



# CYSTIC FIBROSIS AND MENTAL HEALTH

Charisse Radnothy, BS, MSW Intern, PPC Trainee  
The University of Arizona Pediatric Pulmonary Center  
March 25, 2016

# 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

From: American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental health disorders*. DSM-5. (5<sup>th</sup> ed.). Washington, D.C.: American Psychiatric Association

# Depression and CF

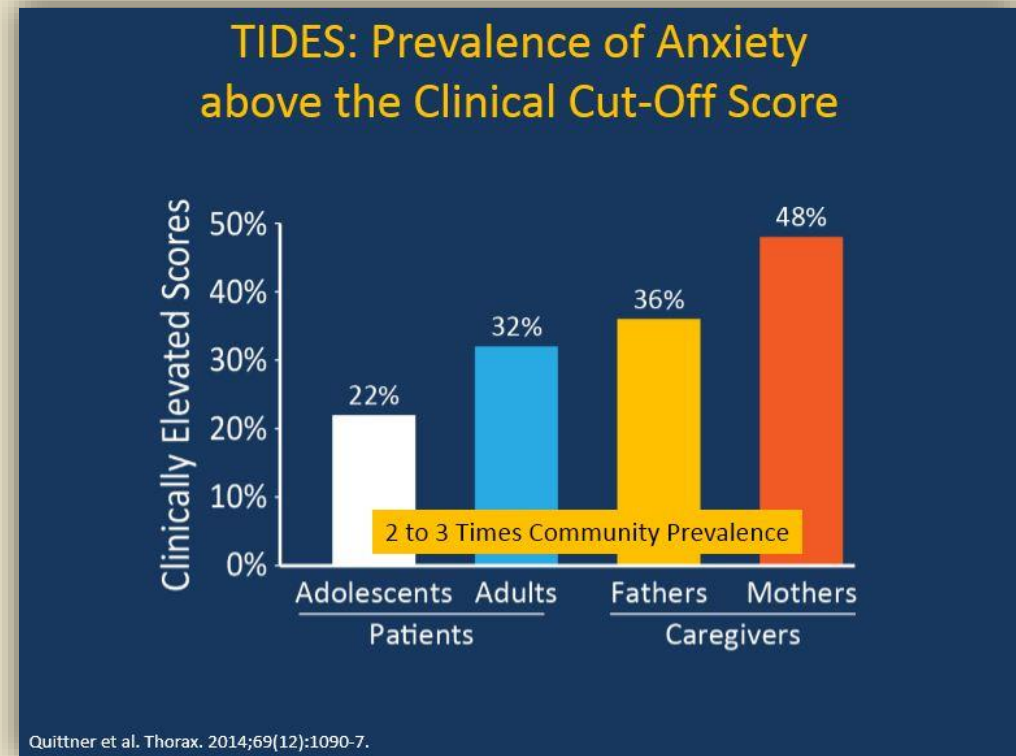
---

- 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

From: Quitter AL, Abott J, Georiopoulos AM, et al., *Thorax* 2016;**71**:26-34.



# 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

From: Cystic Fibrosis Foundation. (2015). Pediatric Pulmonology. Phoenix, AZ: Wiley.

# 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 Radnothy, 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/are 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. Medicare
  - 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? (ie. 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: \_\_\_\_\_

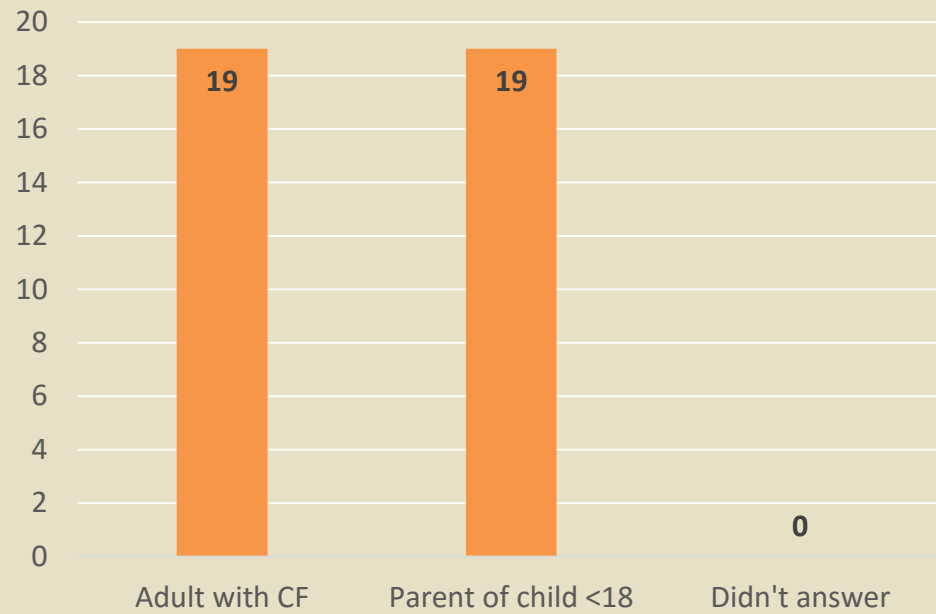
Thank you for your participation!



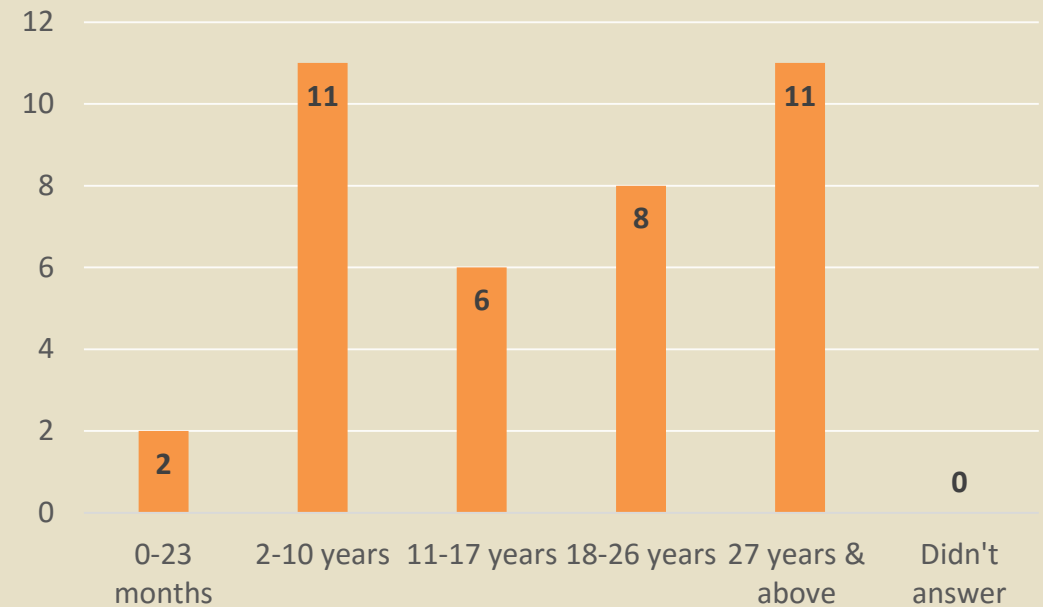
# Data Results/Findings

---

- **Question 1:** Are you an adult or parent?



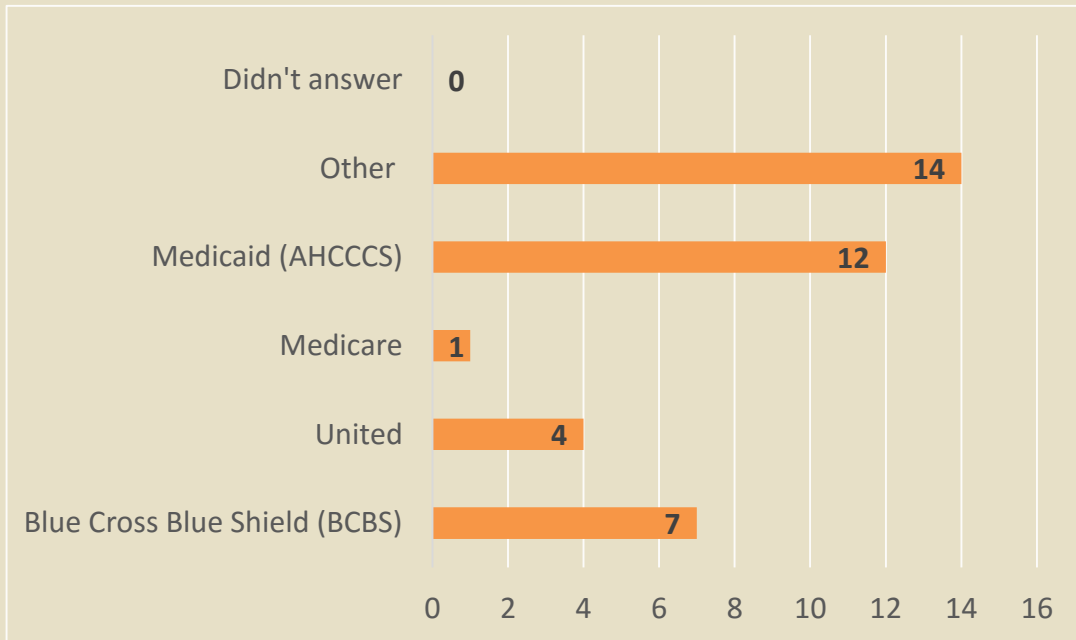
- **Question 2:** What age(s) is/are the person(s) diagnosed with CF?



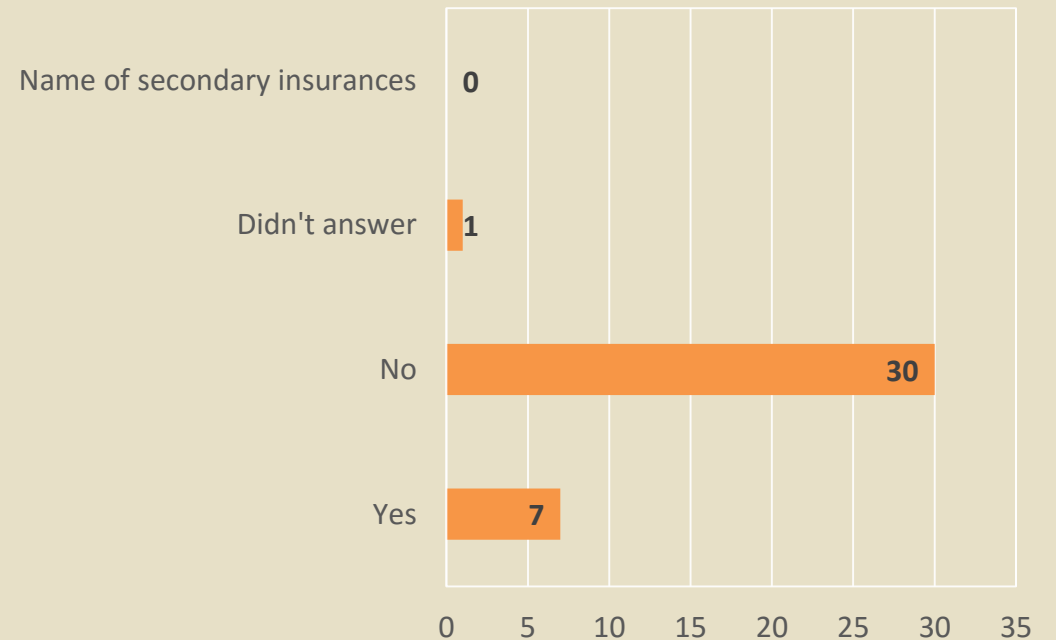
# Data Results/Findings

---

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



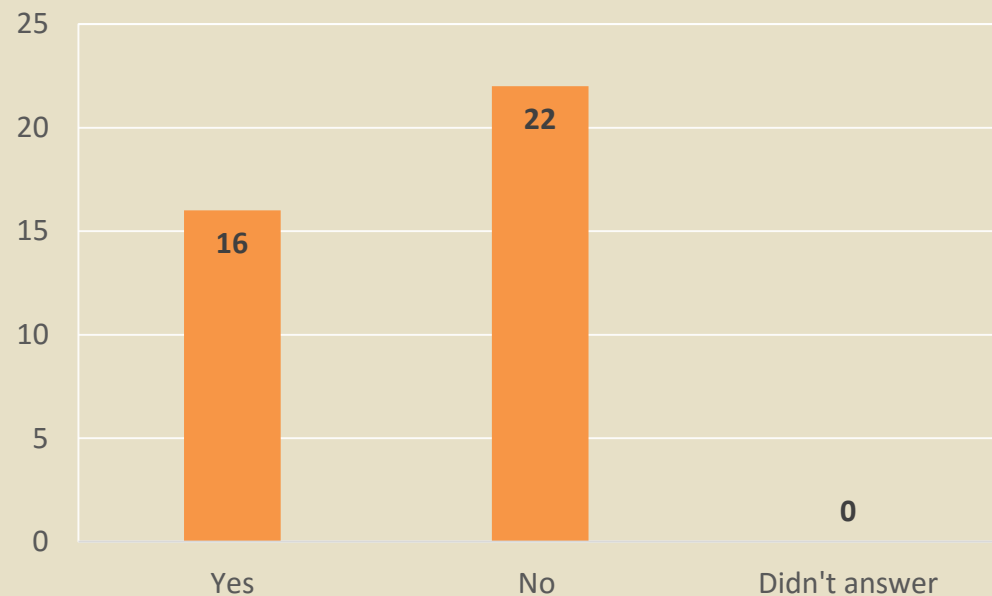
- **Question 4:** Does the person(s) with CF have a secondary insurance?



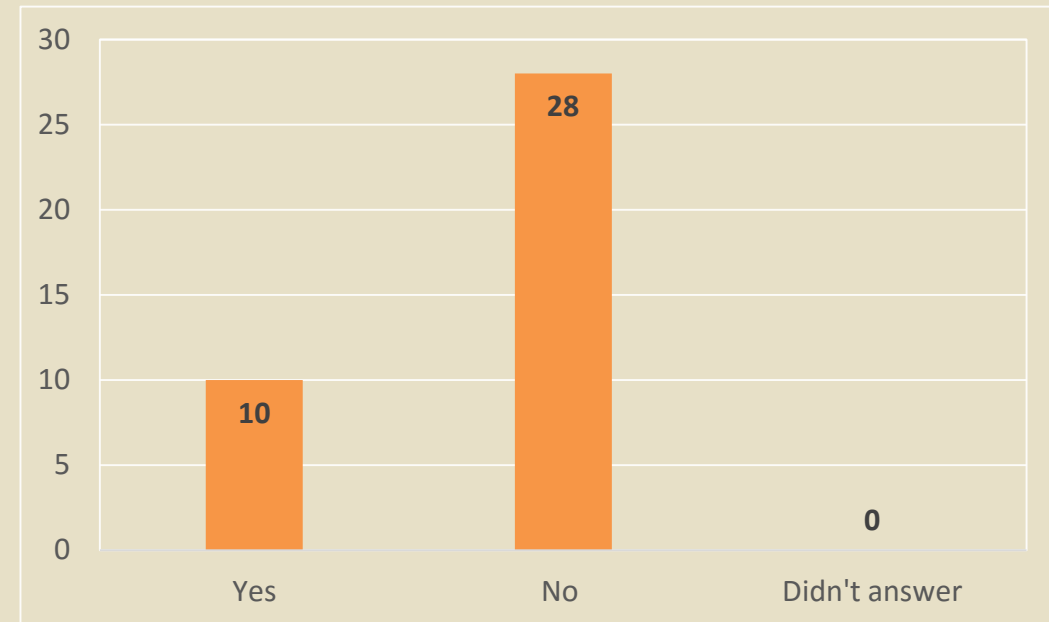
# Data Results/Findings

---

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



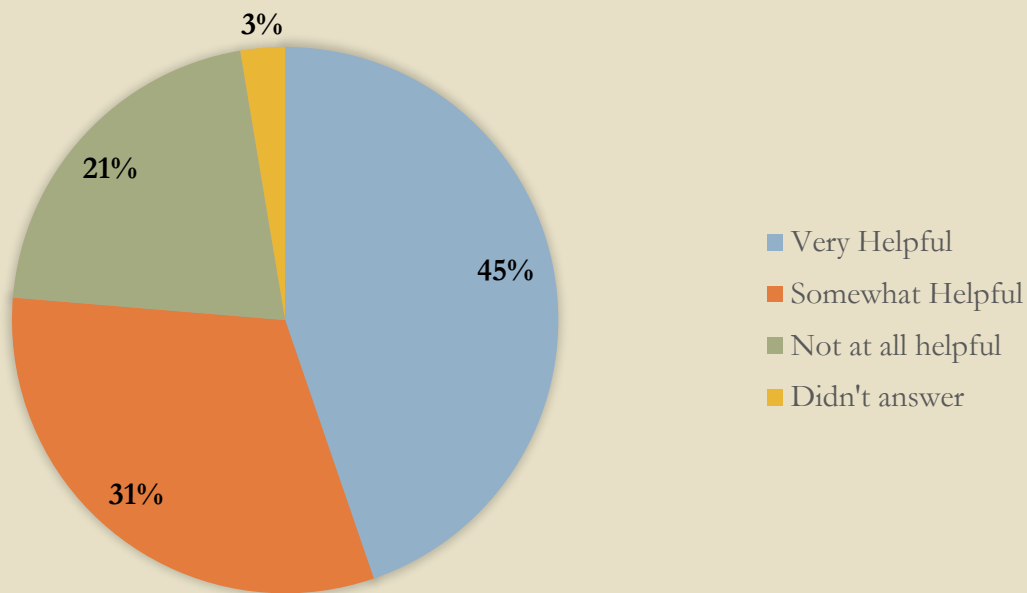
- **Question 6:** Is the person(s) currently using private or community mental health services?



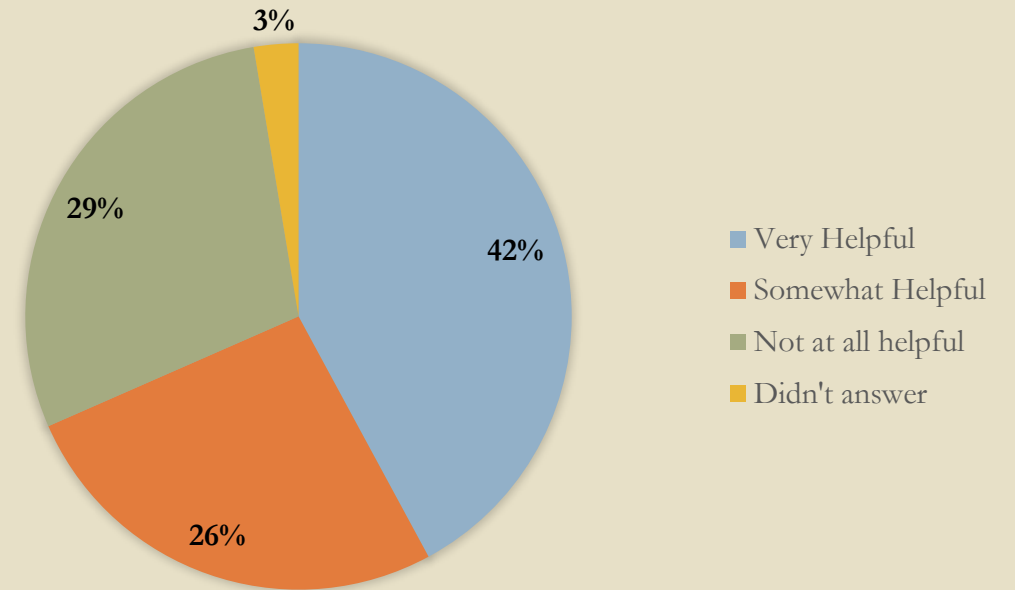
# Data Results/Findings

---

- **Question 7:** Would you find it helpful to have a list of private therapists/psychologists in the Tucson area?

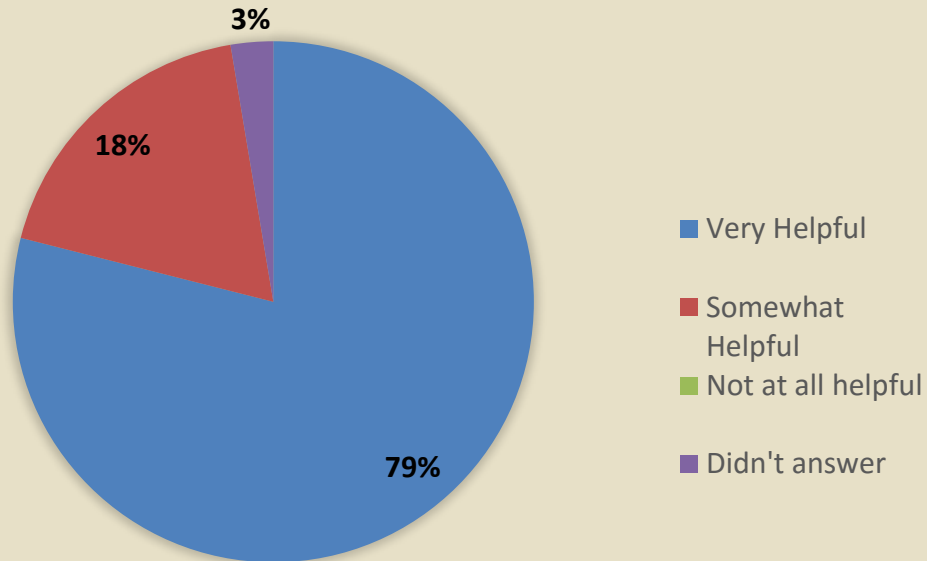


- **Question 8:** Would you find it helpful to have a list of community mental health providers in the Tucson area?

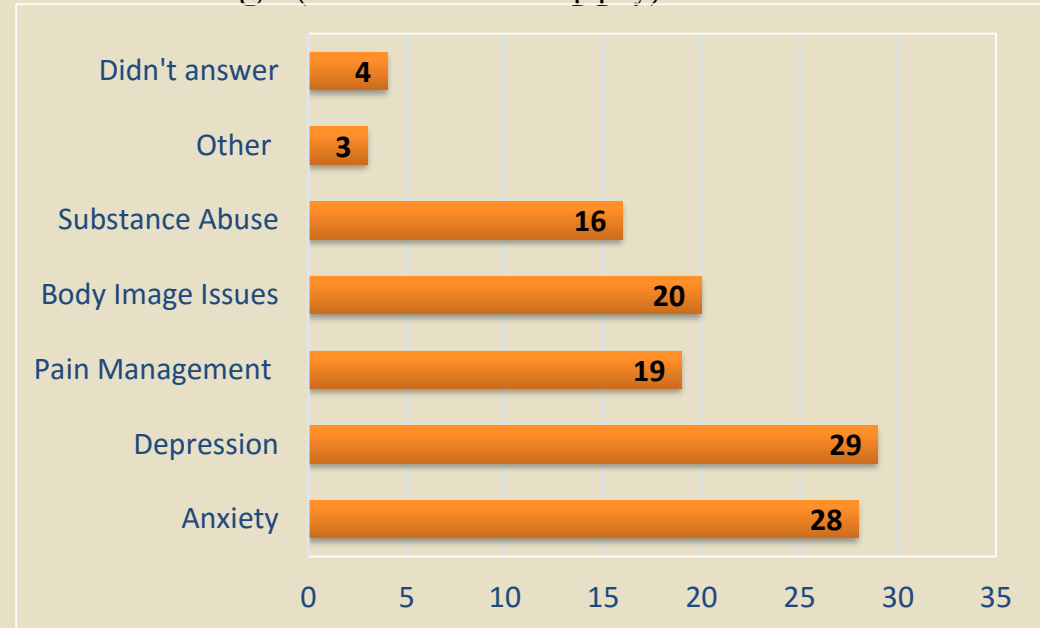


# Data Results/Findings

- **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)





# 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

Mental Health Providers for CF Patients

Provider/Phone	Address	Client Population	Specialties	Insurance	Email/Website
<b>COMMUNITY PROVIDERS</b>					
Provider/Phone	Address	Client Population	Specialties	Insurance	Email/Website
The University of Arizona Department of Psychology Behavioral Health Clinic 520-621-9683	1503 E. University Blvd., Tucson, AZ 85721 Psychology Building, Room 210	Children, Adolescents, Adults, and Families	Behavioral Medicine, Cognitive Behavioral Therapy & Acceptance Commitment Therapy	Sliding fee scale. \$20 for an individual session and \$25 for a couple session. Reduce fees are possible under special circumstances.	<a href="http://psychology.arizona.edu/behavioral-health-clinic">http://psychology.arizona.edu/behavioral-health-clinic</a>
Casa De Los Ninos Behavioral Health Services 520- 881-1292	140 N. Tucson Blvd. Tucson, AZ 85716	Children, Adolescents, & Young Adults under the age of 22	Behavioral Health Services and Trauma Informed Care	AHCCCS	<a href="http://www.casadelosninos.org">www.casadelosninos.org</a>
CODAC Behavioral Health Services, Inc. 520- 318-9222 520-202-1840	630 N Alvernon Way, Tucson, AZ 85711 3130 E. Broadway Blvd, Tucson, AZ 85716	Children, Adolescents & Adults	Behavioral Health Services, Substance Abuse, and Trauma	AHCCCS, Medicare, TRICARE, and private health insurance plans.	<a href="http://www.codac.org">www.codac.org</a>
COPE Community Services, Inc. 520- 881-7217 520-888-6332	1918 N Tucson Blvd, Tucson, AZ 85716 3332 N Los Altos Ave, Tucson, AZ 85705	Adults	Behavioral Health Services and Substance Abuse	AHCCCS, Medicare, TRICARE, and private health insurance plans	<a href="http://www.copecommunityservices.org">www.copecommunityservices.org</a>
Hope Inc. 520-770-1197 928-783-3616	1200 N. Country Club, Tucson, AZ 85716 201 S. 1st Ave, Yuma AZ 85364	Adults	Behavioral Health Services and Substance Abuse	AHCCCS	<a href="http://www.hopetucson.org">www.hopetucson.org</a>



# References

---

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental health disorders*. DSM-5. (5<sup>th</sup> ed.). Washington, D.C.: American Psychiatric Association.
- Bryon, M., Shearer, J., & Davies, H. (2008). Eating Disorders and Disturbance in Children and Adolescents With Cystic Fibrosis. *Children's Health Care*, 37(1), 67-77. doi:10.1080/02739610701766909
- Cystic Fibrosis Foundation. (2016). CFF Homepage. Retrieved February 13, 2016, from <http://www.cff.org/>
- Cystic Fibrosis Foundation. (2015). *Pediatric Pulmonology*. Phoenix, AZ: Wiley.
- Havermans, T., Colpaert, K., Boeck, K. D., Dupont, L., & Abbott, J. (2013). Pain in CF: Review of the literature. *Journal of Cystic Fibrosis*, 12(5), 423-430.
- Quittner, A. L., Abbott, J., Georgiopoulos, et al.. (2015). International Committee on Mental Health in Cystic Fibrosis: Cystic Fibrosis Foundation and European Cystic Fibrosis Society consensus statements for screening and treating depression and anxiety. *Thorax*, 71, 26-34.
- Truby, H., & Paxton, S.J. (2001). Body image and dieting behavior in cystic fibrosis. *Pediatrics*, 107(6), E92.
- Willis, E., Miller, R., & Wyn, J. (2001). Gendered embodiment and survival for young people with cystic fibrosis. *Social Science & Medicine*, 53, 1163-1174.





**Thank you**

**Mary McGuire, MSW**

**Patty Settle, MS, RDN**

**CF Clinic Interprofessional Healthcare Team**

**PPC Traineeship Program Team**