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CF Foundation Areas of Focus for Mental Health

In July 2020, the Mental Health Research Priorities Working Group deployed a survey to ascertain the mental health research priorities of the cystic fibrosis (CF) community including individuals with CF and their caregivers, as well as health care providers. The CF Foundation convened the working group for virtual meetings in September 2020 and March 2021 to discuss the focus areas and review advancements, current research, and gaps in published research. Informed by the survey, participants of the workshop and the Mental Health Advisory Committee created six Areas of Focus for mental health research in CF:

- Impact of CF Management on Mental Health
- Effect of CF on Family Dynamics
- Anxiety
- Depression/Mood Disorders
- Relationships of Mental Health and Physical Health
- Relationships of Comorbidities and Mental Health

Priorities in CF mental health research should not only focus on research gaps that exist as to effectiveness of interventions for the CF community but should also include gaps that exist in accessibility and optimization of behavioral healthcare delivery. Socio-economic status, health disparities and gender identity may also influence mental wellness and should be included in the research-related focus areas described in this document. Improvements in treatments for CF have led to increased age of survival. The unique mental health challenges of the aging CF population as well as those with advanced lung disease and transplant should also be considered in the focus areas below.

Impact of CF Management on Mental Health

The treatment regimen for CF is highly complex, time-consuming, and burdensome. More research needs to be conducted to understand the effects of CF management on mental health, such as treatment burden, treatment side effects, and the transplant journey.

Although, the management of CF has changed dramatically over the past 20 years it is critically important to understand the mental health challenges for those who, for a variety of reasons, do not experience benefits from CF therapies, like highly effective modulator therapy. This includes people who are waiting for modulators targeted to their genetic mutations or those unable to tolerate modulator side effects.

Research Priorities:

- Effects of treatment burden on symptoms of depression and anxiety
- Effects of medications used for the treatment of CF (e.g., modulator therapy, therapies for CF complications) on mental health, including depression and anxiety
- Effects of the transplant process on mental health and quality of life
- Effects of health disparities and/or barriers in treatment related to language, health literacy, immigration status, racial and ethnic identity, etc. on mental health

Effect of CF on Family Dynamics

As more people with CF live through their reproductive years, greater understanding of the effects of parenthood on those with CF is required to help inform their reproductive decisions and better support those who decide to become parents.

In addition to parents with CF themselves, caregivers of children with CF report 2-3 times the rate of depression and anxiety compared to the general population. In addition to mental health impacts, there is little research on the impact of caregiving on the quality of life of parents of children with CF. There is also little research on the impacts on the siblings and other family members of those with CF. More research is needed to better support these groups and understand burden of CF disease.

Research Priorities

- Global impact of parenthood on physical and mental health outcomes of people with CF.
- Impact of highly effective modulator therapy on the interplay between parenthood and CF health.
- Impact of caregiver burden on quality of life for parents, siblings, and other family members of people with CF.
- Interventions to better support parents with CF and parents/family members of children with CF.
- Psychotherapeutic and/or psychopharmacological interventions for depression and anxiety in parents with CF and parents/family members of people with CF.

Anxiety

When managing an unpredictable, complex, and often uncontrollable illness like cystic fibrosis either as a person with CF or as a caregiver, it is common to experience anxiety about the future, as well as anxiety or worry about possible specific negative events or outcomes. More research is needed to understand anxiety and cystic fibrosis.

Research Priorities

- Expanding anxiety research for under age 12 and teens
- Procedural anxiety and distress
- Examination of trauma and Adverse Childhood Experiences (ACEs) on CF health outcomes
- Developing and testing interventions for managing panic symptoms
- Incidence of anxiety and fear related to death specifically, and development of effective interventions
- Cultural considerations when assessing and developing interventions for anxiety in CF

Depression/Mood Disorders

Depression is a common mental illness that affects thoughts, feelings and behaviors and is different from usual fluctuations in mood and time-limited reactions to stress or challenges in everyday life. The risk of depression, and the negative impact on health and wellbeing, for those with chronic medical illness is well established. More research studying depression and cystic fibrosis is needed.

Research Priorities

- Expanding depression research for children under 12 years old
- Predictors of mood disorders in children, adolescents and adults with CF
- Interventions for subclinical distress (prevention of mood disorders)
- Identification of risk factors for depression
- Suicide risk and treatment

- Intervention delivery methods

Relationships of Mental Health with Physical Health

Mental Health disorders cause substantial suffering in themselves but take on additional importance in CF because of their impact on disease self-management, and ultimately on disease trajectory, quality of life, and mortality. In addition, sleep complaints, such as insomnia and obstructive sleep apnea, are reported to occur in a significant proportion of children and adults with CF. While there is not extensive literature in this area, there is a burgeoning interest among investigators and people with CF regarding the impact of sleep disorders on quality of life.

Research Priorities

- Understanding the relationship between mental health and CF disease outcomes
- Understanding sleep disorders in people with CF and determination of their relationship to physical and mental health.

Relationships of Co-morbidities and Mental Health

Research is needed to better understand the prevalence, impact, and management of psychiatric co-morbidities in addition to anxiety and depression in people with CF. These conditions 1) may co-occur with depression and anxiety or present independently, 2) are characterized by distress, impaired functioning or difficulty regulating behavior, and 3) have CF-specific manifestations or effects on CF management and disease course. Examples include, but are not limited to:

- Attention Deficit Hyperactivity Disorder (ADHD)
- Disordered Eating/Eating Disorders
- Pain
- Substance Misuse

Research Priorities

- Prevalence, risk factors, and CF-specific manifestations of common psychiatric co-morbidities beyond anxiety and depression in people with CF
- Bidirectional impact between CF and the co-morbid psychiatric condition

Mental Health Research Priorities Working Group

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For more information on these topics or the work being done in CF, contact MHAC.

For information on funding opportunities, contact Dara Riva.

Relevant publications

Bathgate CJ, Hjelm M, Filigno SS, Smith BA, Georgiopoulos AM. Management of Mental Health in Cystic Fibrosis. Clinics in Chest Medicine, forthcoming, 2021.

Georgiopoulos AM, Christon LM, Filigno SS, Mueller A, Prieur MG, Boat TF, Smith BA. Promoting emotional wellness in children with CF, part II: Mental health assessment and intervention. Pediatr Pulmonol. 2021 Feb;56 Suppl 1:S107-S122. PMID: 32706527.

Muther EF, Polineni D, Sawicki GS. Overcoming psychosocial challenges in cystic fibrosis: Promoting resilience. Pediatr Pulmonol. 2018 Jun;53 Suppl 3: S86-S92.

Prieur MG, Christon LM, Mueller A, Smith BA, Georgiopoulos AM, Boat TF, Filigno SS. Promoting emotional wellness in children with cystic fibrosis, Part I: Child and family resilience. Pediatr Pulmonol. 2021 Feb;56 Suppl 1:S97-S106. PMID: 32658376.

Quittner AL, Abbott J, Georgiopoulos AM, Goldbeck L, Smith B, Hempstead SE, Marshall B, Sabadosa KA, Elborn S; International Committee on Mental Health; EPOS Trial Study Group. 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. 2016 Jan;71(1):26-34. doi: 10.1136/thoraxjnl-2015-207488. Epub 2015 Oct 9. PMID: 26452630; PMCID: PMC4717439.

Quittner AL, Goldbeck L, Abbott J, Duff A, Lambrecht P, Solé A, Tibosch MM, Bergsten Brucefors A, Yüksel H, Catastini P, Blackwell L, Barker D. Prevalence of depression and anxiety in patients with cystic fibrosis and parent caregivers: results of The International Depression Epidemiological Study across nine countries. Thorax. 2014 Dec;69(12):1090-7. Epub 2014 Sep 21. PMID: 25246663.

Schechter MS, Ostrenga JS, Fink AK, Barker DH, Sawicki GS, Quittner AL. Decreased survival in cystic fibrosis patients with a positive screen for depression. J Cyst Fibros. 2021 Jan;20(1):120-126. Epub 2020 Aug 13. PMID: 32800486.

Smith BA, Georgiopoulos AM, Quittner AL. Maintaining mental health and function for the long run in cystic fibrosis. Pediatr Pulmonol. 2016 Oct;51(S44):S71-S78. PMID: 27662107.

Sawicki, GS, Ren, CL, Konstan. MW, Miller, SJ, Pasta, DJ, & Quittner, AL. Treatment Complexity in Cystic Fibrosis: Trends over Time & Associations with Site-specific Outcomes. J Cyst Fibros. 2013 Sep;12(5):461-7. Epub 2013 Jan 24. PMID: 23352205; PMCID: PMC4073628.