Cystic Fibrosis Mental Health Coordinator 101: Getting Started

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This document will be updated as new research and consensus reports are published
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CF Mental Health Coordinator 101 Introduction

Cystic Fibrosis (CF) is a complex recessive genetic disease that affects patients both physically and mentally. Studies have shown depression and anxiety are common in people with CF and their caregivers, which can impact disease management. The CF mental health coordinator is a recommended member of the CF care team and can be a social worker, psychologist, licensed mental health counselor, advanced practice nurse, or a psychiatrist. Responsibilities include prevention, screening, and treatment for anxiety and depression with the support of mental health guidelines. The purpose of the 101 document is to outline the role, responsibilities, and tools/resources for the CF mental health coordinator in both the inpatient and outpatient setting. Much of the information in this 101 document originated from the work of the CFF Mental Health Advisory Committee and can be found in the Mental Health in Cystic Fibrosis Quality Improvement Change Package (Reno, Filigno, Lomas, Mueller, Petren, Sabadosa, Schechter, & Smith).

1. Background
   1.1. A large body of research indicates that children and adults with chronic illnesses, as well as parent caregivers, are at increased risk for psychological difficulties. The International Depression Epidemiological Study (TIDES) found symptoms of depression in 10% of adolescents with Cystic Fibrosis (CF), 19% of adults with CF, and over 30% of their parent caregivers; the prevalence of symptoms of anxiety were even higher (Quittner, Thorax 2014).
   1.2. Anxiety and depression are significant morbidities in themselves, but take on even greater importance in CF because of their impact on disease self-management, and ultimately on the course of lung disease (Riekert 2007 and Fidika 2014).
   1.3. Individuals with CF who report elevated levels of depression have worse adherence to prescribed treatments, higher rates of missed or canceled appointments, increased health care utilization, and higher health care costs. Furthermore, depression is associated with worse health-related quality of life (HRQOL) and higher mortality (Barker 2016, Reikert 2007, Fidika 2014, Yohannes 2012, Smith 2010, Snell 2014).
   1.4. Cystic Fibrosis Foundation and European Cystic Fibrosis Society Consensus Statements for Screening and Treating Depression and Anxiety (Quittner, Thorax 2016)
      - Algorithms
      - Annual screening of depression and anxiety for all individuals with CF, begin at the age of 12, and all parents/caregivers of children with CF from birth to age 17
      - Steps to diagnose and treat mental illness in those with elevated screening results
1.5. One approach that has proven useful in primary care and will likely be successful in CF is the use of a “collaborative care model.” Collaborative Care is an innovative way of treating depression and anxiety, involving multiple health professionals working together to address mental health problems in the context of the medical home. Over the past 15 years, more than 70 randomized controlled trials have established a robust evidence-base for this approach. A Cochrane review found collaborative care is associated with significant improvement in depression and anxiety outcomes compared with usual care and represents a useful addition to clinical pathways for adult patients with depression and anxiety. Within the context of medical illness, integrated collaborative care can improve medical and mental health outcomes including reducing rates of hospitalizations and health care costs, and optimizing health care treatments (Archer 2012; Thota 2012; Cooley 2009, Gordon 2011, Katon N Engl J Med 2010 and Katon Gen Hosp Psychiatry 2010).

1.6. Multidisciplinary team: Collaborative care is not achieved by inserting a mental health provider into a medical clinic. In a collaborative care program, care is provided by a multidisciplinary team including: 1) a primary provider or medical specialist; 2) a mental health coordinator (MHC) based in the medical clinic and trained to provide care coordination, brief behavioral interventions, and to support the treatments such as medications initiated by the medical physician and collaborate with all other CF team disciplines; and 3) a mental health consultant, typically a psychiatrist, who can advise the medical treatment team with a focus on patients who present diagnostic challenges or who are not showing clinical improvements. The MHC can be a licensed psychologist, social worker, or licensed professional counselor who has received special training or certification in mental health, with use of psychiatric consultation for complex cases.

1.7. The CF Foundation has formed a national steering committee. The CF Foundation Mental Health Advisory Committee to oversee and support implementation of the mental health guidelines and continue to identify best practices for screening, education and training of members of CF multidisciplinary staff, and use of evidence-based psychological and medical treatments. Members of this committee can be contacted via email at mentalhealth@cff.org.

2. Establishing the Mental Health Coordinator Role

2.1. Patient/Family Advisory Council: Many Centers have patient and/or family advisory councils who meet regularly to discuss aspects of CF care, quality improvement, and new initiatives at their Center. At the beginning stages of integrating the mental health coordinator role into the CF Care Team, it is beneficial to work with members of the
advisory group to identify goals, solicit patient/family feedback, problem solve barriers (e.g., managing clinic flow, confidentiality, etc.) and create a plan for introducing and implementing the new mental health coordinator role.

2.2. Introductory Materials: It is important to introduce the new mental health coordinator role to other CF care team members and patients/families. Examples of letters to patients/families and introductory materials for care team members exist on the MHC Dropbox.

2.3. Establish a Mental Health Advisory Group: This group should consist of core CF team members that meet quarterly, initially to clarify the roles and processes for mental health care and then to facilitate ongoing integration on continuous quality improvement. Ideal members of this group include all providers directly involved in MH care, physician, clinic coordinator and a patient or caregiver, in order to identify who will assist in the development of the mental health program within the care center as well as to clarify specific roles and responsibilities. This team should initially meet regularly using the meeting skills and rotating roles found in the Action Guide for Accelerating Improvement in Cystic Fibrosis Care, 2nd Edition. Most teams will need to hire a new clinician to serve as the Mental Health Coordinator (AIMS Guidelines on Caseload Size); other Care Centers will be able to provide additional hours and support for an existing staff member to expand his/her role. The MHC should lead the development and oversee the success of the mental health program. This individual would ideally be a licensed mental health professional (LISW/LCSW, licensed professional counselor, psychologist, etc.) or a trained/credentialed NP/PA specifically designated as the case manager for mental health activities. As with all team development and QI processes, it will be important to include at least one patient and/or family member to be part of your mental health QI lead team.

2.4. To further clarify the Mental Health Coordinator role, a sample job description is available from AIMS as well as a training video titled Collaborative Care Manager Role.

2.5. Integration with the CF Care Team: CF care teams should seek to recognize opportunities for collaboration and integration of mental health care within their current care model or be open to changes within their model if needed.

- Definition of Integrated Care: Efforts to provide healthcare services that bring together all the components that make humans healthy. Health involves a variety of factors (psychological, biological, social, communal, economic). An important way to think about integrated care is to consider the models, clinical pathways and perspectives that make up these efforts to bring together parts of the healthcare delivery system that traditionally work in silos. (www.cfha.net).
- MHCs should be fully integrated into the CF team. In addition to having a firm
understanding of the Mental Health Guidelines and effective mental health interventions, they should also gain an understanding of CF care, including medications, treatment recommendations and guidelines, comorbid conditions, and especially the problems of adherence and treatment burden.

- They will need access to and familiarity with Port CF, the CF Mental Health Dropbox folder and the CF Mental Health Listserv. (See Section 5: Tools to Know and Love)
- MHCs should review published literature on mental health in CF including the following articles - “Prevalence of depression and anxiety in patients with cystic fibrosis and parent caregivers: results of The International Depression Epidemiological Study,” “Maintaining Mental Health and Function for the Long Run in CF” and mental health resources found on the CF Foundation website.
- Survey your team’s understanding of mental health guidelines and MHC role in care.
- Establish regular meeting with key staff i.e., Center/Program Director and/or Program Coordinator.
- Optional: psychosocial rounds. This is an opportunity to collaborate with key members of the CF care team who are involved in the mental health, psychosocial, developmental and emotional care of patients and families. This can include MHC, social workers, child life specialists, nurses, etc. Rounding should occur regularly (e.g., weekly) with the goal to review patients scheduled in clinic, inpatients currently admitted, and upcoming admissions. The purpose should be to identify goals for visit, review relevant psychosocial issues, improve communication among psychosocial providers, and discuss recommendations and plan of care.

2.6. Sustainability

- Sustainability is critical in the process of embedding mental health into CF care teams. In order to sustain the embedded mental health position and collaborative care model in CF, it is important to be able understand key components of clinical delivery:
  a) costs of the mental health program at your CF Center
  b) components of funding and revenue generated within the institution, department, and CF Center (e.g., billing revenue, institutional support, department support, federal and foundation grant funding, philanthropy, etc.)
  c) billing models
• In addition to understanding mechanisms of funding and clinical delivery models within one’s institution, it is also important to determine health cost savings as a result of integrated mental health prevention, assessment and intervention. Determining the impact of addressing underlying risk factors for mental health concerns on things such as adherence to medical care, frequency and length of hospitalizations, maintenance of outpatient clinic appointments, and Emergency Room visits can all help contribute to models of sustainability. Identifying cost savings because of embedded mental health services is an important Quality Improvement (QI) opportunity that could result in additional and more permanent funding of the MHC position. (See Section 6: Quality Improvement)

• Mental Health Sustainability Worksheet: This tool was created to help mental health providers and CF care team members plan for and take steps towards sustainability of the integrated model.

• Financial Modeling Workbook in collaboration with the Institute for Family Health and the American Psychiatric Association: This workbook will help centers to identify opportunities for revenue as well as evaluating expenses and sustainability.

• Billing for services: For those whose institutions support the separate billing for mental health services, please review the billing 101 document and the 2017 NACFC Billing presentation.

3. Role of the MHC
   3.1. Development and Implementation of Strategies for Screening and Tracking
   • Questions to answer before you start screening:
     ○ Who are you screening?
     ○ When will you screen?
     ○ Who will administer the tools?
     ○ How much time will the MHC need with patients?
     ○ How will you track follow up?
     ○ How will the treating clinician know screening was complete and the results?
     ○ How will you keep track of screening scores and intervention?
     ○ How will the information be fed back to the team?
     ○ How will you manage suicidal ideation in clinic setting?
   • Identify/Clarify Flowchart for screening, assessment and referral
• **Create a Clinical Workflow**
  - Guide to Implementing Depression and Anxiety Screening
  - Mental Health Screening Implementation Planning Worksheet
  - Action Guide for Accelerating Improvement in Cystic Fibrosis Care, 2nd Edition (see pg. 30 - Creating a workflow)

• Establishing a Referral Database of Community Mental Health Providers
  - There are many tools within the Mental Health Dropbox including PowerPoint presentations with written and audio scripts to teach community mental health providers about CF.
  - The MHC should connect directly with the mental health provider prior to referring patients to discuss infection control guidelines and practices, and to provide CF education.
  - When considering referrals, it will be important to ensure insurance coverage and preferred provider status of mental health clinicians. CF Foundation Compass case managers can assist in contacting insurance companies to determine insurance coverage for mental health services. The case managers can be reached at 844-COMPASS (266-7277).
  - Primary care providers often have knowledge of MH providers in the patient’s local area if working in a large catchment area. In addition both the Association of Cognitive and Behavioral Therapies and The Association for Contextual Science(ACT) have national registries of providers.

• Educating Patients and Families:
  - Letters for adults with CF, parent caregivers, PowerPoint presentations, and newsletter articles.
  - Annual CF Education Day: Many centers have used the annual CF educational day as an opportunity to discuss and provide education regarding the guidelines and implementation. A center may choose to share the handout Depression, Anxiety and Cystic Fibrosis: What the Guidelines Mean For You.

• Coordinating Treatment
  - Providing consultation and education for staff, the institution and community practitioners
  - Facilitating information flow between team clinicians and mental health providers in and outside of the CF Center/institution
**Intervention** ([Quittner et al. Thorax 2016;71:26-34](#))

- The ICMH (International Committee on Mental Health in CF) recommends a stepped care model of clinical intervention be developed and implemented in close collaboration with patients and caregivers, the multidisciplinary CF team and other treatment providers or consultants, such as primary care or mental health specialists. See online supplementary **appendix D tables 1-3** to Quittner et al. Thorax 2016;71:26-34.

- Interventions should be adjusted to account for patient/caregiver preferences, medical status, psychiatric comorbidities, treatment history, resource availability, access to treatments and local practice patterns.

- Adolescents and adults with CF (ages 12 and above) whose depression or anxiety is in the mild range should receive education, preventive or supportive psychological interventions and rescreening at the next CF visit. Evidence-based psychological interventions should be offered to all adolescents and adults with CF whose depression or anxiety is of at least moderate severity. An extensive body of literature supports the efficacy and effectiveness of cognitive behavioral therapy (CBT) for the treatment of both depression and anxiety, whereas some evidence indicates that interpersonal therapy (IPT) is an effective treatment for depression.

- Education and cognitive restructuring are included in CBT interventions for both depression and anxiety, whereas behavioral activation (e.g. engaging in pleasant activities) is an additional core ingredient of most CBT manuals for the treatment of depression. Relaxation training and gradual exposure to triggers of anxiety are considered essential components of anxiety-specific CBT. IPT is a short-term treatment that encourages patients to regain control of mood and functioning. It is based on a treatment alliance in which the therapist empathically engages the patient, helps the patient feel understood and structures success experiences. Comparisons of CBT and IPT suggest there is broader empirical support, dissemination and training and worldwide adoption of CBT versus IPT. CBT has also demonstrated efficacy in treating comorbid depression and anxiety, which occur commonly among those with CF.
4. Knowledge Base of MHC

4.1. CF Care
- Medications: mucolytics, inhaled antibiotics, enzymes, etc.
- Airway Clearance: Order of Therapies
- Treatment recommendations and guidelines
- Comorbid conditions: CFRD, malnutrition, chronic pain
- Problems of adherence and treatment burden
- Transplant
- Palliative Care/Hospice/End of life care

4.2. Mental Health in CF
- Prevalence of depression and anxiety in patients with cystic fibrosis and parent caregivers: results of The International Depression Epidemiological Study, Maintaining Mental Health and Function for the Long Run in CF and mental health resources found on the CF Foundation website.
- Psychotherapy:
  - CBT Based Interventions/2017 NACFC Presentation
  - Interpersonal psychotherapy (IPT)
  - ACT: Acceptance Commitment Therapy
- Medication:
  - SSRIs are recommended: Training in psychopharmacology and special issues in prescribing have been delivered at the North American CF Conference Short Course: Depression and Anxiety Treatment in CF: Therapy, Medications and Preventative Strategies Oct. 2016
  - Clear plan for assessment and triage must be identified prior to implementation of screening keeping in mind logistics of transfer/transport to emergency psychiatric care. If parent/caregiver screening is planned, then procedure for managing emergency care of parents/caregivers must be identified. 2017 NACFC Suicide Resource Packet
- Goals of Treatment: The goal of treatment is to insure 100% of individuals who scored >10 on the PHQ-9 and/or GAD-7 are informed of treatment options and treatment plans are co-created.
  - Follow up and Monitoring: Any individual who agrees to treatment should receive follow-up from the MHC to ensure all patients who agree to treatment, actually receive treatment. The PHQ-9 and GAD-7 should be used to monitor treatment response with a goal of symptoms
returning to a normal range and improved functioning. If anxiety or depressive symptoms continue, or functioning remains impaired, a stepped care approach should be used and alternative interventions offered until symptoms are within normal range. If symptoms are not improving, referral for additional specialty consultation may be indicated.

5. **Tools to Know and Love**

5.1. **CFF Mental Health Dropbox Team Folder.** A folder containing many clinical tools and resources, mental health presentations and introductory materials, educational information for patients/families, relevant articles and publications, and many more helpful resources. Access to the Drop Box can be achieved by emailing mentalhealth@cff.org.

5.2. **Port CF:** To obtain access to the CF Foundation’s Port CF, contact your center director or registry coordinator.

5.3. **CF Mental Health Listserv:** Email Kathy Sabadosa at Kathryn.A.Sabadosa@DARTMOUTH.EDU to be added to the listserv.

5.4. **Anxiety and depression screening tools**
   - **PHQ-9 and GAD-7**
     - Refer to the Clinical Assessment and Treatment section for the algorithm related to the screening scores.
   - A comprehensive resource of adolescent depression tools can be found in a toolkit that accompanies the Guidelines for Adolescent Depression in Primary Care (GLAD-PC).

5.5. **Additional mental health resources for pediatric patients:**
   - Educational materials and screening tools for other mental health issues (e.g., substance abuse, ADHD, oppositional-defiant disorder, and a variety of behavioral health problems) are available at Child and Adolescent Psychiatry for Primary Care website.
   - Academy of Child and Adolescent Psychiatry has developed facts for families, which are concise handouts with up-to-date information on a variety of topics that affect children/adolescents.
   - School-based interventions and resources for mental health concerns. Massachusetts General Hospital School Psychiatry Program Mood and Anxiety Disorders Institute has developed resources aimed at parents, teachers, and clinicians.
5.6. Additional mental health resources and information for adult patients:
   - American Psychiatric Association “Let’s Talk Facts” brochures provide answers to commonly asked questions on mental health disorders and their treatments.
   - National Institute of Mental Health

5.7. Suicide assessment and safety plans:
   - Warning signs for suicide IS PATH WARM tool.
   - Safety Plans. It is important to know your institution’s policies on evaluation of imminent risk (e.g., mental health holds, security, transportation to ER, etc.)
     - Safety Plan Templates:
       - "Coping/Safety Plan"
       - "My Safety Scale"
       - "Coping Plan"
       - "Making your home safe"
   - The Columbia Suicide Severity Rating Scale (C-SSRS). One of the most widely used tools and considered the gold standard to screen for suicidality and risk. The C-SSRS has many versions and can be used for children and adults.
   - SAMHSA Suicide Assessment Five-Step Evaluation and Triage (SAFE-T)
   - Additional suicide resources. National Crisis Hotline: 1-800-279-TALK (8255), Facts For Families-Teen-Suicide, National Suicide Prevention Lifeline, Suicide Prevention Resource Center and Boystown National Hotline

5.8. CFF Mental Health Screening Tracking Log. The use of the CFF MH Screening Tracking Log will aid in the tracking of MH screening and implementation of the MH guidelines. Tracking the timing and results of mental health screening is important to determine appropriate mental health recommendations and patient/family adherence to recommendations. Additionally, tracking of screening is critical for sustainability of mental health positions within CF Centers. (See Section 2.6 for more discussion about sustainability and a link to the sustainability worksheet)
   - Webinar training associated with the use of the mental health screening tracking log

6. Quality Improvement (QI)
   6.1. Implementation of Mental Health Screening and Integrated Mental Health Care as a QI Activity
     - Definition of QI: A systematic, formal approach to the analysis of practice performance and efforts to improve performance. The use of a QI infrastructure
will aid in achieving measurable improvements in both mental health and CF outcomes.

- The booklet *Action Guide for Accelerating Improvement in Cystic Fibrosis Care, 2nd Edition* is a helpful reference to familiarize the CF Care Team with the QI process.

- **How to conduct QI**
  - **Establish your QI team:** The commitment and active engagement of critical team members is required to have successful and sustainable change. A core mental health QI team should involve representatives of the majority, if not all, of the disciplines on the CF care team. In addition to care team members, patient and family perspective is critical in the identification and implementation of any practice change. At least one patient and/or family member should be a part of the mental health QI team.
  - **Identifying goals and priorities for Mental Health-related QI:** The first step is to ensure everyone receives baseline knowledge about depression and anxiety, its prevalence in CF and its effect on disease management and health outcomes. The handout *Depression, Anxiety and Cystic Fibrosis: Guide for CF Clinicians* can be used together with results of the TIDES Study and the published consensus statements. Having this baseline knowledge will help the team have a shared belief that screening for depression and anxiety is important for the health and wellbeing of patients and families. This baseline knowledge will also help inform the group’s goals and priorities for subsequent mental health-related QI initiatives.
  - **Develop a specific aim.** Try to answer 3 fundamental questions:
    a) What are we trying to accomplish?
    b) How will we know that a change is an improvement?
    c) What change can we make that will result in improvement?
  - **Evaluate your progress.** This can include answering the following:
    a) Did your plan result in an Improvement? By how much/little?
    b) Was the action worth the investment?
    c) Do you see trends?
    d) Were there unintended side effects?
  - **Use of Plan-Do-Study-Act Model (See Section 6.2)**
• Institutional Readiness
  o An institution’s organizational structure and readiness for integrating mental health care should be assessed by completing the **Review Organizational Readiness Worksheet**. This document provides an opportunity to review and identify resources and tools available within an institution and the larger community as well as potential barriers. For example, some pediatric programs have faced barriers to screening parent caregivers. It is important for the MHC and CF Team Leaders to identify **key individuals** within the institution (e.g. risk management) and facilitate collaborative relationships with the MHC in order to address the needs and gaps identified before, during and after the assessments.

• Starting Mental Health Screening as a QI Initiative
  o The mental health QI team will need to develop a plan for all aspects of the mental health screening process. This will include identifying who will provide screening tools to patients, score them, respond to positive screens, and enter the data into the charting system. The knowledge and skills needed to effectively carve out these roles should be clearly outlined so new roles can be assigned to the appropriate team member. As the core mental health QI team has full ownership of this process they are better able to support each other through the process and in turn, successfully implement screening.

6.2. Tools for QI

• Teams needing additional information should review the **Action Guide for Accelerating Improvement in Cystic Fibrosis Care, 2nd Edition**

• Plan-Do-Study-Act (PDSA) Model ([http://www.health.state.mn.us/divs/opi/qi/toolbox/pdsa.html](http://www.health.state.mn.us/divs/opi/qi/toolbox/pdsa.html)). PDSA is an iterative problem-solving model for improving a process and making change that is widely accepted in healthcare improvement.
  o The first step in the PDSA model is the Plan phase, which includes identification of a change idea. The second step is the Do phase, where you start to implement your action plan. The Study phase involves examining the effect of the efforts made so far. Using the specific aims drafted in phase 1, and the data gathered in phase 2, determine if the plan resulted in an improvement and if there were unintended side effects. Finally, in the Act phase you reflect on the plan and the outcomes to determine if the plan resulted in success and a standardization of the improvement should begin, or an alternative approach is identified.
• **Driver diagram**: This will serve as the improvement roadmap
• **P-charts** and run charts are useful for short term improvement monitoring
• For long term outcome monitoring, **XmR charts**
• **Online QI trainings:**
  o Institute for Healthcare Improvement ([www.ihi.org/openschool](http://www.ihi.org/openschool)) $300 annual fee if no institutional membership.
  o **National Institute for Children’s Healthcare Quality** Free access with email.
  o PortCF > Resources > Quality Initiative
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