CF-CBT: A Preventive Intervention for Depression and Anxiety in Adults with CF

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Assessing & Treating Depression & Anxiety in CF

Ongoing Prevention & Psychoeducation
Coping with medical stressors
Supportive Care

Clinical Concerns:
Depression/Anxiety

Annual Screening:
Depression/Anxiety Symptoms

Administration of PHQ-9 & GAD-7

Normal Range
Mild Range
Elevated Range:
Moderate — Severe

Supportive Intervention
Psychoeducation

Clinical Assessment:
Impairment — Patient Preferences — Safety

Evidence-Based Psychological and/or Psychopharmacological Intervention

Annual Screening
Rescreen
Clinical Assessment
What exactly is CBT?

- A brief, goal-oriented psychotherapeutic treatment
  - Strong empirical support for preventing and treating anxiety and depression (Butler, Chapman, Forman, Beck, 2006)
- Targets emotions by changing thoughts and behaviors that are contributing to distress (Cully & Teten, 2008)
- A key component of CBT is the focus on skill-building
CBT Treatment Approaches

**Cognition**
- Anticipate or Modify
- Triggering Situation or Event
- COGNITIVE RESTRUCTURING

**Emotion**
- RELAXATION TRAINING

**Behavior**
- ALTERNATIVE COPING RESPONSES
“What if I have trouble breathing when I leave the house? I might have a panic attack. I can’t believe I’m so weak.”

Cognition

Emotion
Anxious

Behavior
AVOIDANCE –
Social Withdrawal, Missed Medical Appointments
"I’ve had difficulty before and survived. It’s o.k. and normal if I am anxious. I can be anxious, and still go. I can take a break and use relaxation skills if I need to. Once out of the house and having fun, I often feel less anxious and can go further than I thought I would.”

Cognition

Emotion
Feeling better, proud, less lonely

Behavior
Getting out with friends; more engaged in treatment
How does traditional CBT need to be tailored for this population?

- Address the connection between emotional and physical health
- **Normalization and destigmatization**
  - One component of overall CF care
  - Use of evidence-based preventive strategies
  - Validation of the emotional challenges that naturally accompany having this disease
  - Worry thoughts may be realistic – focus on acceptance, self-compassion, building resilience
- Help patients to change thoughts and behaviors that impede self-care
- Brief interventions for use in clinic settings
Goals of CF-CBT Program

- To develop a CF-specific CBT preventive intervention tailored to the specific needs of adults with CF
  - 8 sessions covering core CBT skills
  - For adults with mild-range PHQ-9/GAD-7 screens
  - Promote overall well-being, treat mild symptoms, prevent escalation of symptoms
- Flexibly delivered, and integrated into routine CF care
  - Trained interventionists from multiple disciplines who understand CF
  - In-person or by telephone, outpatient or inpatient
- Developed with input from adults with CF and CF care team members
Development of CF-CBT

- Funded by Vertex Circle of Care Award and CFFT
  - Co-PIs Deborah Friedman & Anna Georgiopoulos
- In-depth feedback collected via audio-recorded interviews: 16 adults with CF from 3 CF centers
  - Purposive sampling for gender, age, ethnicity, disease severity
  - Focus groups of CF care team providers
- Iterative development of CF-CBT manual and training incorporated feedback on
  - Intervention structure and content
  - Tailoring CBT strategies to meet CF-specific stressors and needs
  - Integrating into CF care
16 adults with CF from Boston (MGH), Buffalo and Miami participated in semi-structured interviews.

- Aged 21 to 53 years (M=35)
- 50% Female
- 3 identified as Hispanic/Latino
- Patient-reported FEV1 from 25-113% predicted (M=72)
- 1 patient was post-transplant
- 8 reported having had a past or present diagnosis of depression or anxiety
- 13 had participated in mental health treatment (therapy or medication)
Value of Mental Health Care/CBT Access

“It’s an aspect of CF that has been neglected over the years”

“Where have you been all my life?... It’s so fundamentally important... Mental health is a real big issue”

“I have used CBT in the past, but my experience was that it was difficult to access... To say that it changed my life would be an understatement.... It was so helpful, so valuable.... In the end, I really felt different.”

“One of the most helpful things was receiving the validation that this was a significant problem I was having, because I had never gone for mental health treatment before. I was always so focused on physical health. ... This is a valid issue that lots of people struggle with, and I’m not just being a crazy person because I feel like I am having these problems. They are legitimate, and there are ways to treat them and take care of them, just like there are ways to treat cystic fibrosis.”
Feedback: Program Structure

- Positive feedback about overall structure, number, duration of sessions
- Most felt delivery by CF team member was advantageous, citing knowledge of CF, familiarity to patient, easier access
- Some noted possible disadvantage of dual role of interventionist:

“Advantages, I think, are that it’s very easy to access and you don’t have to bring another care provider in, get to know somebody and build a, you know, a level of comfort with them. The only disadvantage I can really think of was if, you know, I know that in our clinic staff pretty much know everything about our lives anyway, but if there was something that you weren’t comfortable discussing or that you wanted to have somebody sort of out of that loop, that would be the only drawback that I could think of if you wanted, you know, to kind of compartmentalize it and to keep that separate.”
Feedback: Program Structure

- Do you see any advantages or disadvantages to being able to participate in the program by telephone?

“I think it’s a great advantage ‘cuz I have a hard time now getting in therapy sessions with my work schedule, so even to be able to set a time on a lunch break, to be able to talk, I think that’s a great idea.”

- How about it being delivered while inpatient?

“Oh, I think that’s huge because that’s such a stressful time and there are always things that arise that, you know, that don’t come up in everyday life. I think it would be incredibly helpful to be able to continue that, you know, while you’re inpatient. Sure. That’s a huge plus.”
Feedback about Content: Top CF-Specific Stressors

- **Worry about Disease Progression**
  
  "Is this going to be my new normal?"

  "When you don’t feel well, everything is dark and scary"

- **Treatment Burden**
  
  "Staying on top of all the different treatments you have to do can be stressful. It’s a constantly moving thing. You are never done with it."

- **Financial Stress**
  
  "The disease can be a real financial burden sometimes"
“When I am having an exacerbation, the first thing I notice is that my mood isn’t as good... I may be more irritable.... It’s very tied together.... And when my mood isn’t good... it’s hard to feel motivated. I feel like ‘I’m feeling lousy anyways, so why does it matter?’ Those thoughts creep in more easily.”

“If you don’t feel well physically, you may ... think more negatively and that can have a dire effect long term... In a way, your mental health may be even more important than your physical health.”
Development of CF-CBT

- Results confirmed the acceptability of the proposed structure and content

- Patient and provider feedback informed the design of the intervention manual, patient workbook, and training program for CF providers

- Direct quotes from adults with CF were included in the workbook, increasing authenticity and resonance of material
**Study Timelines**

February 2018 – October 2018

**Phase 1a**
- Multi-site training: MGH, Buffalo, Kansas

**Phase 1b**
- Each site pilots the intervention with 3-5 adult patients
- Additional feedback on intervention obtained from pilot subjects
- Preparatory work for multi-center RCT

**Phase 1c**
- Multi-site randomized waitlist-control pilot study to examine the feasibility, acceptability, and preliminary efficacy of the intervention.
- Enrollment goal: 60

**Phase 2**
- Multi-site randomized waitlist-control pilot study to examine the feasibility, acceptability, and preliminary efficacy of the intervention.
- Enrollment goal: 60

**Phase I**
- Initiate Intervention Immediately

**Phase II**
- 3-month waitlist
**CF-CBT: Current Studies**

- **Adult RCT**
  - Evaluate **feasibility and acceptability** for broader dissemination in the CF care center setting and **outcomes** of the CF-CBT intervention for adults with CF

- **Adolescent adaptation**
  - Developmentally adapt and pilot the CF-CBT intervention for use in **adolescents** with CF ages 12-17 with input from CF adolescents, families and care teams

- **E-health platform (Minddistrict)**
  - Adapt the CF-CBT intervention manual to a therapist-guided internet-delivered program for adults with CF, in English and Dutch (Vertex Circle of Care Charitable Grant, Verkleij, Friedman, Georgiopoulos)
  - 8 modules delivered through blended care: Face-to-face contact with a psychologist in combination with online modules
# Overview of CF-CBT Program

<table>
<thead>
<tr>
<th>Session Number</th>
<th>CF-CBT Session Title</th>
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<tbody>
<tr>
<td>1</td>
<td>Overview and Introduction to CBT</td>
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<tr>
<td>2</td>
<td>Relaxation Skills</td>
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<td>3</td>
<td>Depression in CF: What Helps?</td>
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<td>4</td>
<td>Adaptive Thinking Skills</td>
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<td>5</td>
<td>Adaptive Thinking Skills, Part 2</td>
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<td>6</td>
<td>Taking Charge of My Health</td>
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<td>7</td>
<td>Anxiety in CF: What Helps?</td>
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<td>8</td>
<td>Maintaining Positive Changes</td>
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How to introduce CBT?

- **CBT as a set of strategies**
  - Manage stress, decrease symptoms of anxiety and depression, increase quality of life

- **Builds on strengths and skills that patients are already using to cope with CF**

- **Be positive**
  - Depression and anxiety can be effectively treated
  - Not “one more thing have to do,” but a set of tools that patients can use

- **Be realistic**
  - Not a “quick fix”
  - Can expect use of strategies will help change the trajectory over time
Structure of CBT Sessions

- Set an agenda (go over the goals)
- Introduce information and a specific skill
- Tailor this to individual patient
- Change involves skill acquisition
  - Teach skills for patient to solve the problem, not simply discuss the issue or offer advice
- Homework is a central part of CBT

Homework in CBT

- Tailor assignments to patients
- Explain in detail
- Call it “practice” if homework is bad word
- Anticipate and prepare for obstacles
- Do not scold for not completing the assignment
  - but also do not dismiss their value
- Ask about and review homework

## Session 1: Objectives

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<thead>
<tr>
<th>Week 1</th>
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<tbody>
<tr>
<td>1</td>
<td>Explains interventionist’s role and discusses limits of confidentiality</td>
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<td>2</td>
<td>Introduction/ Exploring and sharing participant’s experience with CF: Obtains patient’s story and establishes rapport</td>
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<td>3</td>
<td>CF and Stress: Introduces stress and impact on individuals from CBT framework, with patient reflection on top stressors</td>
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<td>4</td>
<td>Presents the CBT model: connecting thoughts, emotions, and behaviors, and the relationship between physical and emotional health, including participant reflection on these relationships in their own life</td>
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<td>5</td>
<td>Introduces CBT as a treatment model and how it can help</td>
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<td>6</td>
<td>Assess the participant’s personal goals for this intervention</td>
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<td>7</td>
<td>Assigns Stress and Coping Tracker and Catching Joy as homework</td>
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**TOTAL:**

PERCENT ADHERENCE (TOTAL/7): *
Session 1

- **Part I: Sharing Experience of Living with CF**
  - Rapport building; setting foundation

- **Part II: CF and Stress**
  - Normalize stress as natural part of life
  - Read through list of CF-related stressors
  - Ask and document patient’s top stressors
CF-Specific Stressors

Exacerbations
TREATMENTS
Dating and relationships
stigma
fatigue
work
SCHOOL
Major disruptions to routine
time management
loss
feeling like a burden
UNCERTAINTY
Disease progression
isolation
financial stress
infection
Fitting-in
family planning
survivor’s guilt

disability
Disclosure
pain
Transitioning
Session 1

Part II: CF and Stress, continued

- Discuss impact of stress on thoughts/feelings/behavior
- Start to make connections between these, and between emotional and physical health; may read quotes to illustrate
- Patient reflects on deeper level on stress in their lives; may start to make connections between thoughts, feelings, and behavior
- Introduce what CBT is and how it helps
Session 1: CBT Model

- Emotions
- Cognitions
- Behaviors
- Physical Functioning
- Relaxation Techniques
- Alternative Responses to Stress
- Adaptive Thinking Skills
Session 1

- Part III: Identify Personal Goals
- Part IV: Week 1 Exercise
  - Stress and Coping Tracker
  - Catching Joy
### STRESS AND COPING TRACKER

Use this scale to rate your level of stress:

1 ← 2 ← 3 ← 4 ← 5 ← 6 ← 7 ← 8 ← 9 ← 10

Not at all stressed  As stressed as you can be

<table>
<thead>
<tr>
<th>Stressful Situation/What happened?</th>
<th>Stress Level (1-10)</th>
<th>Emotions: What was I feeling?</th>
<th>Cognitions: What was I thinking?</th>
<th>Actions: How did I respond? What was I doing?</th>
<th>Coping Response: Did I do anything that was helpful to manage stress?</th>
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