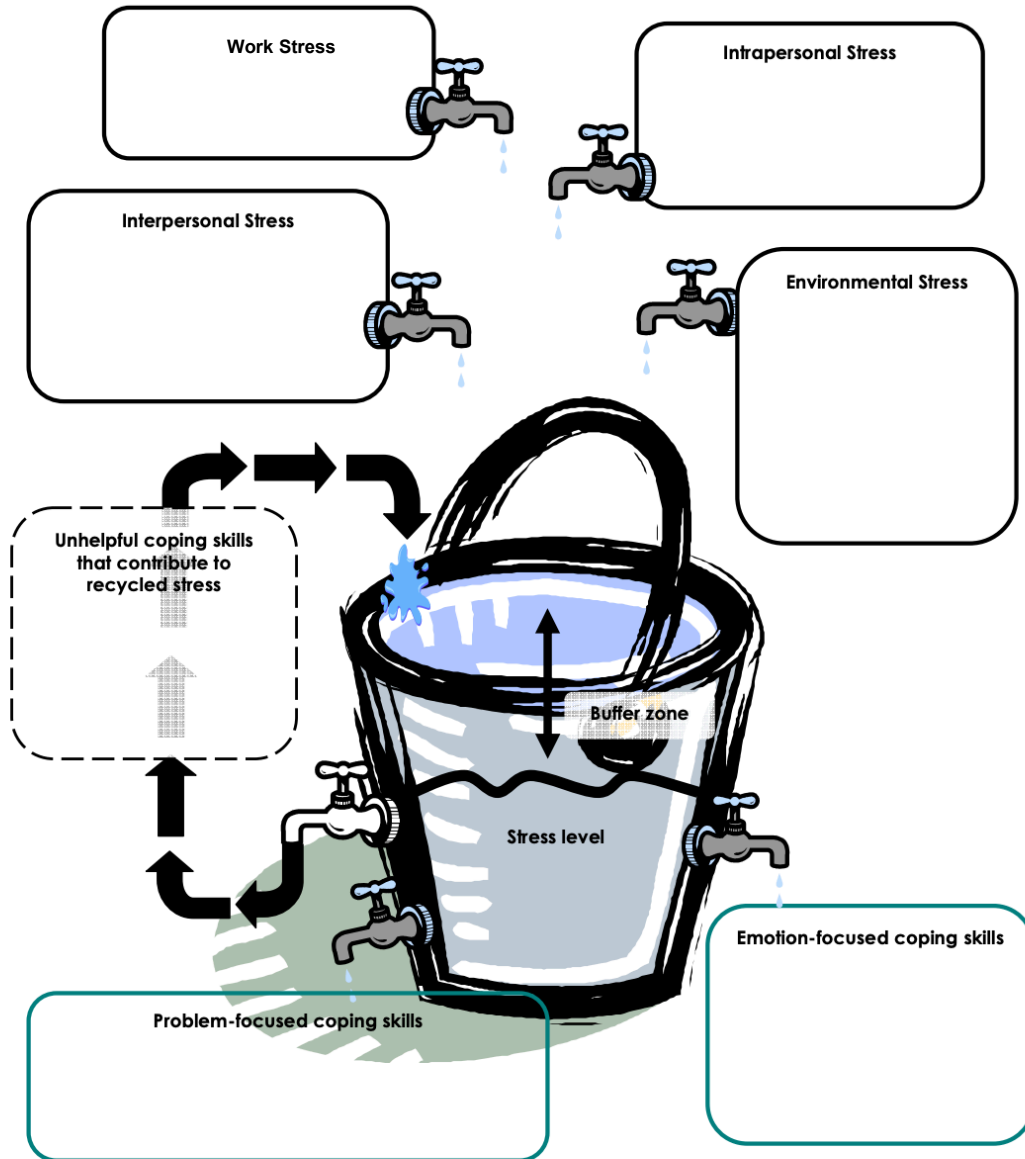


WHAT IS MY BODY TELLING ME?
WHAT DO I NEED & HOW CAN I CARE FOR MYSELF TODAY?

← IS MY CHECK ENGINE LIGHT ON?

@AVANMUIJEN

My Stress Bucket



© 2007 UNSW Counselling Service. Not to be reproduced without the permission of the Director of the Counselling Service. Acknowledgements go to Clare Nabke-Hatton and Leanne Miller for earlier versions of the stress bucket.

This handout is based on the following resources:
 Carver, C.S., Scheier, M.F., & Weintraub, J.K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology*, 56, 267-283.
 Ross, S.E., Niebling, B.C., & Heckerl, T.M. (1999). Sources of stress among college students. *College Student Journal*, 33, 312-317.



Safety Plans Work

There is hope.



1. Write 3 warning signs that a crisis may be developing.

2. Write 3 internal coping strategies that can take your mind off your problems.

3. Who/What are 3 people or places that provide distraction?

(Write name/place and phone numbers)

_____ Phone _____

_____ Phone _____

_____ Phone _____

4. Who can you ask for help? (Write names and phone numbers)

_____ Phone _____

_____ Phone _____

_____ Phone _____

5. Professionals or agencies you can contact during a crisis:

Clinician: _____ Phone _____

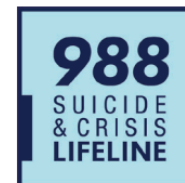
Local Urgent Care or Emergency Department:

Address _____ Phone _____

Call or text 988 or chat 988lifeline.org

6. Write out a plan to make your environment safer.

(Write 2 things)



Step 1

1

2

3

4

Breathe in to a count of 4

BOX BREATHING

Step 4

4

3

2

1

Pause for a count of 4



Hold for a count of 4

Step 2

1

2

3

4

Breathe out to a count of 4

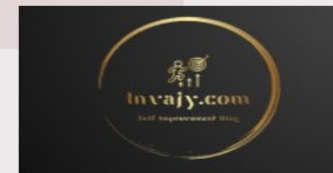
4

3

2

1

Step 3



Stay Calm ♥ Stay Safe ♥ Stay Present



Free printable to help children regulate their emotions.

STRESS
SYMPATHETIC

CALM
PARASYMPATHETIC

PUPILS EXPAND

PUPILS SHRINK

FAST & SHALLOW
BREATHS

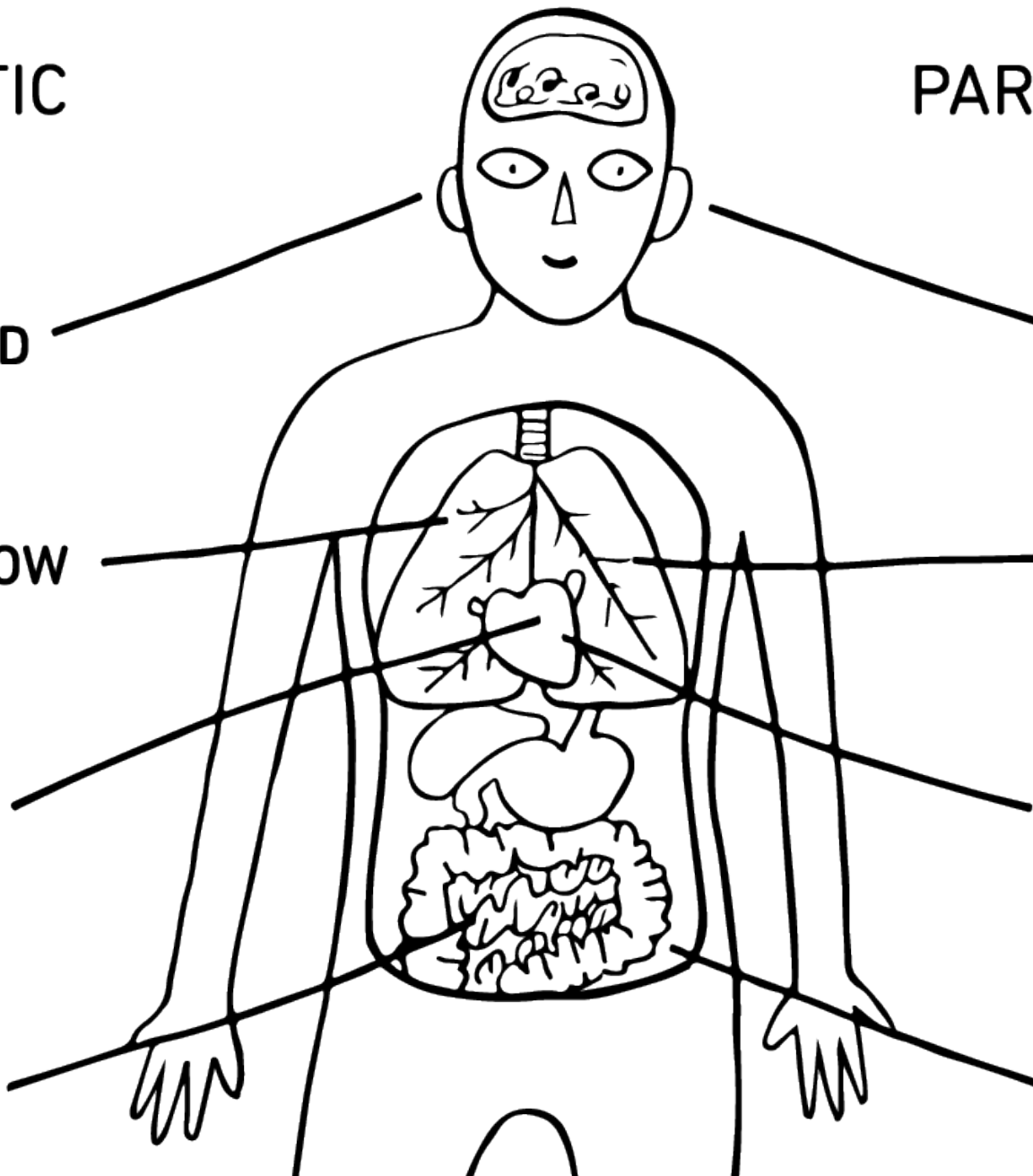
SLOW, DEEP
BREATHS

HEART PUMPS
FASTER

HEART SLOWS

GUT INACTIVE

GUT ACTIVE



Front of the compassion card

Warning signs I'm going south:
Internal strategies to distract myself:
External ways to get my mind off this:
First aid kit: Who, what and where has
worked before to get me back on track?
----- fold here -----
My 2 AM friends I can reach out to
as an island of solace or safety:
NAMES, PHONES, EMAILS, ADDRESSES
When that doesn't help, what else can I try?

Back of the compassion card

BREATHE: Box graphic with arrows, numbers
Circular breathing, 4-7-8, inhale rose
Exhale to blow the candle
SLEEP, WATER, FOOD, SAFETY, AIR
Five senses (5 things I can see, 4 touch, 3 hear, 2 smell, 1 taste)
Power statement or mantra, tapping
Visual calming image with senses
Cold pack on back of neck and forehead or dunk head in ice water
Pet the dog or cat, hum singe, gargle, whistle
Play musical instrument, play favorite music
Aromas lavender, citrus, mint, fidget toys
Meditation, mindfulness, jigsaw puzzles
Arts and crafts, new skill to concentrate on
Nature, exercise, gratitude lists, journaling
Play back recorded messages to self
GABA, tryptophane, magnesium,
Circle: inside what I can control and write outside circle what is out of my control
What can I do for someone else?

My

Card

Warning signs I'm going south:

Internal strategies to distract myself:

External ways to get my mind off this:

First aid kit: Who, what and where has worked before to get me back on track?

My 2 AM friends I can reach out to as an island of solace or safety:
NAMES, PHONES, EMAILS, ADDRESSES

When that doesn't help, what else can I try?

- BREATHE: Box graphic with arrows, numbers
- Circular breathing, 4-7-8, inhale rose, exhale to blow out candle
- SLEEP, WATER, FOOD, SAFETY, AIR
- Five senses (5 things I can see, 4 touch, 3 hear, 2 smell, 1 taste)
- Power statement or mantra, tapping
- Visual calming image with senses
- Cold pack on back of neck and forehead, or dunk head in ice water
- Pet the dog or cat, hum, sing, gargle, whistle
- Play musical instrument, play favorite music
- Aromas lavender, citrus, mint, fidget toys
- Meditation, mindfulness, jigsaw puzzles
- Arts and crafts, new skill to concentrate on
- Nature, exercise, gratitude lists, journaling
- Play back recorded messages to self
- Circle: Inside what I can control and write outside circle what is out of my control
- What can I do for someone else?



Building a community

- Community board
- Continuation of groups with a pRFA
- 1 on 1 consultation with a pRFA
- pRFA Graduation calls (in development)
- Family and Caregiver Advisory Board



Do you want to become a Family Ambassador?

Attend a p-REACH training

Complete brief application

We will connect with you for next steps!

Attend monthly consultation calls



PSYCHOSIS REACH
Recovery by Enabling Adult Carers at Home

UNIVERSITY of WASHINGTON
PSYCHIATRY & BEHAVIORAL SCIENCES
School of Medicine

Psychosis REACH Family Ambassador Info-Guide

What is a Family Ambassador?

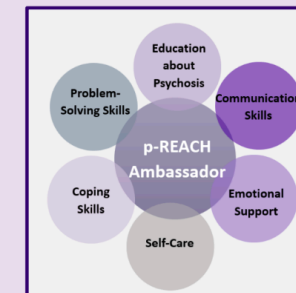
What a Family Ambassador is:

A Family Ambassador is a family member of a loved one with psychosis who has undergone training to provide support to other families and caregivers using the Psychosis REACH (p-REACH) model. A p-REACH Family Ambassador provides three things:

- Emotional support,
- Skills coaching, and
- Reviewing/practicing of CBTp-informed FIRST skills.

What a Family Ambassador is not:

A p-REACH Family Ambassador is NOT expected to act as a case manager, therapist, or family navigator. A p-REACH Family Ambassador is NOT expected to counsel a family in de-escalation techniques or address other safety issues. A p-REACH Family Ambassador makes themselves available, within limits. On-demand access is NOT an expectation for this role.



How do Family Ambassadors work with other caregivers?

Family Ambassadors may choose to connect with other caregivers in a number of ways, including:

- Leading Psychosis REACH groups that meet regularly on an ongoing basis
- Working one-on-one with another family member/caregiver
- Leading a small group training focusing on FIRST skills with or without follow-up

Cultural adaptations of Psychosis REACH in non-western communities

A pilot study in Lahore, Pakistan

Objectives

Part 3

- ✓ Understand the importance of culturally-informed care
- ✓ Discuss a culturally adapted p-REACH pilot study in Lahore, Pakistan
- ✓ Review future directions for culturally adapted p-REACH models of care

Culturally-informed care

Culture plays a role on the effects of psychopathology

“Adaptations ensure relevancy and accessibility”

Racial/ethnic minorities tend to receive poorer quality of care, and have poorer outcomes

Main aim

Can p-REACH be adapted in a community mental health setting in Lahore, Pakistan?

Lahore pilot study background

- More than 80% of people who have mental disorders reside in LMICs
- Family interventions (FI) are recognised to empower caregivers
- Few families with a loved one with SMI have received a FIp (ISMICC, 2016)
- Culturally adapted FI has been shown to be feasible in a study in Pakistan (Husain, 2020)
- Unique challenges

The Team

Prof Shanaya Rathod – CI and SPIRIT Lab Psychosis REACH Team

- Dr Peter Phiri
- Prof Afzal Javed
- Rehmina Iqbal
- Dr Imran Haider
- Ayaat Al-Sudani
- Prof Sarah Kopelovich
- Jennifer Blank
- Dr Akansha Vaswani-Bye
- Prof Kate Hardy
- Prof Doug Turkington

Study location

Fountain house – Lahore, Pakistan



Methods

Translated materials into Urdu

Administered surveys at 3 time points to N=40 caregivers and their loved ones

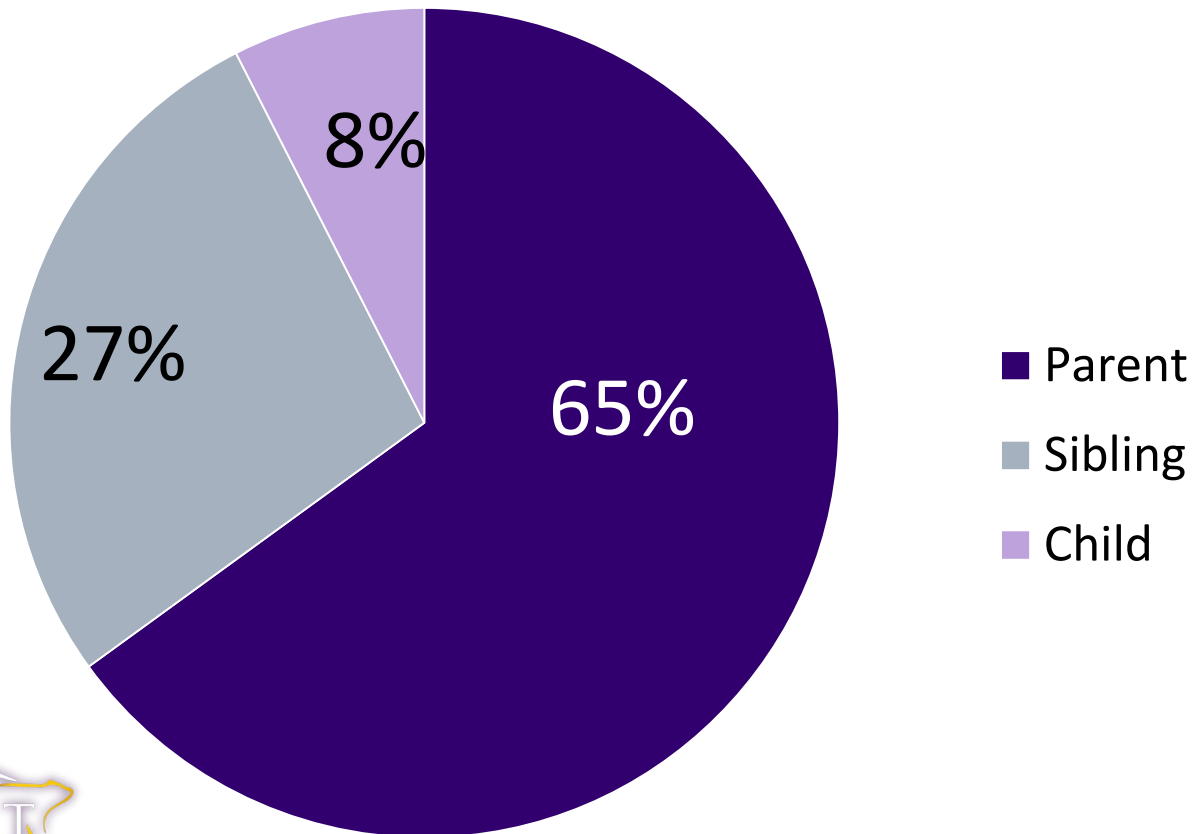
Looked at outcomes before and after culturally-adapted training



Demographics

Caregiver Demographics (N = 40)

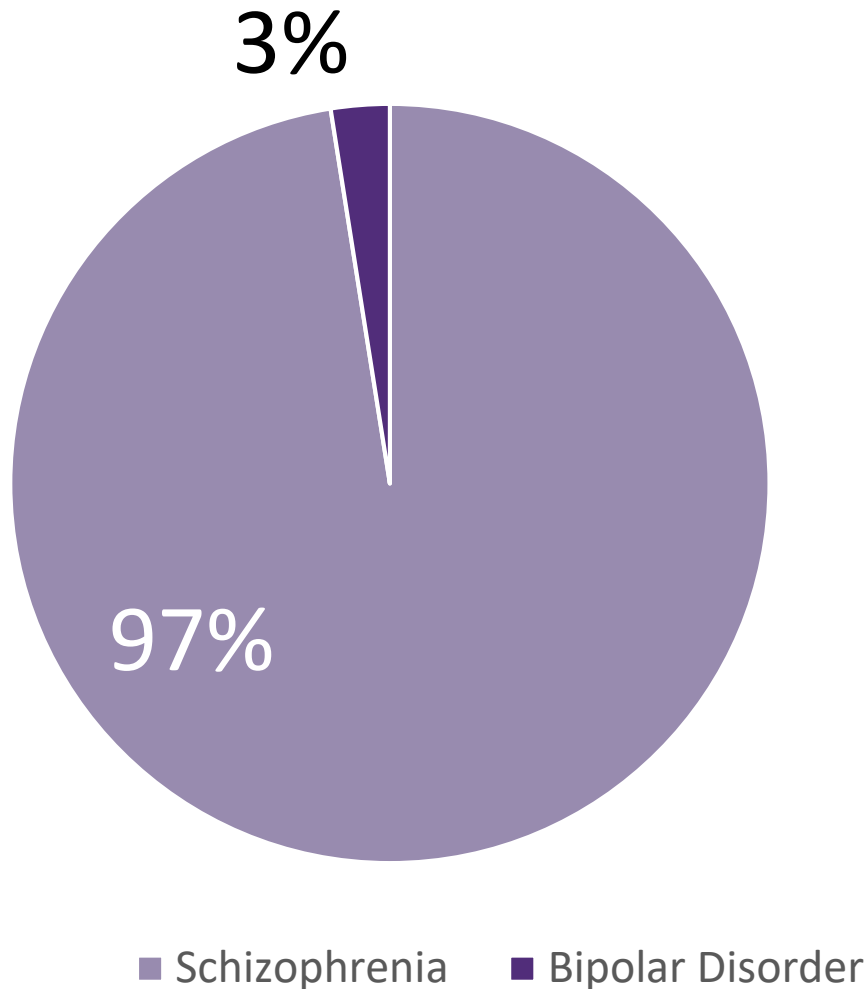
Relationship with Loved One



- A majority (62.5%) were female
- 60% attended school
- 67% were in middle SES
- Half were employed
- 72.5% Married
- 80% urban

Lahore Patient Demographics (N = 40)

Patient Diagnosis



- Average age was 34 years old
- 55% were male
- 60% Punjabi, 25% Afghan
- 62% had some sort of schooling (GED, training)
- 52% were employed
- 55% were married

Caregiver outcomes



Increased comfort with FIRST Skills



Decreased anxiety, depression symptoms, and improvement in psychological wellbeing



Rated highly acceptable, appropriate and feasible to implement

Loved one outcomes



Significant decrease in positive and negative symptoms among (N=34) loved ones after their caregivers took the culturally-adapted-REACH training

Key Takeaways

- The study showed that culturally adapted p-REACH intervention was acceptable, appropriate and feasible in the participant sample in Lahore, Pakistan
- Retention was high
- There was an improvement in caregivers' anxiety levels and all aspects of PWS
- There was an improvement in the patient's positive and negative symptoms
- Implications for further large trial to establish generalizability for other non-western cultures



— Takeaways from today's workshop

Psychosis REACH (Recovery by Enabling Adult Carers at Home)

🏠 [Home](#) » Psychosis REACH Training

What is Psychosis REACH?

Psychosis REACH is a training that offers concrete, evidence-based skills for relatives and friends of individuals with psychotic disorders to better care for and relate to their loved ones. It takes a proven psychotherapy for people with schizophrenia and other psychotic disorders, Cognitive Behavioral Therapy (CBT), and modifies it to the needs of caregivers.

[Click here to download a shareable Psychosis REACH flyer.](#)

Want to Bring Psychosis REACH to Your Region?

Psychosis REACH Trainers and Developers



Translate »

Psychosis REACH website:

www.psychosisreach.org

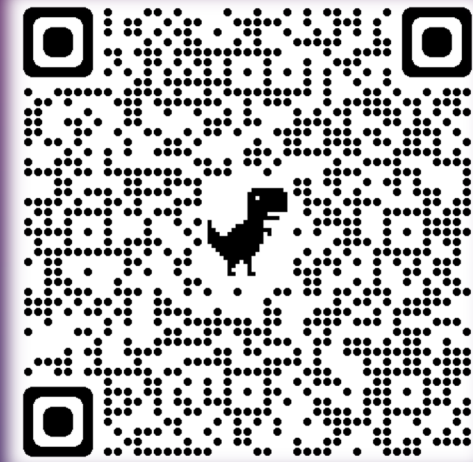
Email us: psychosisREACH@uw.edu



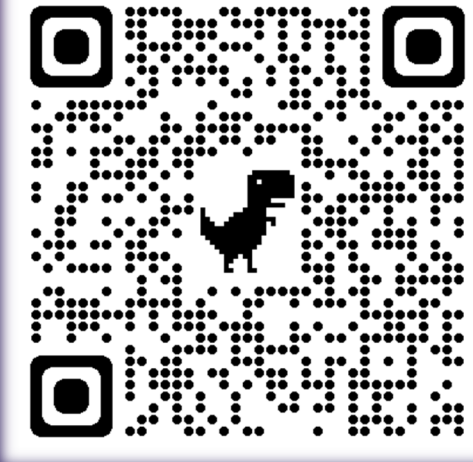
Next training:
December 8th, 2023!

Resources for CBTp learners/practitioners

*To learn more about CBTp Trainings:
Email us at uwspiritlab@uw.edu*



*If you are interested in implementing
CBTp at your agency, please complete
our [CBTp Training Intake Form](#).*



QUESTIONS?
