

CF RD/SW NEWSLETTER

Summer Vibes



It's Heating up over here

CF RD SW CONSORTIUM SUMMER 2025

[HTTPS://WWW.CFRDSWCONSORTIUM.COM](https://www.cfrdswconsortium.com)

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Updates

The Cystic Fibrosis Foundation-funded Success with Therapies Research Consortium (STRC) is conducting a study to gather feedback from people with CF and their family members on what patient-provided data is important to collect to support clinical care and research.

<https://redcap.link/STRCPrioritizationCommunityMemberSurvey>



Congratulations to the two newest CACFD credentialed dietitians:

Rima Kandalaft from Children's Hospital of Orange County
Maegan Cook from Children's Healthcare Atlanta

Articles & Job Postings

Looking for all of your favorite article links that come with your newsletter or the most updated list of open positions in between newsletters? We got you covered. They have a new location that you can see more frequent updates and abstracts right on the consortium website!

Check them out at: <https://www.cfrdswconsortium.com/>

Le Bonheur Children's Hospital in Memphis, Tennessee has an open position for a pediatric CF dietitian. If you are interested in the position, contact Amanda Helton, Director of Nutrition Therapy, at amanda.helton@lebonheur.org.

Next Year's RD/SW Consortium

May 13th-16th 2026, Buffalo Marriott Niagara

Start thinking about your trip! Niagra Falls State Park (the US side) is about a 25 minute drive from the hotel!! The white

RD/SW Consortium Highlights

“Salt in My Soul”



Mallory Smith's memoirs of her battle with cystic fibrosis detail her daily struggles, her hopes for the future, and her resiliency in times of hardship. Her mother and her father have been her biggest advocate and have continued their advocacy work for other patients battling CF. This documentary as well as the written stories from Mallory are a powerful reminder of the depth of CF on the lives of our patients, their strength and resiliency, and the need for never ending hope for life.

“Right to Bite”

This presentation focused on ethics and ethical decision making. The definition of bioethics evolved from abuses of human subjects in research, medical interventions without informed consent, and experimentation in concentration camps in WWII. It has key terminology in autonomy, beneficence, nonmaleficence, and justice. This presentation focused on the collaboration between the Physician, Dietitians, and social workers and their roles in ethical decision making. Medical providers focus on Autonomy, beneficence, and non-maleficence; dietitians focus on non-maleficence, autonomy, and beneficence; Social workers focus on service, social justice, dignity and worth of the person, human relationships, integrity, and competency; all providers have a focus on justice. These roles also emphasized the value of inclusion and its important for the entire care team in order to support patient autonomy. There was also an emphasis on team member ownership and who will be responsible for making decisions.

Key take aways:

How to include ethics in team collaboration: Differentiate social work perspectives, values, and interventions from those of other health care disciplines. Ensure that the SW roles and responsibilities are clearly delineated and communicated to other members of the team. Provide psychosocial insight, guidance, and recommendations to other members of the health care team regarding client and family well-being. Advocate for the client's or client's support system's roles in the team communications and care planning, delivery, and monitoring. Seeking consultation from team members and across other care teams. Develop and maintain partnerships across disciplines and organizations to enhance ethics.

TOADs- Taking on Alternative Diets

in 2024, we saw an amazing concept come out of collaboration between Social Worker and Dietitian to create a fun, interactive pediatric program for kids with CF to come together virtually and learn about important tasks about managing CF care including medication management and cooking classes!

In 2025, TOADs was created to do the same for adults. The topics were appropriate for adults to add in behavioral habit based change, body image, food label reading, swapping out choices depending on needs, fats & modulators, and of course, keeping a virtual cooking class.

Sleep and Cystic Fibrosis

- Snoring is associated with growth failure in children with cystic fibrosis
- Insulin resistances is increased when an individual has lowered sleep volume. This is a consideration for patients with CFRD.
- Those with mental illness have a higher sensitivity and connection to pain within the gut.
- Hypnosis may be an effective therapy for individuals with abdominal pain.

Structured Lipids

If you didnt get to hear this presentation, it was part of the RD advanced practice course. These are some of the amazing tidbits from Dr. Virginia Stallings and her research structured lipids, or as many people know it Encala. Structured lipids may be beneficial in addition to infant formula, breast milk, or toddler formula for patients who struggle with weight gain velocity. Major bone development occurs between 9-11 years old, and therefore starting early to know where expected growth occurs early may aid in long term bone health and growth. It can also be beneficial to pregnant mothers as it has additional choline and can be used in g tubes as a bolus

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The Effects of Progressive Muscle Relaxation on Mental Health and Sleep Quality in Adults with Cystic Fibrosis: A Randomized Controlled Trial

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• PMCID: PMC12027757

• DOI: 10.3390/jcm14082807

Abstract

Background/Objective: Cystic fibrosis (CF) is a chronic genetic disease affecting multiple body systems and having a significant impact on mental health and sleep. Patients with CF frequently suffer from anxiety, depression, and sleep disturbances, but non-pharmacological strategies are understudied. Although progressive muscle relaxation (PMR) has recognized benefits, its impact on CF remains insufficiently explored. The study aimed to analyze the effect of integrating PMR into a standard pulmonary rehabilitation (PR) program on mental health, sleep quality, and quality of life in adults with CF. **Methods:** A total of 22 adult patients with CF were randomly assigned to either the intervention group (PR + PMR) or the control group (PR only). Assessments were performed at baseline, after 21 days of intervention, and at the 48-day follow-up. Outcome measures included the CFQ-R for quality of life, the HADS for mental health, and the PSQI for sleep. **Results:** Compared to the control group, participants who practiced PMR experienced significant reductions in anxiety ($p = 0.05$) and depression ($p = 0.02$) at the final assessment. A significant improvement in sleep quality was also observed ($p < 0.01$). No relevant differences were found in pulmonary function or performance on the six-minute walk test. **Conclusions:** Integrating PMR into pulmonary rehabilitation programs may be an effective strategy for improving mental health and sleep in patients with CF. Due to its accessibility and ease of implementation, PMR could be adopted as a complementary method in the holistic care

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Personal narratives to support learning about lung transplant for people with cystic fibrosis

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• PMID: 40347548

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Abstract

Objectives: Cystic fibrosis (CF) causes progressive respiratory disease and premature death. Lung transplantation (LTx) is an important treatment consideration for people with CF (PwCF). Among PwCF, does preparedness for LTx and knowledge about LTx improve by reading personal narratives from CF LTx recipients ("CF Stories")?

Methods: Adults with CF were recruited and presented with online CF Stories. Pre- and post-intervention questionnaires assessed LTx preparedness, knowledge, and decisional conflict. Deductive thematic analysis of study visits was conducted.

Results: Twenty-five participants were included. Pre-intervention, 24 % (6/25) reported feeling "very prepared" to discuss LTx. Among the remaining 19, preparedness improved post-intervention for 74 % (n = 14, 95 % CI: 51-88 %), with 42 % (n = 8, 95 % CI: 23-64 %) transitioning to feeling "very prepared." Baseline transplant knowledge was high (100 % questions correct) among 48 % (12/25) of participants; among the remaining 13, 92 % (n = 12, 95 % CI: 67-99 %) scored 100 % post-intervention. Decisional conflict improved for 67 % of participants (16/24), with a mean individual Decisional Conflict Scale change of -9.4 (95 % CI: -2.8, -15.9; p = 0.01). Thematic analysis revealed that participants valued practical LTx insights and relatable stories, identifying key medical information for LTx discussions.

Conclusions: CF Stories improved knowledge and preparedness for LTx discussions.

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Psychological Flexibility, Coping Styles, and Mood Among Individuals With Cystic Fibrosis

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• PMID: 40167140

• DOI: 10.1097/PSY.0000000000001387

Abstract

Objective: An emerging body of evidence suggests that psychological flexibility may be an important and underexamined determinant of overall psychological functioning. The chronic nature of cystic fibrosis (CF) may require a greater level of flexibility to navigate complex and dynamic health concerns in an increasingly aging population.

Methods: We examined associations between psychological flexibility, coping styles, psychological grit, and negative affectivity (anxiety and depressive symptoms) from baseline assessments of randomized trials among adults with CF. Regression models controlling for age, sex, income, psychotropic medication use, and pulmonary function were used to characterize associations between psychological flexibility, coping styles, and negative affect.

Results: A total of 124 individuals were included in analyses, 74 (60%) of whom were taking psychotropic medication. Depressive [Beck Depression Inventory-II = 18.6 (SD = 9.9)] and anxious [Beck Anxiety Inventory = 13.8 (SD = 9.3)] symptoms were both elevated. Greater levels of psychological flexibility were associated with lower negative affect, such that individuals reporting less cognitive fusion ($B = -0.59, p < .001$) and greater psychological acceptance ($B = -0.51, p < .001$) exhibited lesser levels of anxiety and depressive symptoms. Psychological flexibility was the most robust correlate of negative affect after accounting for other coping variables ($B = -0.50, p < .001$), and this association was not moderated by forced expiratory volume in 1 second/forced vital capacity levels.

Conclusions: Psychological flexibility is robustly associated with decreased negative affect

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Opportunistic assessment of bone mineral density in cystic fibrosis patients using ultra-low dose thoracic CT

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• PMID: 40650818

• DOI: 10.1007/s11657-025-01578-5

Abstract

In this study, we used routine ultra-low dose computed tomography scans of patients with cystic fibrosis to predict bone mineral density (BMD). A strong correlation was found between the attenuation of trabecular bone in thoracic vertebrae and the BMD in the proximal femur and lumbar spine as measured on DEXA.

Purpose: Osteoporosis is a serious global health concern with millions of people affected worldwide. A particularly vulnerable cohort in developing osteoporosis are patients with cystic fibrosis (CF). Bone mineral density (BMD) is typically measured with dual energy X-ray absorptiometry (DEXA) scanning; however, this comes at a cost to the healthcare system and an exposure to ionising radiation. In our institution, patients with cystic fibrosis undergo routine ultra-low dose computed tomography (ULDCT) for monitoring of disease progression. The aim of this study was to assess the validity of estimating BMD using data derived from ULDCT scans.

Methods: Adult CF patients were included if they had undergone a routine ULDCT scan within 12 months of a DEXA scan. Additionally, 100 non-CF patients with non-contrast standard dose CT scans were selected to act as the control group. Trabecular bone density (T-BD) at T4, T7 and T10 was measured on PACS in Hounsfield units (HU) and compared to DEXA scan results and a formula developed to the predict BMD.

Results: Fifty-two female and 62 male patients were included with mean ages of 34.4 and 35.1 respectively. Moderately strong correlation was found between the T-BD and BMD of both the lumbar spine ($r = 0.629$, $p < 0.001$) and proximal femur ($r = 0.649$, $p < 0.001$). Receiver operator characteristic (ROC) curve analysis found a sensitivity and specificity of 0.700 and 0.714 respectively at predicting osteoporosis at T-BD of 193.33 HU or below.

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Time to replace the oral glucose tolerance test for cystic fibrosis related diabetes first-step screening? Establishing glycemic tools relevant to cystic fibrosis

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Abstract

Introduction: As the life expectancy of people with cystic fibrosis (CF) increases, complications related to CF, such as CF-related diabetes (CFRD), are of great concern. Oral glucose tolerance test (OGTT) is the current gold standard test to screen for CFRD, which is associated with reduced lung function and body mass index (BMI). However, this is a cumbersome test with poor adherence, and emerging evidence suggests that HbA1c or serum fructosamine might be viable alternative screening tools.

Research design and methods: A multi-center study across four Canadian adult CF centers was conducted to determine the ability of HbA1c and serum fructosamine levels to predict screening OGTT results. Cross-sectional outcome data, including ppFEV₁ and BMI within two months of testing, were collected.

Results: A total of 183 CFRD screening encounters over five years were included. HbA1c and the fructosamine-to-albumin ratio had similar predictive performances for CFRD as determined by OGTT-defined cutoffs (AUC both 0.68) and for impaired glucose tolerance (AUC 0.69 and 0.64, respectively). However, the specificity of FAR is lower, meaning fewer OGTTs can be avoided if FAR is used as a first-step screening test when screening for either CFRD and/or IGT compared to HbA1c. The optimal HbA1c cut-off for CFRD screening was $\geq 5.5\%$ (sensitivity, 95%; specificity, 32%). Regression analyses demonstrated a strong inverse correlation between HbA1c and ppFEV₁ ($p < 0.0001$), while the OGTT was inversely correlated with ppFEV₁ ($p < 0.05$), and the fructosamine-to-albumin ratio was inversely correlated with BMI (-0.9 ; 95% CI $-1.5, -0.4$; $p = 0.002$), but not with ppFEV₁ within 2 months of testing.

Conclusion: HbA1c is validated as a first step in screening for CFRD, allowing one-third of the patients to avoid the OGTT. As HbA1c demonstrated a stronger correlation with ppFEV₁ than the

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The association between dysglycaemia and exercise capacity in cystic fibrosis

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Abstract

Abstract

Background: People with cystic fibrosis-related diabetes (CFRD) are known to have reduced exercise capacity (EC), which in turn is related to increased morbidity and mortality. The aim of this study was to examine whether dysglycaemia may independently influence exercise capacity in people with CF (pwCF).

Methods: Results from clinically conducted cardiopulmonary exercise tests were analysed retrospectively in 139 pwCF alongside routine clinical data. Subjects were grouped according to glycaemic status; normal glucose tolerance (NGT; $n = 43$) and dysglycaemia; impaired glucose tolerance (IGT; $n = 17$) and CFRD ($n = 79$). Anthropometric data was assessed using chi-squared tests. Regression models were developed using analysis of co-variance (ANCOVA) to evaluate predictors of exercise capacity and correlations between variables were assessed using the Pearson method.

Results: Maximal oxygen uptake (VO_{2max}) was reduced in the CFRD group compared to NGT and IGT ($p < 0.01$), however this was dependent on higher FEV_1 % in the NGT and IGT groups ($p < 0.001$) and significant differences were no longer present when FEV_1 was accounted for. A higher proportion of those with dysglycaemia were ventilatory limited (NGT; 42 %, IGT; 72 % & CFRD; 65 %, $p < 0.05$). Age, gender, BMI, intravenous antibiotic days and FEV_1 % were significant predictors of VO_{2max} across all patients (adjusted $R^2 = 0.528$, $p < 0.001$). HbA_{1c} is a small but significant predictor of VO_{2max} in patients with dysglycaemia ($p < 0.05$).

Conclusions: Adults with CFRD have reduced VO_{2max} compared to NGT or IGT which is mediated by poorer lung function and higher overall disease burden. In individuals with CFRD, better glycaemic control is associated with a greater EC.

