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## RESPIRATORY MEDICINE (2022)

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**Title: Mental health screening in Cystic Fibrosis as an intervention: Patient and caregiver feedback on improving these processes.**

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## **ABSTRACT**

**Background:** Integration of mental health (MH) screening and treatment in cystic fibrosis (CF) has become the standard of care. The European CF Society (ECFS) and CF Foundation (CFF) MH working groups evaluated how well these processes are working for people with CF (pwCF) and their caregivers.

**Methods:** Adult pwCF and family caregivers of children and adults in Europe and the United States completed a 23-item online survey assessing MH screening and its perceived benefits. Three implementation models were evaluated for their “fit” using thematic analysis with a 75.4% agreement. The model Stages and Determinants of Implementation fit best.

**Results:** Of 474 respondents, 79% were female, 57% European. PwCF and caregivers agreed that MH is an important aspect of CF health (93%); 58% of the sample was not screened for depression/anxiety, mainly because it was not offered. Those who were screened rated CF teams as more interested in their MH and provision of psychological support. Screening was perceived as helping respondents understand their feelings, with most willing to pursue MH care if recommended. Over half of those screened discussed their results with their CF MH clinician; many respondents who had *not* had a conversation “wished there had been one.”

**Conclusions:** PwCF and caregivers viewed the MH screening process itself as an intervention that facilitated a better understanding of their emotional functioning, providing opportunities for psychological support and discussion of MH needs

## HIGHLIGHTS

- ☐ Integration of mental health screening has become a standard of CF care
- ☐ CF Patient and caregiver assessment on processes and benefits of MH screening
- ☐ Comparisons between Europe and US
- ☐ MH seen as an intervention itself and provides motivation to pursue MH support
- ☐ CF patients and caregivers view MH screening as an important part of CF care

**Conflicts of Interest:**

AMG reports personal fees and travel reimbursement from Cystic Fibrosis Australia; grants, personal fees, and travel reimbursement from Cystic Fibrosis Foundation; grants from the Dutch Cystic Fibrosis Foundation; travel reimbursement from the European Cystic Fibrosis Society; personal fees from Johns Hopkins University/DKBmed; personal fees from Saudi Pediatric Pulmonology Association; grants and personal fees from Vertex Pharmaceuticals.

ALQ reports grants from the NIH, FDA, CF Foundation, and the American Cochlear Implant Alliance; grant and travel reimbursement from Cystic Fibrosis Australia; consulting fees from Vertex Pharmaceuticals and Insmed, Inc.

MSS reports research grants from the NIH, CFF, Abbvie, GlaxoSmithKline, Vertex, consulting fees from Astra-Zeneca and CFF, speaking fees from Sanofi Pasteur.

MV reports grants from the Dutch Cystic Fibrosis Foundation, speaker and travel reimbursement from the European Cystic Fibrosis Society and grants from Vertex Pharmaceuticals.

## INTRODUCTION

Cystic Fibrosis (CF) is a progressive, multisystem genetic disease affecting more than 70,000 individuals worldwide, marked by recurrent pulmonary infections and long-term lung damage [1]. Despite treatment advances that have increased average life expectancy, living with CF entails a high burden of daily treatments and pulmonary and digestive symptoms [2, 3]. Elevated depression and anxiety in people with CF (pwCF) and their primary caregivers occur at rates 2–3 times that of the general population [4], and are associated with negative health outcomes, worse treatment adherence, earlier mortality and greater healthcare utilization [5-13].

Despite the prevalence and impact of depression and anxiety in pwCF, a European CF Society (ECFS) and CF Foundation (CFF) survey of 1454 CF health professionals highlighted that mental health (MH) care delivery in CF was inadequate and highly variable across care centers and countries [14]. Therefore, the ECFS and CFF developed international MH guidelines calling for routine MH screening, education and prevention, and treatment of depression and anxiety as standard CF care [15]. Annual screening with the Patient Health Questionnaire-9 (PHQ-9) [16, 17] and the Generalized Anxiety Disorder 7-Item Scale (GAD-7) [18] is recommended for adolescents and adults with CF and primary caregivers of children with CF, providing a valuable first step in identifying, addressing, and improving the MH of CF families.

As specified in the mental health guidelines, those with elevated screening scores should receive follow-up psychological assessment and be offered evidence-based psychological and/or psychopharmacological intervention [15]. Those with mild symptoms are re-screened at their next quarterly CF clinic visit [15]. Brief depression and anxiety screening using the PHQ-9 and GAD-7 can be integrated into more comprehensive processes of annual psychological review or systematic multidimensional needs assessment [2, 8] as institutional resources permit. This

provides an opportunity to reinforce resilience and bolster coping skills [19], increase identification of individuals with CF who desire referral to mental health services for subthreshold symptoms or life stressors [2, 8], and improve ascertainment of other conditions (e.g., substance misuse [20], Attention-Deficit Hyperactivity Disorder [21], disordered eating [22]) that may require intervention.

The ECFS Mental Health Working Group (MHWG) and CFF Mental Health Advisory Committee (MHAC) were established in parallel in 2016 to work closely together and with the CF community to disseminate and implement the MH guidelines. Key facilitators of implementation have included: 1) developing educational materials for pwCF, multidisciplinary CF care team members, and community mental health care providers; 2) presentations and training courses at regional, national and international conferences and in virtual formats; 3) formal and informal consultation to CF care teams initiating screening; 4) fostering national and international networks; and 5) in the US, grant funding to encourage accredited CF programs to add a Mental Health Coordinator role responsible for depression and anxiety screening to the CF care team. Resources are housed on the ECFS, CFF, and CF Australia websites (<https://www.ecfs.eu/mental-health-working-group>; [cff.org](https://www.cff.org); <https://www.cysticfibrosis.org.au/mhr>), the ECFS education platform (<https://www.ecfs.eu/education>) and in the CFF resource library ([my.cff.org](https://my.cff.org) and by request from [mentalhealth@cff.org](mailto:mentalhealth@cff.org)).

Recent evaluations of these efforts indicate that depression and anxiety screening is feasible, acceptable, and gaining momentum across Europe and the United States (US) [23, 24]. However, these studies focus on the perspectives of CF healthcare providers. To augment this picture, the ECFS MHWG and CFF MHAC elicited the experiences and preferences of adults

with CF and family caregivers of children, adolescents, and adults with CF regarding depression and anxiety screening at CF care centers across Europe and the US.

## **METHODS**

### ***Survey development and distribution***

The Research and Evaluation Subgroup of the ECFS MHWG initially developed the survey, which also included patient and parent representatives. It was designed so that it could be completed by a pwCF or caregiver with forced choice and open-ended responses elicited via Survey Monkey, a web-based program. Topics included (a) demographic characteristics; (b) importance of MH; (c) MH support received from the CF team; (d) MH screening process; (e) openness to receiving follow-up MH care; and (f) privacy concerns. The survey was piloted with 9 pwCF who provided feedback and facilitated revisions to clarify meaning. An international core group of the ECFS MHWG and CFF MHAC members then reviewed the survey to ensure it was linguistically and culturally appropriate for both Europe and US, revising the wording of some items.

The survey was hosted by ECFS with separate links for survey completion and database generation for European and US respondents. CF Europe sent the survey out to all national patient organizations and the link was live from 6<sup>th</sup> November 2019 to 28<sup>th</sup> February 2020 via their national platforms. In the US, participants were recruited from members of CFF Community Voice, a group composed of pwCF  $\geq 16$  years of age and family members of pwCF. A study invitation and link to the online questionnaire was sent electronically on behalf of the CFF MHAC. The study period began November 15<sup>th</sup> in Europe and closed on April 23<sup>rd</sup> 2020, closing in the US on 3<sup>rd</sup> June 2020. The survey collected no protected health information and utilized passive informed consent for those completing and submitting the questionnaire.

### ***Data analyses***

We downloaded the numeric survey data from SurveyMonkey to SPSS version 26 and cleaned to eliminate errors (e.g., duplicate cases, impossible values) and determined multiple response frequencies and percentages of responses. We used t-tests and chi -squares to evaluate within and between groups where appropriate. Given multiple testing, the significance threshold was set at  $p < 0.01$ .

To facilitate interpretation of survey responses, a subset of co-authors (SG, AQ, BS) evaluated three different implementation frameworks and each question was evaluated for its “fit” in the model. This approach was used to analyze a prior US implementation survey, and thus, provided continuity in interpreting results of mental health implementation data across Europe and the US [24]. Model 1, *Stages and Determinants of Implementation* [24] included Basic or Pre-implementation, Implementation, Challenges of Implementation, Facilitators of Implementation, and Full Implementation. Model 2 was published by the National Implementation Research Network, *Stages of Implementation* [25], and consisted of Exploration, Installation, Initial Implementation, and Full Implementation. Finally, Model 3, the *Consolidated Framework for Implementation Research* [26], included 5 drivers of implementation: Intervention Characteristics, Outer Setting, Inner Setting, Characteristics of Individuals, and Process of Implementation.

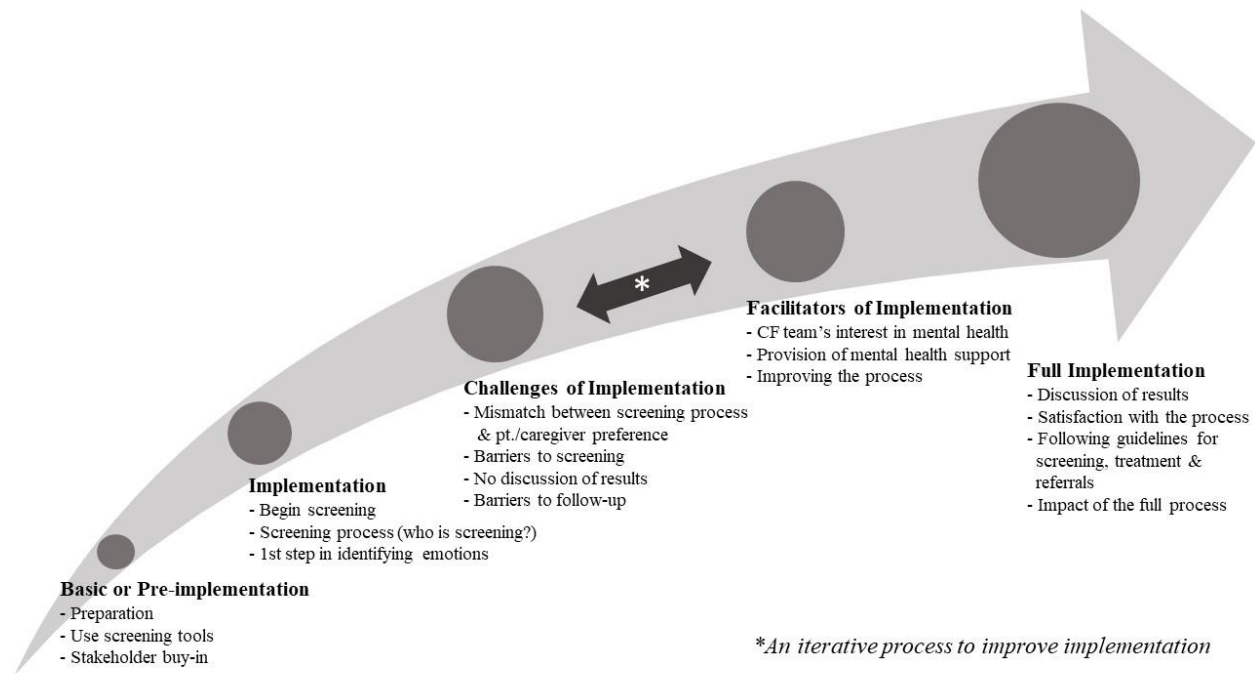
### ***Thematic Coding of Implementation Models***

Given that the first 2 stages of Model 2 had already been completed (e.g., Exploration: data collection on rates of depression and anxiety [4] and Installation: training, coaching, data systems [24]), this model was not considered further. Next, three co-authors independently mapped the 23 survey questions onto Models 1 and 3. We used a conservative approach which

counted partial agreement as a “disagreement,” to assess rater agreement. Each rater designated the appropriate placement of the question into components of both models, yielding 46 decisions for each rater (total of 138 decisions). Pairs calculated percent agreement. The rating team discussed and resolved discrepancies.

Out of 138 paired decisions, 104 were in complete agreement across all pairings and 34 decisions represented partial agreement, yielding 75.4% agreement. Model 1, *Stages and Determinants of Implementation*, provided the best fit, with all survey questions fitting into elements of the model (see Supplement A Table 1). In contrast, none of the survey questions fit with Model 3’s Outer Setting category (e.g., healthcare system) and only one question asked about the Inner Setting (i.e., “Is your CF team interested in your mental health?”). Thus, results be described utilizing the *Stages and Determinants of Implementation* model [27] in Figure 1 below:

**Figure 1: Model 1 Stages and Determinants of Implementation**



For survey comments by theme and respondent, see supplement B.

## **RESULTS**

### ***Demographic Data***

Demographic characteristics of the full sample (n=474) are described in Table 1a, with Table 1b describing those respondents who reported completion of the MH screening questionnaires (e.g., PHQ-9 and GAD-7) at their CF clinic (199/445; 45% of the total sample).

**Table 1a: Demographic Characteristics of All Respondents**

	Europe	US	Total
All survey respondents* n, (%)	271 (57%)	202 (43%)	473 (100%)
	N ( %)	N ( %)	N ( %)
Male	63 (23%)	23 (11%)	86 (18%)
Female	200 (74%)	175 (87%)	375 (79%)
Not reported	8 (3%)	4 (2%)	12 (3%)
Patients	143 (53%)	99 (49%)	242 (51%)
Caregivers	128 (47%)	103 (51%)	231 (49%)
Age of pwCF who completed the survey			
Age 18-24yr	39 (27%)	17 (17%)	56 (23%)
Age 25-39yr	68 (48%)	46 (47%)	114 (47%)
Age 40+yr	36 (25%)	36 (36%)	72 (30%)
Age of pwCF whose caregivers completed the survey			
Age 0-11yr	67 (52%)	45 (44%)	112 (49%)

Age 12-17yr	29 (23%)	20 (19%)	49 (21%)
Age 18+yr	32 (25%)	38 (37%)	70 (30%)

\*Total respondents to the survey = 474. One participant did not report their country; therefore, they are missing from these cross-tabulated data.

**Table 1b: Demographic Characteristics of Respondents Who Had Completed Mental Health Screening**

	<b>Screened</b>	<b>Total</b>
	<b>N ( %)</b>	<b>N</b>
<b>All survey respondents</b>	<b>199 (45%)</b>	<b>445*</b>
Europe	79 (32%)	247
US	120 (61%)	198
Patients	127 (55%)	231
Caregivers	72 (34%)	214
Male	34 (43%)	80
Female	160 (44%)	365

\*Not reported n=29

The tables below describe the results through each implementation phase. These results (%) also compare outcomes between Europe and the US, as well as differences between pwCF and caregivers.

### Stage 1: Basic or Pre-implementation

There was near universal agreement (93%) that MH is an important aspect of CF health with an additional 6% indicating it is “sometimes important”. In Europe, 94% of pwCF and 91% of caregivers agreed it was important to be asked about their MH when attending CF clinic, in comparison to 97% of US pwCF and caregivers.. When pwCF were asked who should have access to their MH screening results, no demographic differences were found in the overall responses (see Table 2). PwCF who had participated in MH screening (40%) were more likely to want results shared with the entire team than those who were not screened (31%) ( $p<.01$ ). When caregivers were queried about where their MH screening data should be recorded, no demographic differences were found (see Table 2). However, caregivers who had been screened (29%), compared with those who had not been screened (15%), were more likely to request that these results be kept in their own medical record ( $p<.001$ ).

**Table 2: Access to MH data and storage**

<b>Who should have access to your MH results?</b>	<b>N (%)</b>
<b>PwCF</b>	<b>N=240</b>
Entire CF team	100 (42%)
MH professional performing screening & physician	80 (33%)
Only MH professional performing Screening	60 (25%)
<b>Where should your MH data be recorded?</b>	<b>N (%)</b>
<b>Caregivers</b>	<b>N=231</b>
Own medical records	102 (44%)
Child's notes	81 (35%)
Should not be recorded	48 (21%)

## Stage 2: Implementation

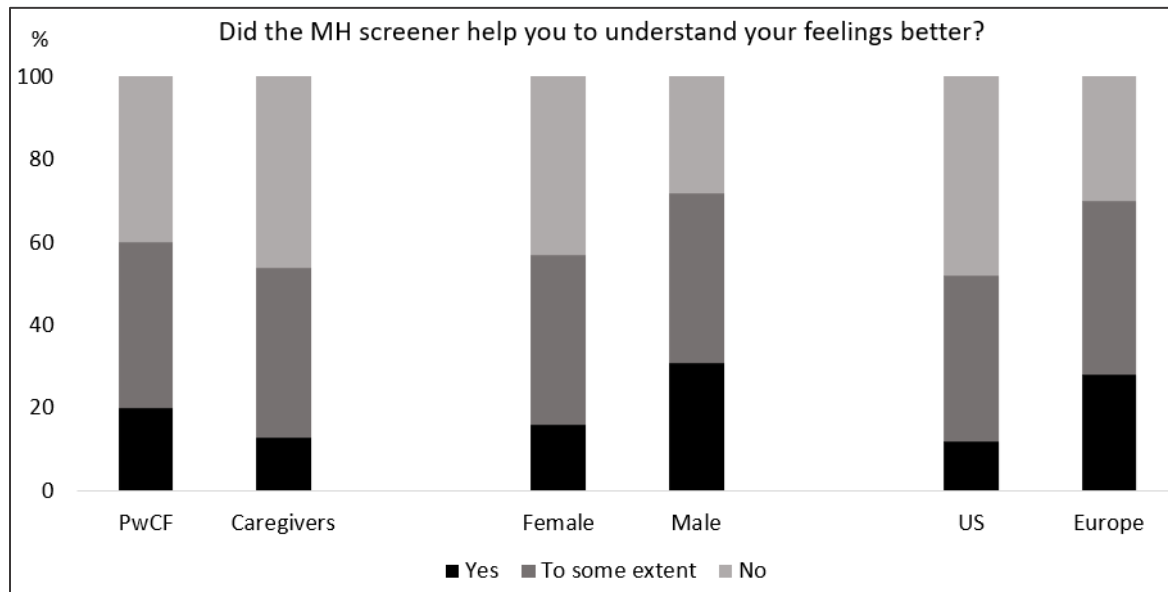
Introduction and administration of the screening tools are presented in Table 3. Psychologists administered the screeners more often in Europe than in the US ( $p<.001$ ), while social workers in the US were more likely to perform screening ( $p<.001$ ). When those who had been screened were asked their preference for who should administer the screeners, in Europe there was a preference for the psychologist to administer the screener ( $p<.001$ ), while US respondents preferred a social worker ( $p<.001$ ). However, importantly, 38% expressed no preference at all.

**Table 3: Introduction and administration of MH Screening**

How did you hear about MH Screening?		
	N (%)	N (%)
	pwCF n=242	Caregivers n=231
CF Team	133 (55%)	108 (47%)
Patient Association	51 (21%)	57 (25%)
Other patients	24 (10%)	18 (7%)
Not aware of screening	34(14%)	48 (21%)
Screening tool administration & after screening preference (N = 199)		
	Profession of screener N (%)	Screener preference N (%)
Social worker	87 (44%)	38 (19%)
Psychologist	56 (28%)	52 (26%)
Nurse	26 (13%)	16 (8%)
Physician	12 (6%)	12 (6%)
Others	18 (9%)	6 (3%)
No preference		75 (38%)

Screening was perceived as helping respondents understand their feelings (Figure 2), especially for males (in comparison with females;  $p<.001$ ) and Europeans (in comparison with US respondents;  $p<.001$ ).

**Figure 2. Did MH Screening help you understand your feelings better?**



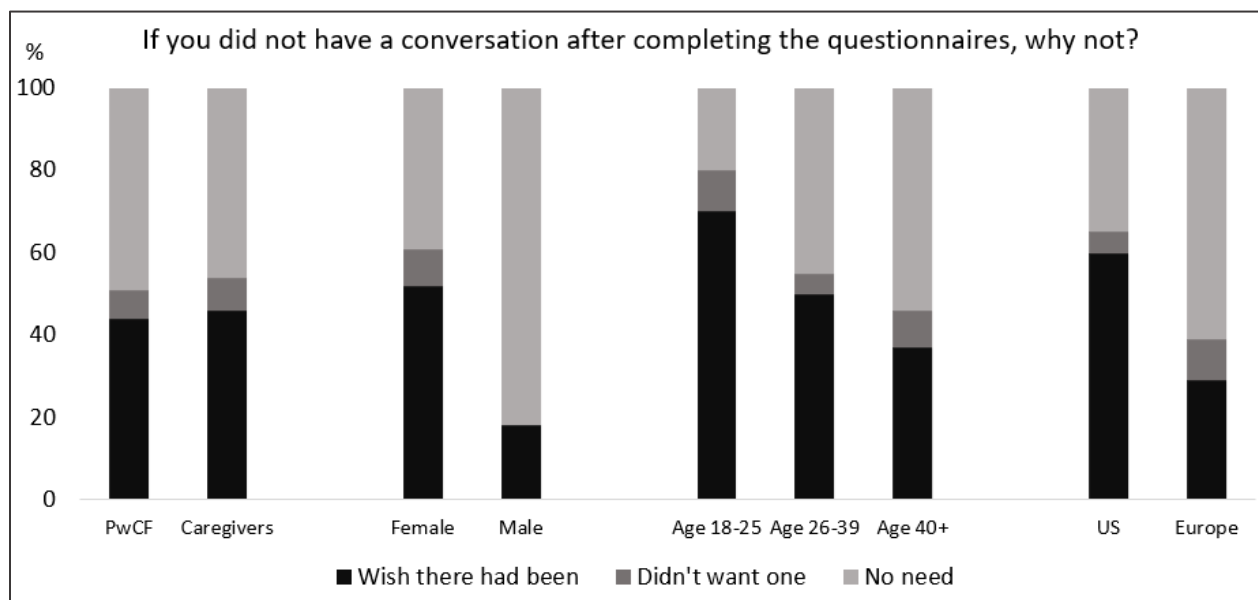
### Stage 3: Challenges of Implementation

The overriding majority (78%) of respondents wanted to be asked about their MH in person at clinic rather than completing the screener alone, or remotely (such as via email or telephone), with no differences found in demographic characteristics. Some open-ended responses expressed the importance of being asked about MH in private.

Ninety-two percent of caregivers and 58% of pwCF who had not been screened in the previous 2 years indicated that MH screening was not offered to them. Other reasons included lack of time and no MH concerns. Implementation of screening was more challenging in Europe, where 52% of respondents were not given the screening tools, compared with 29% in the US ( $p < .01$ ). Some respondents ( $n=68$ ) did not have a follow-up conversation with a CF team member to review the results of the MH screener. Of these, 46% said they would have *liked to have had one*, 47% said

there was no need for a conversation and 7% did not want one. Females ( $p < .001$ ), US respondents ( $p < .001$ ), and 18-24 year olds ( $p < .005$ ) were more likely to wish a conversation had taken place (Figure 3). Of those who had been advised to seek MH care ( $n=62$ ), pwCF ( $p < .001$ ), US respondents ( $p < .001$ ) and males ( $p < .05$ ) were more open to pursuing treatment.

**Figure 3. If you did not have a conversation after completing the questionnaire, why not?**



Of those who had been advised to seek MH care ( $n=62$ ), pwCF ( $p < .001$ ), US respondents ( $p < .001$ ) and males ( $p < .05$ ) were more open to pursuing treatment. Of the 50 respondents who were advised to seek MH care but did not pursue it, 26% reported already seeing a therapist, 22% reported time limitations, 16% cited cost/insurance concerns, 16% reported they couldn't find/access a therapist, 10% didn't believe therapy helps, and 10% reported having their own

support system. Two percent of Europeans, compared with 16% of US respondents, cited cost/lack of insurance coverage ( $p<.01$ ).

#### **Stage 4: Facilitators of Implementation**

When asked if they felt the CF team was interested in their MH, 55% said yes, 38% said sometimes and 7% said no. There was no difference by type of respondent, gender, or geographic area, but those who had been screened (63%) were more likely to believe that the CF team was interested in their MH, compared to those not screened (47%) ( $p<.001$ ). When asked what more could be done to improve their mental health, respondents in the US versus Europe requested more tips on coping strategies in general ( $p<.001$ ), coping strategies for anxiety/depression ( $p<.001$ ), and help with referrals ( $p<.01$ ). See Table 4.

Table 4: Respondents answers on ways to improve MH

<b>What could improve your MH? (n=473)</b>	<b>%</b>
Teaching coping strategies	47
Information on anxiety and depression	42
Tips on staying well emotionally	42
Asking about my life	40
Help with referrals	33
Access to treatment in clinic	29
Information leaflets on MH	26
Regular phone calls	15

Similarly, those who were screened felt more supported by the CF team compared to those who were not screened ( $p<.01$ )

**Stage 5: Full Implementation** Those who had been screened were asked how often they had completed MH questionnaires over the last two years; 25% of pwCF said once, 30% twice, 35% more than twice, and 10% could not remember. Of caregivers, 39% were screened once, 26%

twice, 23% more than twice and 12% did not remember. No significant differences in demographics between the groups were found.

Of respondents who were screened, 58% of patients and 53% of caregivers reported having had a follow-up conversation about the results. Having a conversation was more likely for those from the US than Europe ( $p<.001$ ) and in those aged 26-39 compared to the other age groups ( $p<.01$ ). There was a notable difference in practice between Europe and the US regarding these post-screening discussions. In Europe, 59% were with a psychologist, whereas in the US, 74% took place with a social worker, consistent with other previously described screening practices.

Overall, respondents were very satisfied to satisfied with post-screening conversations, but 12% of caregivers were not satisfied, compared with 8% of pwCF ( $p<.01$ ). Europeans (16%) were dissatisfied more often than Americans (8%;  $p<.01$ ), but there were no significant differences by age or gender. Eighty-two percent of respondents felt the advice they received after screening was appropriate to their needs, more so among Europeans (91%) than US respondents (76%;  $p<.01$ ).

Post-screening perceptions differed between pwCF and caregivers and between respondents in the US vs. Europe. US respondents felt better understood ( $p<.001$ ), more cared for ( $p<.001$ ) and more vulnerable ( $p<.01$ ) than Europeans, with those in Europe reporting feeling 'no different' ( $p<.001$ ).

## **DISCUSSION**

This survey elicited the unique perspectives of pwCF and caregivers on their experiences of MH screening, which is a critical step in evaluating the dissemination and implementation of the ECFS/CFF depression and anxiety guidelines [15]. Notably, there was nearly universal

agreement that MH is an important aspect of CF health. In addition, several key findings about the screening process emerged.

Both pwCF and caregivers overwhelmingly expressed a desire to be asked about their MH, reflecting an implicit acknowledgement of these concerns. Furthermore, most pwCF and caregivers indicated an openness to sharing their screening results with the entire CF team. Participation in the screening process destigmatized MH issues, furthering its acceptance as an integral part of routine CF healthcare, facilitating early detection and implementation of a stepped-care intervention model [14, 28, 29]. Although caregivers were not the ‘identified patient,’ given the high rates of depression and anxiety reported by parents [4, 7], attention to the MH of family members should be recognized as part of comprehensive CF care, particularly in pediatrics.

Notably, the majority of those screened stated that the simple act of MH screening helped them understand their feelings better. Thus, standardized screening of symptoms of depression and anxiety screening may, itself, be considered an intervention because it opens the door to acknowledgement and identification of MH difficulties, which can then be addressed. Just over half of pwCF and caregivers who had been screened had a conversation about the results with their MH clinician, with most rating this conversation as very satisfactory. Importantly, about 45% of respondents who had not had a conversation “wished there had been one.” In addition, the vast majority of those advised to seek further care following screening, were open to pursuing evidence-based MH treatment such as cognitive behavioral therapies, acceptance and commitment therapy, motivational interviewing, behavioral activation, or problem-solving [30]. Even when PHQ-9 and GAD-7 scores were not elevated, screening provided an opportunity for psycho-education, psychological exploration, and primary or

secondary prevention, such as promotion of adaptive coping strategies, and social support and social skills [31]. Several of these treatments are recommended in the MH guidelines [15], derived from evidenced-based studies in other chronic diseases for both children and adults [32, 33]. Fewer than half of respondents reported completing MH screening prior to their response to the survey. Both in the US and Europe, the major barrier to MH screening was not lack of willingness, but rather lack of implementation of the screening process by CF teams. Previous research [23, 24] suggests CF teams should address barriers to screening such as the fear of stigmatization, privacy concerns, and the complexity of making referrals in their local communities. In the US, additional barriers include the high costs of MH care, lack of insurance reimbursement and long waiting lists. A collaborative approach between the CF care teams and MH providers is likely to result in better mental and physical health outcomes for patients and families [34-36].

Most respondents viewed the CF's team interest in their MH quite positively. Importantly, respondents who had been screened were more likely to believe that the CF team was interested in their MH and felt supported by the CF team. The investment in screening appears to foster acknowledgement, validation, and trust [37].

Although a greater proportion of respondents were screened in the US than in Europe (61% vs. 32%), there is still a great deal of room for improvement in both regions. This may be partly due to disparities in resource availability, given recent CF Foundation funding for MH coordinators, differences in the personnel available for MH screening, healthcare reimbursement, and varied national healthcare policies in Europe [23]. Thus, it is essential to examine barriers, facilitators and outcomes in individual countries and regions [38, 39]. Not all European countries

participated in the survey; countries with fewer resources devoted to MH (such as in Eastern Europe) are less likely to conduct MH screening [40].

One significant international difference related to next steps following MH screening. Of those who did not have follow-up conversations, 60% in the US wished there had been one vs. only 29% in Europe. US respondents also made significantly more requests for tips on coping strategies, suggestions for addressing depression/anxiety and help with referrals. This may be due, in part, to differences in the roles of MH providers in the US, which may focus on case management rather than psychotherapeutic interventions [14], and the US insurers' lack of funding for ongoing psychological treatment in comparison to Europe's healthcare systems. US respondents more frequently cited costs and lack of insurance coverage as reasons for not pursuing MH care. Most respondents who completed the screeners perceived that the advice they received after screening was appropriate to their needs, more so among Europeans than Americans. However, in the US, both pwCF and caregivers felt significantly better understood, more cared for and more vulnerable after completing the MH screener. This may point to discrepancies in uptake of the screening process, with less frequent screening performed in Europe and differences in mental health care delivery and follow-up care between the two regions.

These interesting discrepancies in follow-up mental health care in Europe and the US, and indeed within different European countries themselves, warrant further discussion. Mental health systems vary widely by country; this typically reflects different resource allocations as well as distinctive social-cultural differences [41]. It is important to be aware of these differences because they impact the effectiveness and ease of transferring mental health screening programs and follow-up clinical interventions. One such initiative to improve mental health services and

spread out resources is through collaborative care, which includes mobilization of and collaboration with existing community resources and health care providers [42]. This can facilitate integration of mental health care expertise in places in which it is most needed.

## **Limitations**

This was an international survey completed by a diverse array of respondents across a widely distributed geographical area. However, it was a convenience sample that did not include all European countries and clinics in the US, and did not seek out sectors of the CF population that have been under-represented in research, such as low socioeconomic groups and minorities [43, 44]. We did not collect comprehensive data on demographic differences given the wide range of countries we surveyed which had differing racial and economic groups. In addition, the survey was only available in English, which may have limited access for non-English speaking countries. Sampling biases may also have been introduced due to technical barriers (e.g. internet access) and regional differences in the willingness of respondents to share their MH experiences. Note also that more females than males responded to the survey, which may reflect gender differences in prioritizing the importance of MH screening and intervention.

Note that completion of surveys for European participants finished in April 2020 and survey completion in the US ended in June 2020. This overlapped with the start of the COVID-19 pandemic in February/March 2020. Hence, it is difficult to ascertain how the pandemic affected our results, since this was not queried. The overlap period was fairly short but may have had an impact, given the acceptance of using telehealth technologies for psychological evaluations and interventions [45-47]. Future research is needed to determine the impact of this changing care model in terms of online MH screening and implementation of psychological interventions via telehealth methods.

## Conclusions

In conclusion, our results suggest that the MH screening process itself is an intervention and a springboard for encouraging sustained MH care, reinforcing the importance of integrating MH screening, education and treatment into specialized CF care. MH screening seems to be occurring less frequently in Europe than in the US, which indicates that additional support and encouragement may be necessary to increase the uptake of standardized MH screening as a mental health “thermometer” for initiation of prevention and intervention strategies. One way to achieve these goals is to recommend inclusion of MH screening scores in national registries [24]. These data will be critical for reinforcing and refining protocols for MH screening, will add to the empirical literature on the effects of depression and anxiety on health outcomes, and document the potential efficacy of psychological and pharmacological interventions. Areas for future research include: 1) longitudinal studies evaluating the impact of MH on pwCF; 2) examinations of how MH services for pwCF and caregivers may be improved, particularly in countries with limited MH resources (such as using the collaborative care model [42]) ; 3) determining what other MH concerns exist for pwCF aside from anxiety and depression (e.g., disordered eating, substance misuse, neurocognitive dysfunction), and 4) evaluating how new, highly effective modulators affect mental health [45].

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