

Mind the Gap: Exploring the Mental Health Needs of Cystic Fibrosis Patients Who Undergo Lung Transplantation



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BACKGROUND

- Adult patients with Cystic Fibrosis (CF) who undergo lung transplants face psychological challenges in the pre- and post-transplant period.¹⁻³
- There is limited data to identify specific mental health challenges and to inform how to meet these needs.

OBJECTIVES

- To explore the mental health needs of lung transplant recipients with cystic fibrosis (CF-LTR).
- To inform future interventions from the perspectives of patients, caregivers, and healthcare providers.

METHODS

- **Study Design:** Mixed methods study using semi-structured interviews and standardized mental health screening tools.

Quantitative Data Collection:



Patient Health Questionnaire (PHQ-9): Nine-item scale to assess symptoms of depression.

Generalized Anxiety Disorder (GAD-7): Seven-item scale to assess symptoms of anxiety.

Qualitative Data Collection:

Semi-structured interviews with three groups of stakeholders:

CF-LTR
Patients less than 4 years post-transplant.

Caregivers
Individuals who care for patients.

Healthcare Providers (HCPs)
Professionals who care for patients.

- **Data Analysis:** Thematic analysis and NVivo software.

RESULTS

Twenty-five participants were enrolled, which included six CF-LTR, eight caregivers, and eleven HCP.

CF-LTR Participants (n=6):

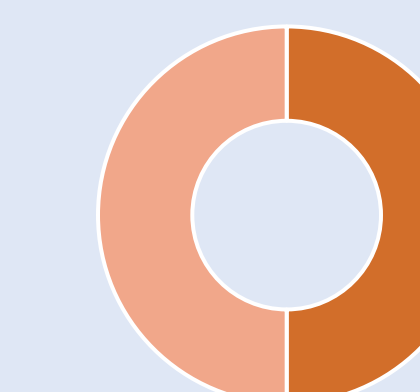
Age	Gender	Race/Ethnicity	Lung Tx #	History of Mental Health Support	Current Mental Health Support
18-30	2 M	2 White	5 First	5 Yes	3 Yes
31-64	3 F	4 Metis	1 Second	1 No	3 No
65+	1				

HCP Participants (n=11):

Discipline	Gender
Nursing	5
Medicine	2 M 2
Nutrition	1
Pharmacy	1
Social Work	1 F 9
Spiritual Care	1

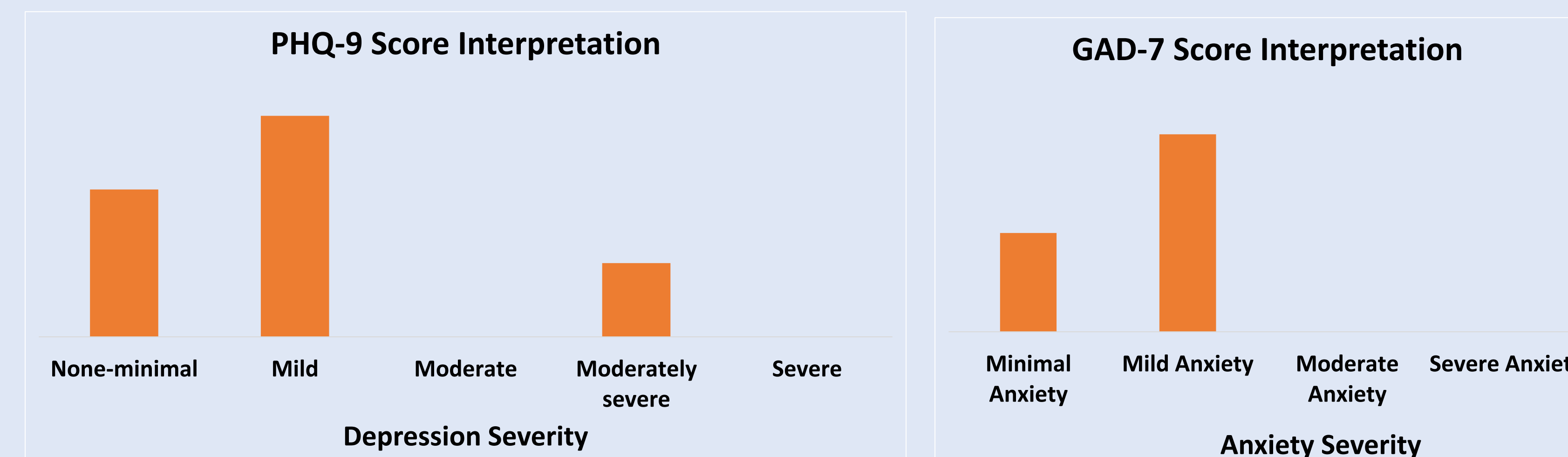
Caregiver Participants (n=8)
(M:3/ F:5):

Relationship to CF-LTR



■ Spouse/Partner ■ Parent

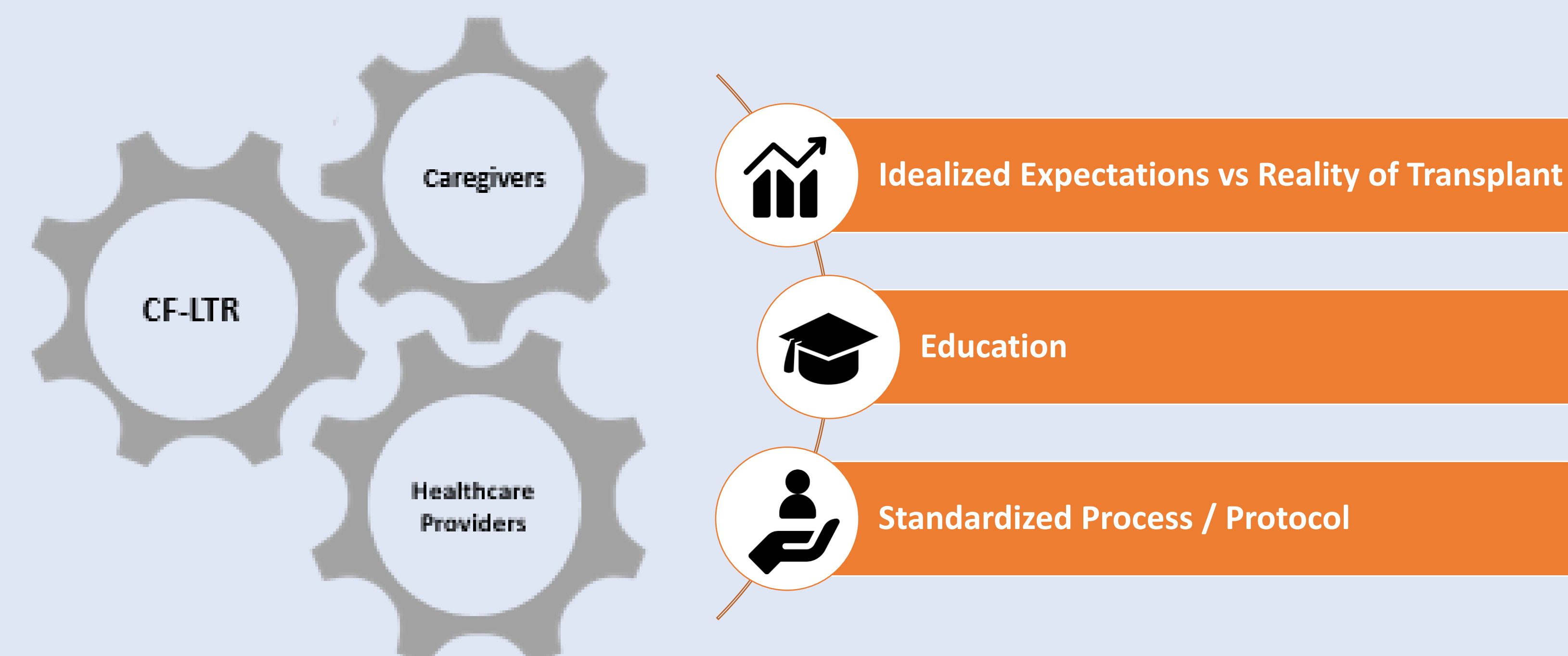
Mental Health Screening of CF-LTRs



"I think we both were worse off than we really realized or understood. I think we should have kind of treated that a little better than we did. I think we didn't really realize that that was something that you needed to treat or seek help for until way after the fact" (CG 04).

"But the fact remains, I mean, you sign up for transplant willing to hopefully trade one set of issues for potentially a lesser set and the biggest is if you don't get transplants you don't live" (CFLTR 03).

Our data revealed **three** main gaps in mental health care for CF-LTR undergoing lung transplantation:



"No. I don't think they're well prepared. But I also don't know how much more prepared we can make people. I think we have to acknowledge that everyone's experience will be different...but 'ready' is subjective. I don't know if they fully appreciate all the things that could happen" (HCP 11).

DISCUSSION

- **Psychological Distress:** Qualitative data suggests most CF-LTR patients experience psychological distress before and after transplant.
- **Mental Health Needs:** All three groups identified that access to mental health resources should be a "mandatory" element of CF patient care; some challenges were consistent among all three groups, while some were specific to the patient's individual lived experience.
- **Insufficient Screening:** HCPs do not routinely screen CF-LTR in the post-transplant period for mental health needs nor do they feel well-equipped to do so.
- **Resources and Support Needed:** Access to mental health resources should be mandatory. We should offer a variety of diverse strategies to support the mental health and wellness needs of these patients.

CONCLUSIONS

While we recognize that an individualized approach is required, a more standardized pathway to approach mental health needs should be developed.

Some ideas include:

- Optimize **patient and caregiver education** to help manage transplant expectations.
- Development and implementation of a **standardized screening process** to identify mental health needs at various points in the transplant journey.
- Appropriate guidance toward a **variety of mental health tools and resources**.

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