

National integration of mental health screening and treatment into specialized care for cystic fibrosis: What predicts success?

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Abstract

Objectives: The CF Foundation sponsored competitive awards for Mental Health Coordinators (MHCs) from 2016-2018 to implement the international guidelines for mental health screening and treatment in US CF centers. Longitudinal surveys evaluated success in implementing these guidelines using the Consolidated Framework for Implementation Research (CFIR). **Methods:** MHCs completed annual surveys assessing implementation from Preparation/Basic Implementation (e.g., using recommended screeners) to Full Implementation/Sustainability (e.g., providing evidence-based treatments). Points were assigned to questions through consensus, with higher scores assigned to more complex tasks. Linear regression and mixed effects models were used to: 1) examine differences in centers and MHC characteristics, 2) identify predictors of success, 3) model the longitudinal trajectory of implementation scores. **Results:** 122 MHCs (88.4% responded): Cohort 1 $N=80$, Cohort 2 $N=30$, Cohort 3 $N=12$. No differences in center characteristics were found. Significant improvements in implementation were observed across centers over time. Years of experience on a CF team was the only significant predictor of success; those with 1-5 years or longer reported the highest implementation scores. Change over time was predicted by >5 years of experience. **Conclusions:** Implementation of the mental health guidelines was highly successful over time. Funding for MHCs with dedicated time was critical. Longitudinal modeling indicated that CF centers with diverse characteristics could implement them, supported by evidence from the CF Patient Registry showing nearly universal uptake of mental health screening in the US. Years of experience predicted better implementation, suggesting that education and training of MHCs and retention of experienced providers are critical to success.

INTRODUCTION

A growing body of evidence indicates that individuals with chronic respiratory conditions, such as cystic fibrosis (CF), primary ciliary dyskinesia (PCD), non-CF bronchiectasis, non-tuberculous mycobacteria

(NTM), and chronic obstructive pulmonary disease (COPD) have elevated rates of depression and anxiety in comparison to community samples.¹⁻⁵ In addition, these psychological symptoms have been linked to worse health outcomes, such as increased inflammation, more frequent exacerbations and earlier mortality.⁶ Additionally, they are associated with worse adherence to prescribed treatments, worse health-related quality of life and increased hospitalizations and healthcare utilization.^{3,7-8} Thus, optimal health and functioning require consideration of both mental and physical health. This study focused on the integration of mental health screening and treatment into the specialized care of individuals with CF, and measured its success in a national cohort of CF programs.

In the largest mental health screening study conducted to date in a chronic respiratory condition, over 6,000 people with CF (pwCF) and 4,200 caregivers were screened for depression and anxiety in 9 countries (TIDES).¹ This study showed that rates of depression and anxiety were 2-3 times higher in this population than community samples. Subsequent studies in the US and Europe have confirmed these results, documenting clinical elevations in 30-45% of pwCF and caregivers.^{2-5,9-10} These findings led to the development of international guidelines sponsored by the Cystic Fibrosis Foundation (CFF) and the European Cystic Fibrosis Society (ECFS), which recommended annual screening of adolescents and adults with CF for symptoms of depression and anxiety, with follow-up treatment for those scoring in the elevated range.¹² These mental health guidelines have been widely disseminated and adopted in the US and Europe.¹³⁻¹⁴ This model of integrated care in CF could promote facilitation of mental health screening and treatment in other chronic respiratory conditions.

Although the development and publication of evidence-based guidelines has been responsible for major advancements in medicine for the past 50 years,¹⁵ implementation of new clinical practices have been relatively slow and inconsistent,¹⁶ with studies showing it can take years for these practices to be adopted. To facilitate implementation of the mental health guidelines, the CFF launched a national competitive grant process to fund a Mental Health Coordinator (MHC) at CF programs for 3 years and also sponsored an international Mental Health Advisory Committee (MHAC), a multidisciplinary committee consisting of healthcare professionals representing multiple disciplines (psychology, psychiatry, social work, pulmonology, nursing), CFF staff and members of the CF community. Implementation of the mental health guidelines was accompanied by intensive efforts to develop educational and training materials for pwCF,¹⁷ families and healthcare providers, and to disseminate continuing education programs to increase mental health expertise among CF care team members (available at cff.org or mentalhealth@cff.org).

The success of this implementation effort was evaluated, in its first year, using the Consolidated Framework for Implementation Research (CFIR) to identify the essential barriers and facilitators of mental health screening and treatment.¹⁷ CFIR is considered the “gold standard” for assessing implementation of new guidelines, and measures key stakeholders’ perceptions of the primary barriers and facilitators of implementation success. The central objective of this study was to evaluate the longitudinal success of these implementation efforts for 3 separate cohorts of CF programs over a period of 3 years. The first aim was to identify the major barriers to implementation as well as the successes that resulted from implementation of systematic mental health screening and treatment. The second objective was to evaluate the success of implementation in these cohorts over time. The final aim was to identify predictors of implementation success, including CF program characteristics (e.g., center size, pediatric versus adult), and years of experience on a CF team.

METHODS

From 2016 through 2018, the CF Foundation sponsored competitive awards for grants to fund a MHC to implement the international mental health guidelines in US CF programs.¹⁷ Three cohorts were funded, each for 3 years: Cohort 1 N = 84, Cohort 2 N = 36, Cohort 3 N = 18. Survey data was collected to evaluate the success of each program in implementing the Mental Health Guidelines. Additionally, respondents rank ordered barriers and facilitators of implementation and long-term success.

Participants and procedure

The CFF distributed the survey (via SurveyMonkey) to the first 84 CF pediatric and adult programs that

received the award in the fall of 2016 and subsequently each fall for the next 2 years. As additional CF programs received funding (Cohort 2, N = 36; Cohort 3, N = 18) they were included in this distribution as well. Surveys were sent to the grant Principal Investigator (typically the CF Program Director) and MHC, with instructions requesting that the MHC complete the survey questions. Data was collected from September 2016-December 2016, September 2017-May 2018, and October 2018-December 2018.

Measures

Survey questions were developed by members of the MHAC using an iterative, consensus-based process. Each year, the set of questions was revised to reflect evolving challenges in implementation, such as development of newly developed, condition-specific interventions for depression and anxiety, use of telehealth, and sustainability of the mental health program as the 3-year funding cycle was ending. Items that had 100% endorsement in Year 1 (e.g., use of recommended screening tools, ability to score them) were removed from subsequent surveys to make room for questions related to more advanced implementation. In Year 1, the survey had 50 items, in Year 2 this was expanded to 80 items, and in Year 3, a total of 71 items were included.

To quantify implementation success, points were assigned to survey answers (0-1, 0-3, 0-4) based on the level of difficulty in achieving them. Discussions among study co-authors were held to reach consensus on level of implementation difficulty. For example, success in counseling individuals with moderate to severe symptomatology was assigned more points than counseling those reporting mild symptoms. See Table 1 for example items and scoring.

Application of the CFIR model

First, survey questions assessing each CF Program's experience were grouped into 1 of the 5 primary domains of the CFIR model: 1) *Intervention Characteristics* —annual mental health screening, provision of psychological interventions by CF care team members, referrals for treatment; 2) *Outer Setting* —educational materials developed by the MHAC, courses and presentations focused on mental health at the North American CF Conference (NACFC), leadership at the CF Foundation; 3) *Inner Setting* —program characteristics, the practice of utilizing a multidisciplinary team, training in quality improvement, family education days, leadership provided by the CF Center Director; 4) *Characteristics of Individuals* —professional background and training of the MHC and years of experience working on a CF team; and 5) *Processes of Implementation* —development of the role of the MHC on the multidisciplinary team, integration of mental health data into team discussions, plans for execution of annual screening, follow-up of elevated scores and/or suicidal ideation and provision of mental health interventions.

The next step of this pragmatic application of the CFIR model¹⁸ quantified each CF program's success with implementation based on response scores that ranged from basic to advanced. As seen in Figure 1, levels of implementation were categorized as follows: 1) Pre-implementation/Basic, 2) Implementation of standardized screening, 3) Addressing barriers to implementation, 4) Full Implementation, and 5) Sustainability.

Analytic approach

Across the 3 cohorts, 122 CF Programs participated in the study (80 in Cohort 1, 30 in Cohort 2, & 12 in Cohort 3), which represented 88.4% of grant recipients. Programs in Cohorts 1 and 2 completed multiple yearly surveys, and 39 programs had more than one provider complete the survey for a given year. All analyses were performed at the level of the CF program and scores from multiple providers were aggregated within each program using the mean implementation score and the maximum number of years at the program across providers. Descriptive statistics were calculated for each cohort and compared across cohorts using chi-square tests of independence. To account for nesting of programs within years, a random intercept linear mixed effect model was used to estimate the total implementation score by cohort and year. To examine differences in implementation across programs and to identify predictors of implementation scores, we used a linear regression model with the following predictors: type of program (pediatric, adult, both), size of the program (small, medium, large), and years of experience working on the CF team. Cohort was included as a

covariate. To examine differences in implementation over time, we used a random effect model to predict both initial implementation and change in implementation across time (i.e., interactions between predictors and year) using grant year, type of program, program size, and MHC years of experience as predictor variables. Random effects included the intercept and year. All analyses were performed using the *lme4 v1.1-26*, Table one *v0.13.0*, and *stats v4.0.3* R packages.

Results

Descriptive statistics are presented by CF program cohort in Table 2 and represent aspects of the Inner Setting. There were no statistically significant differences in characteristics of CF programs across cohorts and thus, analyses were conducted across programs.

The first aim was to analyze the top-ranked barriers and successes of this implementation effort. Barriers were rank-ordered in terms of their significance, and successes were evaluated by their frequency of endorsement.

Barriers to implementation. Respondents were asked to rank order a list of 9 potential barriers each year from 1 (most significant) to 10 (least significant). Rank ordering of barriers for Cohort 1 across the 3 years was highly consistent, with staff time, dedicated space (e.g., to screen adolescents privately from parents), and perceived patient burden (time and availability) ranked as the top 3 barriers to implementation. Rank ordering of barriers across all cohorts and years yielded similar results, in a slightly different order: #1) patient burden, #2) space limitations, and #3) limited staff time. These barriers represent characteristics of the Inner Setting that are difficult to ameliorate.

Successes of implementation. Respondents were asked to report the top 3 successes of implementation. The 4 most frequently endorsed successes in 2018, representing the 3rd year of implementation were (representing Cohort 1 year 3, Cohort 2 year 2, and Cohort 3 year 1) were: #1) early identification of depression/anxiety (mental health issues); **tied** –#2) improved access to psychological services and interventions and #2) increased awareness/education in the CF team about depression/anxiety. The 4th most frequently endorsed success was reduced stigma about mental health/normalization.

The second objective was to evaluate the success of implementation in the first year and whether it improved over subsequent years, using the survey scoring criteria outlined above. As can be seen in Table E.1 (supplement), implementation scores were very similar across cohorts in Year 1, ranging from 21.12 to 26.17. Implementation scores increased significantly over time (see 95% confidence intervals), nearly doubling with each year of implementation. The longitudinal trajectories of these implementation scores were then modeled over time for individual programs. The estimated implementation scores and 95% confidence intervals for each cohort across the 3 years of the study are depicted in Figure 2, along with the trajectories for individual centers. As expected, there was a pronounced increase in implementation scores over time, with improved implementation reported each year. In addition, there was marked variability among programs both in terms of initial implementation and progression across time.

The third aim was to identify predictors of implementation success, considering Characteristics of the Inner Setting and of Individuals. Predictors for the first year of implementation are listed in Table 3 and indicate that the mental health providers' years of experience on the CF team was significantly related to higher implementation scores. Predictors for changes across time for Cohort 1 are presented in Table 4. Similar to the first-year model, years of experience on the CF team was significantly related to both implementation scores in Year 1 and changes in implementation over time.

Convergent validity using registry data. An external source of data from the Outer Setting, the Cystic Fibrosis Foundation Patient Registry (CFFPR),¹⁹ was used to evaluate convergent validity with the survey results. Annual data from the CFFPR on national rates of mental health screening were obtained for the year *prior* to the initiation of MHC grants in 2015 and for the 3 years of the implementation study (2016-2018). Responses to the following 2 questions were recorded: “*Was the patient screened for symptoms of classic depression using the Patient Health Questionnaire (PHQ-9) or other valid depression screening tools?*” [yes, no, unknown]; “*Was the patient screened for an anxiety disorder using the Generalized Anxiety Disorder*

Tool (GAD-7 or similar?)?” [yes, no, unknown]. As expected, rates of screening in 2015 for depression were quite low: 21.4% for those 12-17 years (adolescents) and 24.1% for those 18 and older (adults). Similarly low rates of screening for anxiety were documented: 17.6% for adolescents and 19.5% for adults. In 2016, when the MHC grants were launched, depression screening rates more than doubled to 57% for adolescents and 61.2% for adults; anxiety screening rates increased to 53.2% for adolescents and 59.2% for adults. Screening rates for depression continued to increase in 2017 and 2018 to 69% and 73.2% for adolescents and 75.1% and 80.1% for adults, respectively. Anxiety screening demonstrated similar increases across those two years: 67.2% and 72.5% for adolescents and 73.9% and 79.5% for adults.¹⁹

Discussion

To our knowledge, this is the largest systematic, national effort to integrate routine mental health screening and treatment into the care of adolescents and adults with a serious, chronic illness. This study was conducted with a geographically diverse, nationally representative group of CF programs including large and small programs and those from urban and rural areas. As recommended by the mental health guidelines, CF programs began to implement annual screening of depression and anxiety using 2 brief, validated tools with suggested practices for intervention and follow-up.¹² A well-established implementation model was utilized to evaluate the process over 3 years in 3 cohorts of CF programs. Results demonstrated substantial increases in implementation scores both at the cohort and individual program level, with confirmation of success implementing of screening in the CFFPR.

Dissemination and implementation of new practice guidelines is extremely challenging and often delayed by the complexity of the healthcare system, the difficulties of hiring and retraining staff, and the ever-present time constraints faced by busy clinics.¹⁵⁻¹⁶ It is hard to over-estimate the challenge for CF programs of adding systematic assessment and treatment of mental health symptoms to the existing difficulty of addressing a complex, chronic disease affecting multiple organ systems. Barriers to implementation included introduction of new standardized measures and scoring procedures, the necessity of addressing suicidal ideation if endorsed, the addition of a new role for a mental health expert on the multidisciplinary team, and the perennial shortages of staff time and clinic space. How did this implementation effort succeed?

First, the CFF (Outer Setting) took a leadership role in supporting the development of the mental health guidelines (i.e., co-sponsoring the guidelines with ECFS, with an executive member of the CFF serving on the guidelines committee) and the subsequent establishment and funding of competitive grants for a Mental Health Coordinator for 3 years. This greatly facilitated the hiring, training/retraining and financing of a team member with mental health expertise.

The establishment of the MHAC by the CFF was a critical contributor to implementation success. The MHAC research subcommittee documented implementation barriers, successes and training needs. To augment the Implementation Guide included as an Appendix to the mental health guidelines,¹² the MHAC offered a CF mental health Quality Improvement Change Package and a customized, interactive screening tracker. New MHC's had access to 1:1 consultations and peer mentoring, a group peer supervision program, and in-person networking events. As a centerpiece of creating robust psychosocial conference programming, guided by MHC survey needs assessment and CF healthcare provider feedback, the MHAC developed a series of specialized 4-8 hour training courses delivered at the NACFC and later adapted for international use; from 2016-2018, these included: *Depression and anxiety treatment in CF: Therapy, medications and preventative strategies*; *Mental health in CF: Taking your team to the next level to support emotional wellness for individuals with CF*; *Foundational motivational interviewing skills for every CF clinician*; and *Advanced strategies to address misuse of alcohol & other substances*. An “emotional wellness” section was added to the public-facing CFF website (cff.org), to house multimedia content targeted to the needs of CF healthcare providers and CF community members. Topics initially included depression, anxiety, substance misuse, and caregiver resilience, with subsequent expansion to include helping CF siblings cope, procedural anxiety, and strategies for adults with CF who become parents). To further promote communication and dissemination of their work, the MHAC created an international mental health listserv, a “Dropbox” of resources accessible to all healthcare providers, and an email point of contact, mentalhealth@cff.org.

The CF Foundation Care Center Network’s support of a multidisciplinary team approach also augments characteristics of the Inner Setting, making inclusion of a new team member, or new role for an existing team member, a “normal” part of the culture of CF care. Inner Setting characteristics, such as regular Family Education Days at CF programs, also fostered communication about the new mental health guidelines to pwCF and their families. Our prior analysis of data from the first year of Cohort 1 demonstrated substantial “buy in” from the CF community, with over 95% of pwCF and caregivers rating the new mental health screening program “somewhat to very” positively.¹⁷

Importantly, the only significant predictor of implementation success identified by our study was length of MHC experience on the CF team. This has important implications for the larger healthcare system—reinforcing the importance of investing in healthcare staff and promoting continuity of care providers. The experience and longevity of providers may be particularly important when implementing new clinical guidelines that require a higher level of knowledge of the patient population and their clinical challenges, familiarity with the complexity of their own healthcare system, knowledge of referral sources within the hospital as well as within the community, and establishment of trust among multidisciplinary team members.

As implementation progressed over time, concerns about the sustainability of these positive changes in clinical care increased and were expressed by CF care teams and advocates in the CF community. Efforts to seek funding from departmental and hospital sources, to identify cost savings related to addressing mental health concerns (e.g., improved adherence and clinic attendance, reduced hospitalizations) and information about billing for psychological services, were all explored as options to maintain mental health screening and treatment. There was widespread reluctance to lose the gains that had been made in addressing mental health while caring for pwCF and their families. The Outer Setting leadership at the CFF shared these concerns and recognized the importance of mental health care delivered by the CF programs. A line item was added in the 2020-2021 CFF care center grants to maintain the role and function of the Mental Health Coordinator across the US. This may be the strongest indicator of implementation success; the healthcare system shifted to permanently establish a minimal level of psychological support in CF care.

Limitations and Future Directions

Data on implementation was generated via self-report by Mental Health Coordinators at these CF programs. There is always a potential for self-report data to be biased, given its reliance on the perspectives of the respondent. However, the perspective of those implementing the mental health screening protocol was invaluable, and the alternatives, which included collecting observational data or generating program-level quality improvement evidence was not feasible at a national level. Additionally, since patient-level data on screening scores were not collected for this study, this analysis could not identify the potential benefits of assessing and treating mental health symptoms on short- or long-term health outcomes.

This suggests critical directions for future research. First, the impact of the CF Mental Health Guidelines cannot be precisely measured without collecting data on CF patient mental health. Currently the CFFPR only collects data on whether screening occurred but not the results of that screening. The addition of depression (PHQ-9) and anxiety (GAD-7) screening scores would provide valuable data on the associations of mental health with CF outcomes (frequency of hospitalizations, health-related quality of life, mortality), adherence, and side effects of medications such as modulators, and would also allow measurement of the effects of mental health screening and interventions. Complex questions about the long-term trajectories of depression/anxiety and their impact could also be addressed. Second, the mental health guidelines that served to direct this integration of mental health into CF care, as well as these implementation efforts, may need to be updated. Given the recent recommendation of the US Preventative Task Force to implement anxiety screening in preadolescent children,²⁰⁻²¹ a consideration of mental health screening in this age group of children with CF is timely and appropriate.^{22,23} Lastly, elevated rates of depression and anxiety have been consistently reported in other chronic respiratory diseases (e.g., non-CF bronchiectasis, primary ciliary dyskinesia, NTM).³⁻⁵ This model of mental health screening and intervention implemented in CF could serve as a model for the integration of mental and physical health in other respiratory conditions.

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