September 2022

Cystic Fibrosis Dietitian & Social Worker Consortium
RDSWCONSORTIUM@GMAIL.COM
EIN: 88-2745812.

CF RD AND SW CONSORTIUM

Monthly Newsletter

Special Thanks To

- MVW Nutritionals
- Alcresta
- Callion Pharma
- Nestle

2022 Consortium Board Member:

- Kim Altman, MS, RD, CDN
- Denise Flores, MSW, LCSW
- Amanda Leonard, MPH, RD/LDN, CDCES
- Terri Schindler, MS, RDN, LD
- Kay Vavrina, MPA, RD, LD, CNSC
- Shayla Wilson, MSW, LCSW, C-ASWCM

CHECK OUT OUR NEW WEBSITE!

https://www.cfrdswconsortium.com/

SAVE THE DATE!!

The annual CF Dietitian and Social Worker Consortium will be held in Louisville, KY on April 3-5, 2023 at the historic and beautiful Brown Hotel.

Registration will be limited to the first 150 registrants, so plan ahead! Registration date will be announced in the Fall. Call for case studies and QI project submissions to be sent to the RD and SW listserv forums by October 2022.

Mental Health Resources for CF patients and their families:

Support Groups of Interest:

⇒ **CF Adults who are post-transplant**
Sponsored by CFRI: facilitated by Sonya Haggett, LCSW
https://us02web.zoom.us/meeting/register/tZUpdeqorj4vEte6OGBdTWNg-i3HKbTw7eDF

⇒ **Teenagers with CF**
Sponsored by CFRI: facilitated by Teresa Priestley, MSW and Deborah Menet, LCSW
The group meets on the third Wednesday of every month, beginning March 16, 2022, from 5:30 p.m. to 6:30 p.m. Addresses the unique issues faced by teenagers between the ages of 13 and 18 years of age with CF.
https://www.cfri.org/teen-support-group-registration/

Other Resources:

⇒ **The Nourished Breath:** a virtual, bimonthly journaling workshop for adults in the CF Community. These 60-90 minute workshops are grounded in a warm, online environment that prioritizes the connection and comfort of the writers who join. The Nourshied Breath is led by Aimee Lecointre, an adult with CF. https: www.thenourishedbreath.com

⇒ **Exercise Training for Teenagers with CF:** Led by clinical exercise physiologist and pulmonary exercise specialist Taylor Lewis, this virtual program helps teens with CF learn proper exercise techniques to build personalized exercise routines, avoid injury, strengthen performance, and enjoy physical activity. https://pulmonary-performance.com

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Mental Health Resources for CF patients and their families (cont.):

⇒ **I Can Imagine:** Led by artist and adult with cystic fibrosis Dylan Mortimer, this program offers virtual art sessions for adults with CF to create visual representations of their unique experiences living with the disease. The program aims to display select artwork in CF care centers and hospitals across the country to inspire hope and healing. https://www.dylanmortimer.com/i-can-imagine

⇒ **Finding Calm Through Restorative Yoga:** Classes will be held on Saturdays, from 9:00 a.m. to 10:15 a.m. PT, starting August 20. The class is free to individuals with CF. as well as parents, spouses, partners and siblings of those with CF. While there is no charge, you must register for the class in order to participate. Once registered, you will have access to a recording of each session, should you miss a class. https://41224.thankyou4caring.org/yoga-finding-calm-aug-2022?erid=10573847&trid=4456593e-c7bf-4e3b-979b-40ce3bcfef4d

⇒ **Counseling support services:** Children and adults with CF as well as their family members (parents, siblings, spouses/partners) are eligible to receive financial support for **six individual therapy sessions per year with a licensed provider of their choice.** CFRI will cover the cost of your insurance co-pay for six sessions, or pay up to $120 per session for six sessions if you have no insurance, or your provider does not accept insurance or is outside of your network. CFRI will pay the provider directly. Participants must live in the United States. You can select a licensed therapist in your community (for a referral, you can ask your CF social worker). https://www.cfri.org/education-support/psychosocial-support-programs/

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Recent abstracts:

Chest

2022 Jul 19:S0012-3692(22)01248-X

Treatment Preference Amongst People with Cystic Fibrosis: The Importance of Reducing Treatment Burden

PMID: 35868349
DOI: 10.1016/j.chest.2022.07.008
https://doi.org/10.1016/j.chest.2022.07.008

Abstract

Background: There is a growing consensus that the perspective of the patient should be considered in the evaluation of novel interventions.

Research question: What treatment outcomes matter to the people with cystic fibrosis (CF), and what trade-offs would they make to realize these outcomes?

Study design and methods: Adults attending a specialist CF center were invited to complete an online discrete choice experiment (DCE). The DCE required participants to evaluate hypothetical CF treatment profiles, define d by impact on lung function, pulmonary exacerbations, abdominal symptoms, life expectancy, quality of life, inhaled medicines usage and physiotherapy requirement. Choice data were analyzed using multinomial logit and latent class models.

Results: 103 people with CF completed the survey (median age 35 years (range 18-76); 52% female; mean 99FEV1 69% (SD22)). On average, an improvement in life expectancy by 10 years or more had the greatest impact on treatment preference, followed by a 15% increase in lung function. However, it was shown that people would trade substantial reductions in these key outcomes to reduce treatment time to burden. Preference profiles were not uniform across the sample: three distinct subgroups were identified, each placing markedly different importance on the relative importance of both life expectancy and lung function compared to the other attributes.

Interpretation: The relative importance of treatment burden to people with CF, compared to life expectancy and lung function suggests it should be routinely captured in clinical trials as an important secondary outcome measure. When considering the patient perspective, it is important that decision makers recognize that the values of people with CF are not homogenous.

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Recent abstracts:

J Patient Exp
2022 Jul 14;9:23743735221112629.
doi: 10.1177/23743735221112629.eCollection 2022.

Evaluating Differences in the Disease Experiences of Minority Adults with Cystic Fibrosis

PMID: 35860790
PMCID: PMC9289912
DOI: 10.1177/23743735221112629
https://doi.org/10.1177/23743735221112629

Free PMC article

Abstract

Extensive research has demonstrated disparities in health outcomes and survival between non-Hispanic Caucasian (NHC) and non-Caucasian or Hispanic (minority) persons with cystic fibrosis (CF) in the United States (US). However, very little research has been done to explore the disease experiences of racial and ethnic minority persons with CF. Adult subject with CF were approached for study participation and to characterize their experiential disease perceptions. Survey data were analyzed using Chi-Square tests and Mann-Whitney U-test for basic categorical and continuous variables, and Kruskal-Wallis one-way ANOVA using ranks for Likert scales. Minority persons reported significantly lower scores (more negative experience when comparing themselves to others with CF (15.18±2.89 vs 18.40 ± 3.18, P < .01), particularly in the areas of representation in research, experience, and support. We were able to identify the unique experiences of minority persons with CF, including perceived lower disease understanding and poorer representation compared to most others with CF. Further large studies are needed to develop and assess interventions that may be useful for serving these diverse populations.