Annual Report ECFS Mental Health Working Group

Overall summary of the last year 2019-2020

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The ECFS Mental Health Working Group has divided into two subgroups:

1. **Treatment/intervention group, coordinated by Edwina Landau**
2. **Research/evaluation group, coordinated by Marieke Verkleij**

The two subgroups have monthly tele-conferences and continue to develop a network of CF Health Professionals who act as ‘Country Captains’, assisting with the collection of country specific information.

Treatment/Intervention Group

The treatment/Intervention subgroup has focused on the following areas this year:

- Follow up of treatment guidelines
- Developing the resource area on the ECFS website to provide easy access to resources to facilitate implementation of MH screening in many European languages.
- Making treatment available also for low resource countries
- Flyers with links to website, resources in different languages
- Peer support network and sharing experiences
- Extending the focus on positive psychology
- Providing opportunities for training

In particular:

1) The sibling and caregiver handout from the American CFF website are currently being translated into many different languages.
2) We have listed and provided short descriptions of different treatment modalities/ interventions for helping people with CF with depression and anxiety to be put on the website in the coming month. 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.
3) We have been working on expanding the work of the working group into more Eastern European countries,
4) In addition, 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.

Research Group

Publication ECFS MHWG 2019:

Abbott J, Havermans T, Jarvholm S, Landau E, Prins Y, Smrekar U, Staab D, Verity L, Verkleij M; ECFS Mental Health Working Group. Mental Health screening in cystic fibrosis centres across Europe. J Cyst Fibros. 2019 Mar;18(2):299-303.

Abstract

Objectives: The Cystic Fibrosis (CF) International Mental Health Guidelines Committee published consensus statements for screening and treating depression and anxiety in individuals with CF and their caregivers. This work aimed to evaluate the dissemination and implementation of the guidelines in Europe two years following their publication.
Methods: A 28-item survey was developed by the multidisciplinary ECFS Mental Health Working Group and emailed to approximately 300 CF centres across Europe. The survey evaluated (a) who should be responsible for mental health (MH) care, (b) the current awareness and agreement of the guidelines, (c) the provision of recommended MH screening and follow-up care, and (d) successes, barriers and required resources/training needs.
Results: Responses were received from 187 centres (28 countries represented). There was consensus that a psychologist should be responsible for MH care, although members

of the multidisciplinary team (MDT) believed they should also share this responsibility. Sixty-two percent of respondents were aware of the guidelines; 82% percent fully, and 12% partially, agreed with them. Fifty percent (94 centres) had implemented screening. In the past year approximately 6000 patients and 2000 caregivers had been screened, with 80% of respondents using the recommended screening tools. Respondents reported 551 referrals for moderate/severe psychopathology and 84 urgent suicide ideation referrals.

Conclusions: The challenges of different healthcare systems and language barriers are being overcome with a greater awareness of the importance of mental health among the MDT. MH screening is feasible and gaining momentum in both Western and Eastern Europe.

Please find the full paper at: https://pubmed.ncbi.nlm.nih.gov/30268370/

Currently running in Europe and the USA: *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%20 Survey%20Data_All_200128%283%29.pdf.

Mental Health Guidelines

The International Mental Health Guidelines Committee (IMHGC) in Cystic Fibrosis set up consensus statements for screening and treating depression and anxiety in individuals with CF and their caregivers. These statements are advocated in the published guidelines. The guidelines were informed by feedback from the CF clinical, parent and patient communities in Europe and the US. They recommend annual anxiety and depression screening for adults and adolescents (12+ years), and at least one primary caregiver of children under 18 years.

If resources are available, annual interview assessment for all participants would be the ideal. This is not possible in many centers but the screening tools are easy to administer, and providing referral pathways are available. Therefore they can be valuable where time is limited. The screening tools recommended by the ICMH, the Patient Health Questionnaire 9 (PHQ-9) for symptoms of depression and the Generalized Anxiety Disorder Scale (GAD-7) for anxiety have been shown to be suitable in general populations. The Mental Health Guidelines provide a valuable first step in recognizing, addressing and improving the mental health of CF families.

The research subgroup has focused on the following areas this year:

1) Positive psychology and the strengths of CF-patients and caregivers which may reduce the burden of CF. Therefore, resilience is one of the topics which should be taken into account when screening for psychological distress.
2) Screening of psychosocial problems in younger kids with CF < 12 yrs. and family functioning may prevent adolescents from anxiety and depression, since psychological interventions can start at earlier stage.
3) To gain more insight into specific CF-related complaints, since they can be associated with psychological distress.

CFF AWARD

Professor Janice Abbott has received a prestigious international award from the Cystic Fibrosis Foundation. ***The Carolyn and Richard Mattingly Award*** is given each year in recognition of distinction. The award recognises research and leadership in mental health care and a commitment to the mental health and well-being of individuals with cystic fibrosis. Janice received the award at the North American Cystic Fibrosis Conference in Nashville, 2019.

Training and Networking Opportunities to date

Due to the cancellation of the conference in Lyon because of the Corona crisis, our plans for the conference have had to change. 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.

Currently the following events are being planned through digital means:

Annual General Meeting: The aim will be to meet with the representative 'Captains' from all over Europe as well as mental health representatives from the working group in the US. We will give an update of our ongoing projects and open up the meeting to discuss goals for next year.

Tomorrow's lounge: Title: We are screening…now what? Different treatment modalities in CF mental health (Lyon, 2020) Scheduled for June 2020

Meet the Experts session: Psychological impact of not being eligible for new treatments (Lyon 2020) Scheduled at another time in the year.

Evidence based pre conference workshop course:

PRACTICAL THERAPEUTIC MODALITIES TO MANAGE PSYCHOLOGICAL PROBLEMS, SLEEP AND PAIN IN ROUTINE CF CARE

This year we decided to combine the groups of the ECFS Mental Health Working Group and European Psychosocial Special Interest Group (EPSIG for a joint one-day course on the use of different therapy modalities in supporting CF patients to manage psychological problems, sleep and pain. The course is aimed at all members of the MDT including doctors, nurses, physiotherapists, dietitians, psychologists, social workers etc.

The course will introduce individuals to the concepts of Cognitive Behavioural Therapy (as recommended by the mental health guidelines) and Systemic and Family Focused Therapy facilitated by two experienced psychologists; Lori Willem (BE) and Joanna Gardecki (DE). The emphasis is on the evidence for their effectiveness, the practical implications of using them in clinical settings, and a discussion about the next steps regarding further training and support. Participants will be given various case studies in groups in order to try and apply the concepts that have been discussed in a more practical way.

This course will take place online at a date to be announced.

Goals for Next Year

- Continued translation of resource handouts
- Extend treatment modalities by case studies
- Finish patient/caregiver survey
- How to stay connected even when we cannot meet up
- Implications of Covid-19 for CF patients and mental health workers

Long Term Goals

- Continue studies of resilience, GI symptom tracker
- Address screening of younger children under 12
- Address mental health screening of siblings
- Documenting research on efficacy of different therapeutic methods for CF patients
- Developing the resource area on the ECFS website to provide easy access to resources to facilitate implementation of MH screening in many European languages.
- Making treatment available also for low resource countries
- Flyers with links to website, resources in different languages
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- Providing opportunities for training