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Duff, AJA, Bowmer, G, Waldron, R et al. (3 more authors) (2016) Implementing ICMH-CF (International Committee on Mental Health in CF) guidance on screening for depression and anxiety symptoms: a feasibility and pilot study. Journal of Cystic Fibrosis, 15 (3). e33-e34. ISSN 1569-1993

https://doi.org/10.1016/j.jcf.2016.02.007

Implementing the International Committee on Mental Health in CF (ICMH-CF) guidance on screening for depression and anxiety symptoms in the UK; a feasibility and pilot study.

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Sir,

Elevated depression and anxiety symptom-scores in people with cystic fibrosis (CF) are associated with worse adherence, higher frequency of missed appointments, reduced quality of life, increased uptake of healthcare, and higher healthcare costs [1-3]. In response, the CF Foundation (CFF) and ECFS commissioned an International Committee on Mental Health (ICMH-CF), whose guidelines on preventing, assessing and treating depression and anxiety, have recently been published [4].

We evaluated the feasibility of administering the recommended measures - Patient Health Questionnaire (PHQ-8) and Generalised Anxiety Disorder scale (GAD-7), to adults with CF (>17 years) and parents of a child/young person with CF, during routine out-patient appointments (November 2014 to May 2015). Scores were logged in patients' Electronic Care Records (ECRs) and, as recommended by the ICMH-CF, participants who scored in the 'moderate' range on either/both measure/s, were psychologically assessed. Participants and staff also rated acceptability of these measures if used regularly for screening on five-point Likert scaling, and gave feedback on completing them.

Ninety-five participants were screened (n=65 parents of children and young people with CF, aged 0-16 years inclusive, 57 [88%] female; n=30 adult patients, >17 years, 14 [47%] female). The PHQ-8 has a maximum score of 24 with thresholds for

depression symptoms being: 5 ‘mild’, 10 ‘moderate’, 15 ‘moderately severe’ and 20 ‘severe’. On this 17% of parents and 10% of patients scored on or above the ‘moderate’ threshold. The GAD-7 maximum score is 21 and cut-off points for anxiety symptoms are: 5 ‘mild’, 10 ‘moderate’, 15 ‘severe’ and 22% of parents and 10% of patients had elevated on or above 10. Fifteen parents (23%) and five patients (17%) scored above 10 on either measure or both. Of these 6 parents (40%) and 2 patients (40%) were not already known to, or engaged in work with, the teams’ psychologists (1.1whole time equivalent per unit).

ICMH-CF screening recommendations and measures were well-accepted by parents and patients with 87% and 77% respectively either agreeing/strongly agreeing with these. The majority of parents and patients agreed/strongly agreed that the PHQ-8 (73% and 55%) and GAD-7 (75% and 61%), were appropriate measures which captured their feelings, and thought they should be used in routine practice (75% and 69% respectively). All self-report measures of mental health must balance the need to accurately capture mental state with being brief enough to be used routinely. It is encouraging that the majority felt these measures enabled them to express feelings adequately.

Qualitative analyses revealed three themes: (i) clear perceived benefit of annual screening for psychological symptoms, (ii) acknowledgement of fluctuating symptoms because of, for example, time of the year, health or infection status. This may necessitate more regular screening (adding weight to the use of case-tracking during episodes of psychological therapy where therapists use data to inform practice and, (iii) exercising caution that the questionnaires do not fully capture the range of CF-specific psychosocial symptoms (Table 1).

Table 1 Participant qualitative feedback

	Parents of children & young people with CF (n=65)	Adults with CF (n=30)
Clear perceived benefit	*I think it's important to monitor mental health* as it impacts massively on physical health, and vice versa. It gives an outlet and will hopefully help pick up on emotional stress factors in their early stages. This service should be provided and introduced to all families before issues arise.	It addresses common aspects as to what a CF patient's mind-set goes through on a daily basis. It addresses the right questions and aspects of mental, physical and emotional responses.
Potential fluctuations in scores	I think the answers will be different at different times, depending on how well/ill child may be. Although things are fine for me at the moment I do realise that things may change due to *[child]'s health.*	
Concerns about application to CF	I feel the questionnaires could be more CF specific.	PHQ-8 doesn't take into account sleeping is disturbed by cough symptom of CF.

Staff voiced concerns that screening was time-consuming for patients/parents who were; already in clinic for a long time or reluctant to complete another "test" (particularly if there were "no problems"). Some parents requested taking the measures home to complete, but this risked missing non-return and therefore unchecked symptoms. Conversely staff felt screening identified difficulties unrelated to CF but that impacted on 'coping', raising awareness that 'other' support was being accessed or required.

To the best of our knowledge, this is the first in situ feasibility study of ICMH-CF recommended measures, which include a suite of GAD and PHQ questionnaires. We opted for the PHQ-8, which omits suicidal ideation, as we had

sufficient resources to undertake timely assessment of participants with elevated scores and thought it more appropriate to address suicidality in the context of a face-face consultation. Centres opting for the PHQ-9 which includes this question need to ensure rapid scoring and have processes in place for urgent psychology referral if suicide risk is indicated.

We found elevated depression and anxiety scores in 17% and 22% of parents respectively, and in 10% of patients, commensurate with US data using the same measures [5] and UK/International rates from alternative ones in The International Depression/Anxiety Epidemiology Study (TIDES) [1,2]. With 40% of participants not known to, or engaged with the teams' clinical psychologists, our results provide further evidence for implementing the ICMH-CF screening measures even when there are good psychosocial resources. These were welcomed and well-tolerated by our participants, the majority 'agreeing' or 'strongly agreeing' that they appropriately captured their feelings, and that they should be used in routine practice. Whilst some differences were observed between parents and patients views, low numbers and missing data rendered statistical analyses meaningless.

Implementing the guidelines over 7 months led us to believe that this is too long a phase to be viable. Although there are advantages and disadvantages of a 'screening season' (albeit a more concerted one), in units with large patient numbers this could overwhelm resources, requiring too many follow-ups to be undertaken in a comparatively short space of time, and administration over longer periods would alleviate this pressure. However in smaller units, a 3-month screening season might be more focused and manageable, removing potential seasonal variations in patients' health.

Whilst our results are derived from a small sample in single paediatric and adult centers, they show that screening for psychological symptoms is welcomed and accepted by patients and parents. We focused on screening parents (almost all mothers, 88%) and adult-patients, who are identified as being particularly at risk [1,2], but there are no obstacles to extending this work to paediatric populations, particularly adolescents. Our data support the feasibility of routinely screening for psychological symptoms as recommended [4] and we are encouraged to find ways of more rapid administration and scoring and facilitating secure on-line completion outside the clinic environment. (953 words)

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