CYSTIC FIBROSIS FOUNDATION AND EUROPEAN CYSTIC FIBROSIS SOCIETY SURVEY OF CYSTIC FIBROSIS MENTAL HEALTH CARE DELIVERY

Abbott J [a], Elborn JS [b], Georgiopoulos AM [c], Goldbeck L [d], Marshall BC [e], Sabadosa KA [f], Smith BA [g], Quittner AL [h].

[a] School of Psychology, University of Central Lancashire, Preston, PR1 2HE, UK
[b] School of Medicine, Queen's University Belfast, BT7 1NN, UK
[c] Department of Child and Adolescent Psychiatry, Massachusetts General Hospital, Boston, MA 02114, US
[d] Child and Adolescent Psychiatry, University Ulm Medical Centre, D-89075 Ulm, Germany
[e] Cystic Fibrosis Foundation, Medical Department, Bethesda, Maryland, MD 20814, US
[f] The Dartmouth Institute for Health Policy and Clinical Practice, Lebanon, NH 03766, US
[g] Department of Psychiatry, University of Buffalo, NY 14202, US
[h] Department of Psychology, University of Miami, FL 33146, US

Corresponding Author
Professor Janice Abbott
E-mail   jabbott@uclan.ac.uk
Phone +44 (0)1772 893790

Word count = 2,501

Keywords: depression, anxiety, screening

Running title: CFF and ECFS survey of Mental Health care delivery

Abstract

Background: Psychological morbidity in individuals with cystic fibrosis (CF) and their caregivers is common. The Cystic Fibrosis Foundation (CFF) and European Cystic Fibrosis Society (ECFS) Guidelines Committee on Mental Health sought the views of CF health care professionals concerning mental health care delivery.

Methods: An online survey which focused on the current provision and barriers to mental health care was distributed to CF health care professionals.

Results: Of the 1454 respondents, many did not have a colleague *trained* in mental health issues and 20% had no one on their team whose primary role was focused on assessing or treating these issues. Insufficient resources and a lack of competency were reported in relation to mental health referrals. Seventy-three percent of respondents had no experience with mental health screening. Of those who did, they utilized 48 different, validated scales.

Conclusions: These data have informed the decision-making, dissemination and implementation strategies of the Mental Health Guidelines Committee sponsored by the CFF and ECFS.

1. Introduction

Recent advances in the diagnosis and clinical management of cystic fibrosis (CF) have led to increased survival, but CF remains a life-limiting disease and requires adherence to a complex and demanding treatment regimen of up to four hours per day [1]. The evidence for the association between physical illness and psychological morbidity, and its effects on outcome, is robust [2]. Children and adults with chronic conditions, and their parent caregivers, are at increased risk for depression and anxiety, and depressed patients are three times less likely than non-depressed patients to follow through with prescribed treatments [3-4]. Psychological distress in people with CF has been associated with worse pulmonary function, self-management and health-related quality of life [5-8], in addition to increased hospitalizations and health care costs [9].

The International Depression and Anxiety Epidemiological Study (TIDES) recruited over 6,000 patients with CF and 4,000 parent caregivers, across nine countries, to answer long-standing questions about the prevalence of depression and anxiety in individuals with CF and parent caregivers. Depressive symptoms, above the clinical cut-off, were reported by 10% of adolescents, 19% of adults, 37% of mothers, and 31% of fathers; symptoms of anxiety, above the cut-off, were reported by 22% of adolescents, 32% of adults, 48% of mothers and 36% of fathers. Adolescents whose parents reported elevated depressive symptoms were more than twice as likely to report psychological distress themselves [10]. The prevalence of psychological morbidity in CF requires serious consideration; therefore, the Cystic Fibrosis Foundation (CFF) and European Cystic Fibrosis Society (ECFS) established a multidisciplinary Guidelines Committee on Mental Health. To inform the committee's deliberations

concerning mental health care delivery in CF, the views of the international CF clinical community were sought via a survey in both the US and Europe.

2. Methods

2.1 Survey development and distribution

A short, 14-item, survey was developed by the authors to assess the current provision of, barriers to and perceived needs for mental health care delivery, including the potential implementation of standardized screening for depression and anxiety and associated training and resource needs (Figure 1). To aid completion, forced choice responses and the ranking of items were developed, with an opportunity to add further comments. The survey was administered using the web-based tool 'SurveyMonkey' [11] and distributed by the CFF and ECFS to CF health care professionals. In the US, the survey was distributed to approximately 2,500 individuals: all CF Centre Directors, Program Directors, and Affiliate Directors and to discipline-specific electronic mailing lists (some of which have European and Australasian members). In Europe, the ECFS removed duplicates and distributed the survey to an additional 1,500 professionals across Europe and beyond. The survey was available for completion from 3rd November 2013 to 28th February 2014.

2.2 Data analysis

The data were downloaded to SPSS 21. Multiple response frequencies and the mean rank order of appropriate items were determined. Thematic analysis of respondents' comments regarding the potential impact of screening was undertaken according to the process described by Braun and Clarke

[12] (familiarisation with the data; coding; searching for, reviewing and defining themes). To aid reliability, two independent coders manually identified and agreed on the emergent themes.

3. Results

There were 1454 respondents, yielding a response rate of approximately 36%. Forty-five percent of the sample came from the US, 49% from 33 European countries, and almost 4% of the sample was located in 14 other countries, with the majority from Canada, Australia, New Zealand, South Africa, South America and Russia. Two percent did not provide a location. Table 1 provides the characteristics of the sample by location and profession for respondents who provided this information (n=1409). The largest professional categories of respondents were physicians, physiotherapists and nurses. Social workers, mainly from the US and psychologists, predominantly from Europe, were also well- represented among respondents.

Table 1. Characteristics of the sample: Location and Profession

	All % (n)	US % (n)	Europe % (n)	Other Location* % (n)
Physician	23.9 (336)	23.0 (150)	24.6 (173)	24.1 (13)
Physiotherapist	20.2 (284)	11.5 (75)	28.3 (199)	18.5 (10)
Nurse	18.2 (257)	23.3 (152)	13.9 (98)	13.0 (7)
Social Worker	11.6 (163)	17.2 (112)	6.7 (47)	7.4 (4)
Dietician	9.0 (126)	11.4 (74)	6.5 (46)	11.0 (6)
Psychologist	6.0 (85)	1.2 (8)	10.5 (74)	5.6 (3)
Researcher	5.2 (73)	8.2 (53)	2.6 (18)	3.7 (2)
Pharmacist	1.8 (26)	2.5 (16)	0.7 (5)	9.3 (5)
Psychiatrist	0.8 (11)	0.5 (3)	0.6 (4)	7.4 (4)
Other Profession[+]	3.3 (48)	1.2 (8)	5.6 (40)	0 (0)
Total sample (providing both location and profession)	1409	651	704	54

*Other Location e.g. Canada, Australia, New Zealand, South Africa, South America, Russia.

[+]Other Profession e.g. Microbiologist, Geneticist, lung function assistant, hospital teacher, registry coordinator, counsellor.

3.1 Current mental health care delivery

In the US, the responsibility for mental health issues primarily rested with social workers (59%) and physicians (20%), whereas in Europe it rested with psychologists (52%) and physicians (26%). Of the 618 respondents in the US and 627 respondents in Europe who replied to question 4, many did not have a colleague *trained* in the specific skills needed to manage mental health conditions: cognitive behaviour therapy, counselling and supportive therapies, mental health screening, and prescribing medication. The percentages of respondents reporting specific mental health skills training in a CF team are provided in Table 2. Twenty-seven percent of US respondents and 37% of those in Europe were unable / unsure if they could refer to mental health clinicians in their hospital, and only 52% in the US and 39% in Europe had up-to-date lists of mental health resources and referrals to provide to patients and families.

**Table 2. Respondents reporting specific mental health skills training in
a CF team member in the US and Europe**

	US (n=618)	Europe (n=627)
Cognitive Behaviour Therapy	27.2 (168)	31.3 (196)
Counselling & Supportive Therapies	65.4 (404)	47.5 (298)
Mental Health Screening	51.3 (317)	32.4 (203)
Prescribing Medication	22.0 (136)	17.2 (108)
No one trained in any of these areas	18.3 (113)	27.4 (172)

The majority of respondents (73%) did not have personal experience with systematic screening for anxiety and depression. Of those who did, there was a wide variation in the screening measures they used. Respondents were asked to identify which screening measure they used from a list of twelve validated instruments. The most common were the Hospital Anxiety and Depression Scale (HADS:

predominantly used in Europe), Beck Depression Inventory (BDI) and the Patient Health Questionnaire – 9 (PHQ-9: predominantly used in the US) (Figure 2).   However, respondents reported the use of an additional 36 measures, each used by five or fewer respondents, indicating that a total of 48 different validated scales were in current use to measure depression and anxiety in CF.

3.2 Perceived barriers and resource recommendations

Respondents were asked to rank a list of eight potential barriers to screening and seven types of assistance that would be helpful in implementing a mental health screening program (from most to least significant barrier / helpful assistance). The responses are presented in Table 3. Further comments concerning mental health screening were provided by 472 individuals and these text responses were analysed thematically. 165 (35%) reported either no concerns at all or benefits of mental health screening. The respondents who voiced concerns (n=307) predominantly perceived problems with referrals or in-house capacity for intervention. For example, 30% (n=93) of those raising concerns believed it was unethical to screen if they didn't have the resources to follow through with referral. The lack of trained personnel to administer and score the measures (22%, n=68), the time required and clinic flow disruptions (15%, n=46)) were also seen as problematic. Patient / family issues were perceived as barriers by 12% (n=36) of respondents, as people with CF and their caregivers may be unwilling to be screened or unlikely to follow through referral. The stigma of 'labelling' individuals as having mental health difficulties was also a concern (9%, n=28). Few (2%, n=7) respondents believed that screening was not warranted. A few suggested that more comprehensive mental health screening, not limited to anxiety and depression, should be implemented. Insufficient space to comply with infection control guidelines and provide patient privacy was reported by 5%

(n=16) of respondents. In the US, 5% (n=14) reported that patients may have difficulty obtaining insurance coverage for mental health referrals while this barrier was not raised as a concern in Europe or other countries.

Table 3. Barriers and type of assistance perceived to be most helpful in implementing a mental health screening program

Mean rank order of 'barriers' and % of respondents who highly ranked barrier to screening (n=1028)		
	Mean Rank order (ranked 1-8)	% respondents ranked within top 3
Limited staff time	2.49	76
Limited personnel	3.21	61
Lack of qualified personnel to provide referrals or interventions	3.60	56
Patient burden (e.g. patients' time)	4.52	30
Difficult logistics (e.g. screening data storage)	4.71	31
Patient unwillingness to complete measure	5.32	22
Space limitations	6.03	16
Maintaining patient confidentiality / privacy	6.10	7
Mean rank order of 'assistance' and percentage of respondents who highly ranked assistance need (n=906)		
	Mean Rank order (ranked 1-7)	% respondents ranked within top 3
Additional funds to support a mental health professional	2.75	62
Access to a list of local mental health resources and referrals	3.22	59
Training in mental health screening	3.56	53
Access to electronic tools (e.g., tablets, computers) for administration and scoring	4.08	40
Access to a mental health hotline for guidance	4.18	40
Training in behavioural interventions (e.g., Cognitive Behavioural Therapy)	4.38	31
Training in pharmacological interventions (e.g., antidepressants)	5.84	14

3.3 Interest in further training

Of the 1454 respondents, 968 (67%) expressed an interest in further training in various aspects of mental health care. Interested respondents were asked to rank order four potential training topics.

Taking into consideration the top two rankings, there was significant interest within the CF community for mental health training at either the North American or European CF Conference. Training in mental health screening was requested by 53%, training in counselling or supportive therapy skills by 53%, and training in cognitive behavioural therapy by 47%. Eighteen percent of the total sample requested training in prescribing psychotropic medication. This included 62% of the physicians who responded to the survey, as well as several health care professionals working in roles less commonly licensed to prescribe medication in the US and Europe.

4. **Discussion**

The data from this survey indicates that the current state of mental health care delivery in CF is inadequate and highly variable across care centres and countries. Together with evidence from (a) targeted literature reviews, (b) the TIDES data, (c) existing national and international guidelines on depression and anxiety in general and in chronically ill populations, and (d) multidisciplinary expert opinion, these data from the CF community additionally informed the deliberations of the CFF and ECFS Mental Health Guidelines Committee in developing the depression and anxiety guidelines in CF.

The administration of 48 different scales to measure depression and anxiety in CF is astounding. There is a clear need for use of standardized instruments with good sensitivity and specificity to allow for consistency and comparability between centers and across countries, and to monitor and improve individual and populations outcomes over time. In addition, standardizing the choice of screening instruments enhances the feasibility and utility of training programs that can support centers in implementation [13], possible inclusion of these scores into existing CF registries, and further research

to understand and promote best practice [14]. An additional strength of systematic screening is that it creates an opportunity to consider appropriate preventive and supportive interventions for early signs of distress, rather than waiting to respond until a more severe psychological impairment emerges. Annual screening also provides the opportunity for the CF community to monitor any changes in the mental health care needs of patients over time, and to undertake research that focuses on the predictors of depression and anxiety and the impact of new disease-modifying therapies on mental health outcomes.

When screening for depression, the National Collaborating Centre for Mental Health (UK), U.S. Preventive Services Task Force, and Institute for Clinical Systems Improvement advocate the use of the PHQ-2 and PHQ-9 where there are appropriate diagnostic, treatment and follow-up services [15-18]. The PHQ-9 is also recommended in the DSM-V for depression severity assessment [19] and endorsed by the American Academy of Pediatrics in their preventive health guidelines [20]. When screening for anxiety, the National Collaborating Centre for Mental Health, National Institute for Health and Clinical Excellence, British Psychological Society and The Royal College of Psychiatrists endorse the use of the Generalised Anxiety Disorder measure, GAD-2 and GAD-7 [21].

 There was considerable support from respondents to screen for depression and anxiety, although presently, the barriers to implementing annual screening require attention and action. Different national implementation strategies will be required to integrate mental health care into CF because of the different health care delivery and payment systems in place around the world. For example, obtaining insurance coverage and reimbursement are central issues for the US, but not for most European countries. The availability, training, and scope of practice of mental health professionals as

part of CF teams also differs by country and region, as determined by local licensure, resources, and practice patterns. For example, European CF teams are more likely to include a psychologist, while social workers are more likely to be responsible for mental health services in the US. The primary role of CF social workers in the US can vary from case management to skilled psychotherapeutic intervention, with disparate caseloads dependent on local practice structures [22,23]. Some US teams additionally have access to consultation by psychologists and psychiatrists trained in the care of individuals with medical illness. However, the experience of CF clinicians in prescribing psychotropic medications and the comfort of mental health clinicians in treating individuals with CF can range widely. In the US, the growing role of pediatric primary care clinicians, family practitioners and internists in mental health care enables mental health screening to take place in a primary care setting. This may provide a helpful adjunct for children and adolescents with CF as these practices are child and family-friendly and may help to de-stigmatize mental health issues [24,25]. However, in the UK and US, few patients with CF are seen in primary care.

Participation in online surveys is considered easy for people with internet access. It is an appealing method when the sample is widely distributed geographically and the embedded database reduces the chance of human error and ensures the integrity of the dataset. However, one major concern is that online surveys typically have a lower response rate than mail and phone surveys [26-28] and e-mail surveys may be as low as 13% among doctors [28]. The results of this survey may have been influenced by non-responder bias in terms of the number of respondents and the varied distribution across Europe. However, the response rate of 36% generated representation from all key CF health professionals and with a sample size of 1454 generated a low margin of error. This robust sample may be attributed to the recognition of the importance of mental health issues from the CFF and

ECFS, and the growing interest in mental health within CF multidisciplinary teams. It is also recognised that some recipients of the survey may not have completed it because another member of their CF team had previously responded. As there was more that one respondent from some CF Centres this may have also caused bias. Only 295 (20%) of 1454 participants provided an address, but of these, 203 CF Centres were represented.

As a self-selecting group, respondents were likely to have been more interested and engaged in mental health care. If this was the case, it is possible that those who did not respond have less training than those who did, reinforcing the need for training and implementation. Nonetheless, this survey reveals substantial interest among CF team members in developing additional skills in mental health screening, psychotherapy and psychopharmacology. It is encouraging that large numbers of social workers, psychologists and physicians on CF teams are willing to receive further training to improve mental health care. Training should address barriers by reviewing the mental health care evidence; addressing concerns such as the fear of stigmatizing or alienating patients and caregivers; building mental skills in CF health care professionals; and helping CF health care professionals navigate local mental health care systems by identifying and addressing gaps, including existing internal and external resources and identifying new opportunities. The needs and current resources available to support resilience among members of CF care teams in managing the complex stressors inherent to their roles were not addressed by this survey but are worthy of future attention [29,30].

The challenge for the future is to make an investment in improving the mental health care capacity in CF. As an initial step the CFF and ECFS Committee is developing flexible algorithms for the systematic screening, diagnosis and management of depression and anxiety in CF as part of the guideline

recommendations. Implementation will require providing CF health care professionals with (a) training, easy access to resources and a toolkit that will enable the implementation of annual mental health screening, (b) training for, and the provision of preventive and supportive interventions and (c) training and development of referral networks for the subsequent psychological and/or pharmacological management of clinically diagnosed depression and anxiety. These steps should decrease common barriers to adherence, improve health outcomes and improve the quality of life of children and adults with CF and their caregivers.

References

[1] Sawicki GS, Rasouliyan LR, McMullen AH, et al. Longitudinal assessment of health-related quality of life in an observational cohort of patients with cystic fibrosis. Pediatr Pulmonol, 2011;46:36-44.

[2] Clarke DM, Currie KC. Depression, anxiety and their relationship with chronic diseases: a review of the epidemiology, risk and treatment evidence. MJA 2009;190:S54-S60.

[3] DiMatteo MR, Lepper HS, Croghan TW. Depression Is a Risk Factor for Noncompliance With Medical Treatment. Meta-analysis of the Effects of Anxiety and Depression on Patient Adherence. Arch Intern Med. 2000;160:2101-2107.

[4] Moussavi S, Chatterji S, Verdes E, et al. Depression, chronic diseases, and decrements in health: results from the World Health Surveys. Lancet, 2007;370(9590):851-858.

[5] Smith BA, Modi AC, Quittner AL, et al. Depressive symptoms in children with cystic fibrosis and parents and its effects on adherence to airway clearance. Pediatr Pulmonol, 2010;45(8):756-763.

[6] Riekert KA, Bartlett SJ, Boyle MP, et al. The association between depression, lung function, and health-related quality of life among adults with cystic fibrosis. Chest, 2007;132(1):231-237.

[7] Havermans T, Colpaert K, Dupont LJ. Quality of life in patients with Cystic Fibrosis: association with anxiety and depression. J Cyst Fibros 2008;7(6):581-584.

[8] Fidika A, Herle M, Goldbeck L. Symptoms of depression impact the course of lung function in adolescents and adults with cystic fibrosis. *BMC Pulmonary Medicine* 2014;14:205 doi:10.1186/1471-2466-14-205

[9] Snell C, Fernandes S, Bujoreanu IS, et al. Depression, illness severity, and healthcare utilization in cystic fibrosis. Pediatr Pulmonol. 2014;49:1177-81.

[10] Quittner A, Goldbeck L, Abbott J, Duff A, Lambrecht, P, Solé A, Tibosch MM, Bergsten Brucefors A, Yuksel H, Catastini P, Blackwell L, Barker D. Prevalence of depression and anxiety in patients with cystic fibrosis and parent caregivers: Results of the International Depression Epidemiological Study (TIDES) across Nine Countries. Thorax (In Press).

[11] Survey Monkey, The simple way to create surveys [Online] Available from: https://www.surveymonkey.com/

[12] Braun V & Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology 2006;3:77–101.

[13] Godfrey MM, Oliver BJ.. Accelerating the rate of improvement in cystic fibrosis care: contributions and insights of the learning and leadership collaborative. BMJ Qual Saf 2014;23:i23-i32

[14] Boyle MP, Sabadosa KA, Quinton HB, Marshall BC, Schechter MS. Key findings of the US Cystic Fibrosis Foundation's clinical practice benchmarking project. BMJ Qual Saf 2014;23:i15-i22

[15] National Collaborating Centre For Mental Health (UK). Treatment and Management of Depression in Adults. National Institute for Health and Care Excellence (NICE). Leicester (UK). British Psychological Society; 2010 (Clinical guideline; no.90)

 [16] National Collaborating Centre for Mental Health (UK). Depression in adults with a chronic Physical health problem. Treatment and management. London (UK): National Institute for Health and Clinical Excellence (NICE); 2009 Oct. (Clinical guideline; no. 91).

[17] Screening for depression in adults: U.S. preventive services task force recommendation statement. Ann Intern Med 2009;151:784–92.

[18] Mitchell J, Trangle M, Degnan B, et al. Adult depression in primary care. 16th ed. Bloomington, MN: Institute for Clinical Systems Improvement; 2013. Available from: https://www.icsi.org/ asset/ fnhdm3/Depr-Interactive0512b.pdf.

[19] Diagnostic and Statistical Manual of Mental Disorders (DSM-5). American Psychiatric Association. 2013 Edition

[20] Recommendations for Preventive Pediatric Health Care. American Academy of Pediatrics 2014.

[21] Mental Health Disorders. The NICE Guideline on identification and pathways to care. National Collaborating Centre for Mental health. The British Psychological Society & The Royal College of Psychiatrists, 2011.

[22] Cystic Fibrosis Foundation Patient Registry: 2011 Annual Data Report to the Center Directors. Bethesda, Maryland, 2012: 19-20.

[23] Stern M, Bertrand DP, Bignamini E, Corey M, Dembski B, Goss CH, et al. European Cystic Fibrosis Society Standards of Care: Quality Management in cystic fibrosis. J Cyst Fibros 2014;13:S43–S59.

[24] Foy JM. for the American Academy of Pediatrics Task Force on Mental Health. Pediatrics 2010;125:S69

[25] Foy JM, Kelleher KJ, Laraque D for the American Academy of Pediatrics Task Force on Mental Health. Enhancing Pediatric Mental Health Care: Strategies for Preparing a Primary Care Practice. Pediatrics 2010;125:S87

[26] Shih TH, Fan XT. Comparing response rates from Web and mail surveys: A meta-analysis. Field Methods 2008; 20:249-271.

[27] Manfreda KL, Bosniak M, Berzelak J, Haas I, Vehovar V. Web surveys versus other survey modes - A meta-analysis comparing response rates. International Journal of Market Research 2008; 50:79-104.

[28] Nulty DD. The adequacy of response rates to online and paper surveys: what can be done? Assessment & Evaluation in Higher Education 2008;33:301–314

[29] Lewiston NJ, Conley J, Blessing-Moore J. Measurement of hypothetical burnout in cystic fibrosis caregivers. Acta Paediatr Scand 1981;70:935-9.

[30] West CP, Dyrbye LN, Rabatin JT, Call TG, Davidson JH, Multari A, Romanski SA, Hellyer JM, Sloan JA, Shanafelt TD. Intervention to promote physician well-being, job satisfaction, and professionalism: a randomized clinical trial. JAMA Intern Med 2014;174:527-33.

Figure 1. Mental Health Screening and Intervention: Survey of CF Centres

1. Please indicate the title below that best describes your role on the CF team:
Advance Practice Nurse
Dietitian
Individual with CF
Nurse Assistant
Nurse
Parent/Caregiver
Pharmacist
Physician Assistant
Physician
Physical Therapist
Psychiatrist
Psychologist
Research Coordinator
Respiratory Therapist
Social Worker
Spouse/Partner
Other (please specify):

2. Where do you live?

3. Do you currently have someone on your team whose primary role is to address mental health issues?
Nurse
Physician
Psychiatrist
Psychologist
Social worker
No one holds this role
Other (please specify):

4. Does anyone on your CF team have training in these areas? Check all that apply.
Cognitive Behavioral Therapy (CBT)
Counseling or supportive therapy
Mental health screening
Prescribing medications for depression or anxiety (e.g., antidepressants)
No one on our team is trained in any of these areas
Other (please specify):

5. Do you have any experience with mental health screenings?
Yes
No

6. Which screening measures do you currently use? Check all that apply.
Beck Anxiety Inventory (BAI)
Beck Scale for Suicidal Ideation (BSI)
Beck Depression Inventory (BDI)
Center for Epidemiologic Studies Depression Scale (CESD)
Children's Depression Inventory (CDI)
Hospital Anxiety and Depression Scale (HADS)
Patient Health Questionnaire – 2 (PHQ2)
Patient Health Questionnaire – 9 (PHQ9)
Revised Child Anxiety and Depression Scale (RCADS)
Revised Children's Manifest Anxiety Scale (RCMAS)
Self-Report for Childhood Anxiety Related Disorders (SCARED)
Zung Depression Inventory
Other (please specify):

7. What barriers do you foresee in implementing screening in your CF care center? Please rank order the list below, (1 = most significant barrier, 2 = second barrier, etc.).
Difficult logistics (e.g., how and where to store data from screening)
Lack of qualified personnel to provide referrals or interventions
Limited staff time
Limited personnel
Maintaining patient confidentiality/privacy
Patient burden (e.g., concern about patients' time and availability)
Patient unwillingness or refusal to complete questionnaires
Space limitations

8. Do you have any concerns about the possible impact of mental health screenings on your clinic? If so, what concerns do you have?

9. Are you able to make referrals to mental health clinicians in your hospital?
Yes
No
I am not sure

10. Do you have an up-to-date list of mental health resources and referrals for patients/caregivers in your area?
Yes
No
I am not sure

11. Would you be interested in training in any of the following at the North American CF Conference (NACFC) or the European CF Society (ECFS) conference? If so, please rank order the list below (1 = of most interest, 2 = second interest, etc.).
Cognitive Behavioural Therapy (CBT)
Counselling or supportive therapy
Prescribing medications for depression or anxiety (e.g., antidepressants)
Training in Mental Health Screening

12. Please list other mental health training topics that would be of interest to you that could be offered at the NACFC or the ECFS conference.

13. What type of assistance would be most helpful in implementing a mental health screening program? Please rank order the list below (1 = most helpful, 2 = second most helpful, etc.).
Access to a list of local mental health resources and referrals
Access to a mental health hotline for guidance
Access to electronic tools (e.g., tablets, computers) for administration and scoring
Additional funds to support a mental health professional
Training in behavioral interventions (e.g., Cognitive Behavioral Therapy)
Training in mental health screening
Training in pharmacological interventions (e.g., antidepressants)

14. Please list other types of assistance that would be helpful to you to implement mental health screening at your CF center.

Figure 2. Number of respondents using specified instruments in Europe ■ and the US □ (only measures used by more than 5 respondents are included)