Outline

- Cystic Fibrosis Overview
- Mental Health and Cystic Fibrosis
- Cystic Fibrosis Foundation Mental Health Treatment and Screening Guideline
- Mental Health Needs Assessment
- Data Results and Findings
- Provider Information Packet
- Referral List of therapists/psychologists
- Considerations
Cystic Fibrosis (CF) Overview

- Autosomal recessive disease affecting chloride channels in epithelial tissue of the body
- Results in production of thick mucous which can have systemic implications related to
  - Respiration
  - Digestion and nutrition status
  - Reproduction
- Life expectancy traditionally has been 2-3 decades, but…
Anxiety and CF

- Studies have shown that people with CF, as well as caregivers, are more likely to experience anxiety than people in the general population.

- Symptoms of anxiety include:
  - Excessive worry
  - Difficulty controlling the worry
  - Restlessness
  - Irritability
  - Muscle tension
  - Difficulty concentrating
  - Sleep disturbance
  - Fatigue

Depression and CF

- Researchers found that people with CF and caregivers are more likely to experience depression than people in the general population.

- Symptoms include:
  - Depressed mood most of the day, nearly every day
  - Diminished interest in pleasurable activities
  - Significant weight loss or weight gain
  - Insomnia or hypersomnia
  - Fatigue or loss of energy
  - Feelings of worthlessness or excessive inappropriate guilt
  - Diminished ability to think/concentrate or indecisiveness
  - Recurrent thoughts of death, recurrent suicidal ideation without specific plan, or suicide attempt or specific plan for committing suicide

Mental Health and CF

- A recent study in nine countries screened 6088 patients with CF ages 12 years through adulthood and 4102 parents.
- Elevated symptoms of depression were found in 130 adolescents (10%), 913 adults (19%), 1165 mothers (37%), and 305 fathers (31%).
- Anxiety was reported by 281 adolescents (22%), 1503 adults (32%), 1496 mothers (48%), and 343 fathers (36%).
Mental Health and CF

- Psychological symptoms in both patients and parents have been associated with
  - Decreased lung function
  - Lower body mass index
  - Worse treatment adherence
  - Worse health-related quality of life
  - More frequent hospitalizations
  - Increased healthcare costs

Pain and CF

- Havermans, Colpaert, Boeck, Dupont, & Abbott, (2013) found
  - High incidence of pain is reported in CF
  - Chest and abdominal pains were most commonly reported
  - Pain was negatively associated with pulmonary exacerbations, quality of life and treatment adherence
  - Pain reduces the quality of life of chronically ill patients and may negatively impact the ability to participate in disease-related daily care
Substance Abuse and CF

- The National Survey on Drug Use and Health (NSDUH) in 2013 identified an estimated **21.6 million persons** in the U.S. aged 12 or older were classified with a substance dependence or abuse in the past year.

- Overall, **17.3 million** had alcohol dependence or abuse, and **6.9 million** had illicit drug dependence or abuse.

- Little is known about the long-term effects of substance addiction in people living with CF.
  - Believed to have a negative impact on health, well-being and longevity of any individual who struggles with a substance use disorder

Eating Disturbance and CF

- **Bryon, M., Shearer, J., & Davies, H. (2008)**
  - Youth with a BMI 17.5, 5% avoided weight gain
  - 53% demonstrated disturbed eating attitudes and 16% disturbed eating behaviors

- **Truby and Paxton (2001)**
  - In girls with CF, at or below 50th BMI percentile, 54% wanted to stay the same or be thinner
  - In girls with CF, body dissatisfaction was a significant predictor for BMI
  - In boys with CF, body dissatisfaction and body esteem were significant predictors of BMI

- **Willis, Miller, and Wyn’s (2001)**
  - Girls are generally happy with their slender body shape and do not wish to gain any weight or wished to lose weight
  - Boys reported wanting to gain weight and become more muscular and strong
CF Foundation Policy

- Mental Health Treatment and Screening Guideline
  - The Cystic Fibrosis Foundation and the European Cystic Fibrosis Society worked with CF mental health experts to integrate screening and treating depression and anxiety into CF care.

- Recommendations include:
  - All patients 12 years and older should receive annual screening for depression and anxiety.
  - Parent caregivers of patients aged 0-17 years should be offered annual screening for depression and anxiety.
  - A stepped process for prevention, screening, assessment and intervention. This can include talk therapy, medication or a combination of the two.
Needs Assessment Survey

- Needs assessment was created to assess CF patient and caregiver mental health needs
- CF Clinic social worker and social work intern identified mental health concerns of
  - Depression
  - Anxiety
  - Substance abuse
  - Pain
  - Body image issues
- Distributed to patient/caregiver in CF clinic and via telephone
- 38 patients total completed the survey
My name is Charisse Rodnathy, and I am a social work trainee with the University of Arizona Pediatric Pulmonary Center. Finding a private or community mental health provider can often be a difficult process, especially finding a provider familiar with cystic fibrosis (CF). My goal is to educate mental health providers on CF, and create a referral list of therapists and psychologists familiar with CF. This referral list would be categorized by major insurance companies in the region. To start this process, I would like to take a few moments of your time to ask you to complete these survey questions. Thank you.

1. Are you an adult with CF, or a parent of a child with CF?
   a. Adult with CF
   b. Parent of a child with CF under the age of 18

2. What age(s) is/or the person(s) diagnosed with CF?
   a. 0-23 months
   b. 2-10 years
   c. 11-17 years
   d. 18-26 years
   e. 27 years and above

3. What is the primary insurance of the person(s) with CF?
   a. Blue Cross Blue Shield (BCBS)
   b. United
   c. Medicaid
   d. Medicaid (AHCCCS)
   e. Other

4. Does the person(s) with CF have a secondary insurance?
   a. Yes
   b. No

   If yes, please list ___________________________

5. Has the person previously received mental health services? (i.e. met with a psychologist or therapist)
   a. Yes
   b. No

6. Is the person(s) currently using private or community mental health services?
   a. Yes
   b. No

7. Would you find it helpful to have a list of private therapists/psychologists in the Tucson area?
   a. Very helpful
   b. Somewhat helpful
   c. Not at all helpful

8. Would you find it helpful to have a list of community mental health providers in the Tucson area?
   a. Very helpful
   b. Somewhat helpful
   c. Not at all helpful

9. Would you find it helpful if the providers had an awareness of the CF diagnosis and its correlation with mental health?
   a. Very helpful
   b. Somewhat helpful
   c. Not at all helpful

10. Would you find it helpful to have information about therapists/psychologists who provide counseling services for one of the following? (please circle all that apply)
    a. Anxiety
    b. Depression
    c. Pain Management
    d. Body Image Issues
    e. Substance Abuse
    f. Other ___________________________

If you would like to be contacted to provide further information, please list your contact information below

Name: ________________________________

Contact number/email: ________________________________

Thank you for your participation!
Data Results/Findings

- **Question 1:** Are you an adult or parent?
  - 19 Adults with CF
  - 19 Parents of child <18
  - 0 Didn’t answer

- **Question 2:** What age(s) is/are the person(s) diagnosed with CF?
  - 2-10 years: 11
  - 11-17 years: 6
  - 18-26 years: 8
  - 27 years & above: 11
  - Didn’t answer: 0

- 0-23 months: 2
- 2-10 years: 11
- 11-17 years: 6
- 18-26 years: 8
- 27 years & above: 11
- Didn’t answer: 0
**Data Results/Findings**

- **Question 3:** What is the primary insurance of the person(s) diagnosed with CF?

- **Question 4:** Does the person(s) with CF have a secondary insurance?

**Table: Primary Insurance**

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<th>Insurance Type</th>
<th>Number</th>
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<td>Medicaid (AHCCCS)</td>
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<td>Medicare</td>
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<td>United</td>
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<td>Blue Cross Blue Shield (BCBS)</td>
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</table>

**Diagram: Secondary Insurance**

- **Yes:** 7
- **No:** 30
- **Didn't answer:** 1
Data Results/Findings

- **Question 5:** Has the person previously received mental health services? (i.e., Met with a psychologist or therapist)

- **Question 6:** Is the person(s) currently using private or community mental health services?
Question 7: Would you find it helpful to have a list of private therapists/psychologists in the Tucson area?

- Very Helpful: 45%
- Somewhat Helpful: 21%
- Not at all helpful: 31%
- Didn't answer: 3%

Question 8: Would you find it helpful to have a list of community mental health providers in the Tucson area?

- Very Helpful: 42%
- Somewhat Helpful: 29%
- Not at all helpful: 26%
- Didn't answer: 3%
Data Results/Findings

- **Question 9:** Would you find it helpful if the providers had an awareness of the CF diagnosis and its correlation with mental health?

- **Question 10:** Would you find it helpful to have information about therapists/psychologists who provide counseling services for one of the following? (circle all that apply)

  - Very Helpful
  - Somewhat Helpful
  - Not at all helpful
  - Didn't answer

<p>| | |</p>
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<td>Body Image Issues</td>
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<td>Depression</td>
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<tr>
<td>Anxiety</td>
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Provider Information Packet

- Information packet provided to potential mental health providers
- Includes:
  - Letter to the Provider
  - Overview of CF
  - Symptoms of CF
  - Diagnosis & Genetics
  - What to Expect
  - Anxiety & CF
  - Depression & CF
  - Video link with Tucson CF Center Director, Dr. Cori Daines & a patient
- Journal Abstracts & Key Points
  - Anxiety/Depression & CF
  - Pain & CF
  - Substance Abuse & CF
  - Eating Disturbance & CF
Referral List

- Categorized by
  - Private insurance providers
  - Community providers (Medicaid)
  - Sliding fee scale

- Includes:
  - Specialty/treatment modalities
  - Population
  - Insurance
  - Contact information
<table>
<thead>
<tr>
<th>Provider/Phone</th>
<th>Address</th>
<th>Client Population</th>
<th>Specialties</th>
<th>Insurance</th>
<th>Email/Website</th>
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</thead>
<tbody>
<tr>
<td>The University of Arizona Department of Psychology, Behavioral Health Clinic</td>
<td>1503 E. University Blvd., Tucson, AZ 85731 Psychology Building Room 210</td>
<td>Children, Adolescents, Adults, and Families</td>
<td>Behavioral Medicine, Cognitive Behavioral Therapy, Acceptance Commitment Therapy</td>
<td>Sliding scale: $30 for an individual session and $35 for couples. Reduced fees are possible under special circumstances.</td>
<td><a href="http://psychology.cats.us/">http://psychology.cats.us/</a></td>
</tr>
<tr>
<td>Casa De Los Ninos, Behavioral Health Services</td>
<td>140 N. Tucson Blvd., Tucson, AZ 85716</td>
<td>Children, Adolescents, &amp; Young Adults under the age of 22</td>
<td>Behavioral Health Services and Trauma Informed Care</td>
<td>AHCCCS</td>
<td><a href="http://www.casdelosninos.org">www.casdelosninos.org</a></td>
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<tr>
<td>CODAC Behavioral Health Services, Inc.</td>
<td>630 N Alvernon Way, Tucson, AZ 85711</td>
<td>Children, Adolescents &amp; Adults</td>
<td>Behavioral Health Services, Substance Abuse, and Trauma</td>
<td>AHCCCS, Medicare, TRICARE, and private health insurance plans</td>
<td><a href="http://www.codac.org">www.codac.org</a></td>
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<tr>
<td></td>
<td>520-118-9122</td>
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<tr>
<td></td>
<td>520-202-1840</td>
<td>3100 E. Broadway Blvd, Tucson, AZ 85716</td>
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<tr>
<td>COPE Community Services, Inc.</td>
<td>1918 N Tucson Blvd., Tucson, AZ 85710</td>
<td>Adults</td>
<td>Behavioral Health Services and Substance Abuse</td>
<td>AHCCCS, Medicare, TRICARE, and private health insurance plans</td>
<td><a href="http://www.copecommunityservices.org">www.copecommunityservices.org</a></td>
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<tr>
<td></td>
<td>520-181-7117</td>
<td></td>
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<td></td>
<td>520-888-6332</td>
<td>3332 N Los Altos Ave, Tucson, AZ 85705</td>
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<tr>
<td>Hope Inc.</td>
<td>1200 N. Country Club, Tucson, AZ 85716</td>
<td>Adults</td>
<td>Behavioral Health Services and Substance Abuse</td>
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<td><a href="http://www.hoptuscc.org">www.hoptuscc.org</a></td>
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<tr>
<td></td>
<td>928-783-3616</td>
<td>201 S 1st Ave, Yuma AZ 85364</td>
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Considerations

• Sample Size
• Mental Health Stigma
• Barriers to Overcome Mental Health Stigma
References


Thank you
Mary McGuire, MSW
Patty Settle, MS, RDN
CF Clinic Interprofessional Healthcare Team
PPC Traineeship Program Team