

MENTAL HEALTH WORKING GROUP

Year of report: 2020-2021

Name of Working Group:
Mental Health Working Group
Subgroups: Treatment group & Research group

Date of initial approval of working group:
Starting date: June 2016
Extension date: June 2019

Coordinator Treatment group:
Edwina Landau
Coordinator Research group:
Marieke Verkleij

Long term aims of the working group (maximum 100 words) including estimated achievement date:

Background: The MH Working Group was initiated in 2016 in response to the TIDES study (The International Depression and anxiety Epidemiological Study) which demonstrated elevated symptoms of depression and anxiety in people with CF and their caregivers, and the publication of the Guidelines for screening and treating depression and anxiety in individuals with CF and their caregivers. The work has predominantly focused on screening, diagnosis of mood disorders and treatments. During the second phase of the MHWG from 2019 a shift in focus has promoted preventative strategies, resilience and emotional wellness.

Aims:

1. To develop a multidisciplinary network of clinicians and researchers to facilitate and support the dissemination and implementation of the Mental Health Guidelines.
2. To monitor the implementation of Mental Health Screening and identify the range of clinical practice and treatment referral pathways across Europe.
3. To determine patient and parent-reported effectiveness / impact of MH Screening and Care.
4. To promote preventative mental health strategies, resilience and emotional wellness
5. To promote excellence in Mental Health research across the European CF Community.

Treatment group:

The treatment/intervention subgroup has focused in general on the following areas this year:

- 1) Update on the website a list of evidence based treatment modalities/ interventions for helping people with CF with depression and anxiety Examples of different treatments include: ACT, existential therapy, CBT, mindfulness, play therapy, psychodynamic therapy, parent centered therapy, systemic family therapy, psycho-analytic therapy, IPT, parent management training, DBT. These can be used a resource to help professionals and healthcare workers.
- 2) Expanded the work of the working group into more Eastern European countries,
- 3) Due to the Corona crisis, we have set aside time in the teleconference meetings to provide support to one another during this challenging time, sharing our individual experiences in our respective countries. This has in turn has enabled sharing knowledge of professional treatment methods
- 4) In collaboration with the mental health advisory committee in the US, Dr Anna Georgiopoulos as the US representative, handouts on a variety of prevalent topics are being shared and translated on the website (with permissions from the American CFF website). These include, sibling, caregiver and parenting handouts dealing with a range of issues.

- 5) We organized a series of training webinars, together with EPSIG (European Psychosocial Interest Group). This was called the CF lunch time series. The aim was to reach **all** multidisciplinary team member of CF teams from all countries globally. We succeeded in reaching over 34 countries including Europe, Eastern Europe, Asia, USA as well as Australia and New Zealand.

Topics included:

- a) Challenges and complexities of care in transition
- b) Food and CF: Friend and Foe?
- c) How covid-19 changed the clinic: learning as we move along in uncertain times
- d) New challenges of care: physiotherapist and pharmacist joining forces
- e) Women's health and cystic fibrosis

Research group:

The research groups has focused on research on mental wellbeing in CF patients and parents around Europe, and keeping track and documenting research carried out in this field.

Survey to evaluate the impact of the MH guidelines from the patient/caregiver perspective.

Health care professionals have reported that MH screening has been successfully implemented in many CF Centres. From these data, we now have some understanding of the benefits and barriers of mental health screening. To complete this picture, we are interested in the importance that patients and caregivers put on mental health, their preferences and experiences of screening and any follow-up care.

First results: The initial survey monkey slides are provided on the website:

https://www.ecfs.eu/sites/default/files/general-content-files/working-groups/Mental%20Health?MH%20Survey%20Data_All_200128%283%29.pdf.

We are now in the process of writing up results of this survey for a paper, together with the CFF Mental health advisory committee. This research will be presented as an oral presentation at the ECFS digital conference in June 2021, in the workshop 11 on 11.6: - **Anxiety and stress in cystic fibrosis through a challenging 2020 and novel interventions**

See abstract below:

Mental health screening as an intervention: how patients and caregivers contribute to improving our processes

On behalf of the ECFS and CFF Mental Health Working Group/Advisory Committee

Objectives: To evaluate how adults with CF and caregivers perceive mental health screening. Questions focused on the screening process, discussion of results, perceived benefits of screening, the CF Team's demonstrated interest and commitment to mental health. **Method:** An online survey was sent out in November 2019 with 4 months to respond, to adults with CF and caregivers in the EU and US. A total of 474 respondents, 79% female ($n=374$), completed the survey (CF $n=240$, caregivers $n=233$), with 57% from Europe ($n=271$; US $n=203$). **Results:** There was nearly universal agreement among respondents that mental health is an important aspect of health (93%). A majority of adults with CF (82%) and caregivers (75%) preferred to discuss mental health issues in person, with privacy. More than half of the sample had not been screened (58%) because the tools were not offered. When asked about the CF Team's level of interest in mental health, those who had been screened were *more likely* to endorse their team's interest, as well as receipt of adequate psychological support. Screening was perceived as helping respondents understand their feelings (54-60% responded "yes" or "to some extent"), with a majority willing to pursue mental health care if recommended. Of those screened, 58% of adults with CF and 52% of caregivers had a conversation about the screening results with their mental health clinician, with the majority rating this conversation as "very satisfactory" to "satisfactory." Importantly, 44-46% of respondents

who had *not* had a conversation “wished there had been one.” **Conclusion:** Results indicated that the screening process is itself an intervention. It provides opportunities to help adults with CF and caregivers better understand their emotional functioning, receive psychological support, and “open-up” a discussion on their needs for mental health. Mental health screening has been recently integrated into CF care, and these data suggest several ways to improve the process.

Aims for the coming year (please state year) (max 50 words):

Treatment group:

- Continued encouraging implementation of screening and follow up of treatment guidelines
- Developing the resource area on the ECFS website for health care professionals
- Peer support network and sharing experiences
- Encourage screening with new modulator therapies

Research group:

- Finish and prepare paper of patient/caregiver survey
- Collaboration between research projects in Europe, especially focusing on positive psychology, resilience and the strengths of CF-patients and caregivers which may reduce the burden of CF

Training and Networking Opportunities:

Due to the Covid-19 crisis conference in Lyon and Milan were cancelled:

The focus will be on strengthening the network of European and International CF mental health care specialists. In order to promote and stimulate the exchange of information about CF in the mental health field, we hope to plan virtual meetings and relevant courses later in the year.

The following events took place last year 2020 through digital means:

Tomorrow's lounge: Title: We are screening...now what? Different treatment modalities in CF mental health

Meet the Experts session: Psychological impact of not being eligible for new treatments.

Evidence based pre conference workshop course:

Practical therapeutic modalities to manage psychological problems, sleep and pain in routine CF care

The following events have been planned for this year's ECFS 44th digital conference:

Tomorrow's lounge: Title: Treatment throughout the ages

Meet the Experts session: Impact of modulator Therapy

Evidence based pre conference workshop course: (this is organized jointly with EPSIG)

Power Threat Meaning Framework

A non-diagnostic approach to conceptualising distress in all of us developed by psychologists and experts by experience. It will focus on the implications of the framework for responding to psychological distress in the context of physical healthcare, with opportunities to practice applying it to CF case examples.

Breakdown of expenses (please include total amount received as well as expenditure and, if applicable, the outstanding balance (Euros)):

Not applicable

Budget amount requested for next year (please give the amount in Euros and the year):

ECFS conference 2022 (Travel costs, conference fee and annual meeting MHWG)

500 euros each for co chairs for travel expenses/registration; AGM for conference 2022

500 euros for 2 speakers for pre-conference day

500/1000 euros for CFF mental health advisory board representative

List of current Members

Current members:

Janice Abbott – UK (Psychologist)
Klara Benesova – Czech Republic (Psychologist)
Urszula Borawska – Poland (Psychologist)
Riccardo Ciprandi – Italy (Psychologist)
Johanna Gardecki – Germany (Psychologist)
Anna Georgiopoulos - US (Psychiatrist.
Sonia Graziano-Italy (Psychologist)
Trudy Havermans - Belgium (psychologist)
Pavla Hodkova - Czech Republic (Psychologist)
Stina Järholm – Sweden (Psychologist)
Diana Kadosh – Israel (Social Worker)
Annette Katscher-Peitz – Germany (Psychologist)
Maya Kirszenbaum – France (Psychologist)
Horst Mitmansgruber – Austria (Psychologist)
Jacquelin Noordhoek – CF Europe (President)
Olga Polaetva – Russia (Psychologist)
Yvonne Prins – Netherlands (Adult with CF)
Ulrike Smrekar – Austria (Psychologist)
Ralf Thalemann- Germany (Psychologist)