

# Opportunities for Trauma-Informed Medical Care in Cystic Fibrosis

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To the Editor:

People living with Cystic Fibrosis (PwCF) face a lifetime of potentially traumatic medical experiences. These experiences can range from invasive medical treatments (e.g. venipuncture, nasogastric tube placement) to daily illness-related events (e.g. illness related bullying). These experiences place PwCF at high risk for a type of posttraumatic stress called Medical Traumatic Stress (MTS)[1]. With the growing recognition of the high prevalence and impact of MTS, we anticipate that cystic fibrosis care teams may soon be tasked with integrating trauma-informed medical care into their clinical practices. CF care teams are well poised to prevent and screen for MTS because they 1) create the environment for many illness-related experiences; 2) have established workflows for mental health screening; and, in many cases, 3) have trusting relationships with PwCF and their families. Here, we seek to highlight the opportunities for implementing trauma-informed medical care within the cystic fibrosis-specific context.

MTS is defined as the psychological and physiological responses of children and their families to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences[2]. MTS is common in PwCF – 55% of these youth report experiencing potentially traumatic medical experiences and 30% report MTS symptoms[1]. MTS symptoms have the potential to impact medical care, health outcomes and quality of life[3].

While highly effective modulator therapies may decrease the frequency and severity of medical care, PwCF have identified these therapies as an additional source of potentially traumatic experiences[4]. New potentially traumatic medical experiences in modulator-eligible PwCF can include lost sense of purpose as their identity shifts from a “sick” person to a “well” person; survivor guilt from benefiting from therapies not available to others; and financial distress as they face planning for a longer than anticipated life expectancy [4]. The challenge of navigating the healthcare system, such as advocating with care teams and insurance companies, has been identified as potentially traumatic by PwCF, particularly those who are modulator-ineligible[4].

A trauma-informed approach to medical care may be helpful for cystic fibrosis care teams to mitigate MTS. The Pediatric Psychosocial Preventive Health Model (PPPHM) provides a framework for tiered implementation of trauma-informed medical care[5]. It includes recommendations for *universal practices* gauged towards all children and families, *targeted approaches* for those at high risk of developing MTS, and *treatment* for those with severe, escalating, or persistent MTS symptoms (Figure 1).

Universal MTS interventions for PwCF include prevention and screening. Preventive interventions can include MTS awareness education for all PwCF, family members of PwCF and cystic fibrosis care team members. This education can highlight approaches to modifying potentially traumatic medical experiences and identifying MTS symptoms that indicate the need for further support. Universal systems interventions

may also include the implementation of workflows to minimize the traumatic potential of healthcare experiences (e.g. workflows to minimize needle distress with comfort positioning, numbing cream, and distraction as part of standard care. Care teams can also integrate shared decision-making processes to optimize patient perception of control and implement systems that facilitate communication between cystic fibrosis care team and PwCF.

While annual mental health screening for depression and anxiety is the current recommendation for all PwCF, healthcare providers should consider integrating routine MTS screening into their practice. Screening workflows can include screening for patient risk factors and MTS symptoms, as well as family member symptoms of MTS. Currently, there are no screening tools designed to specifically capture the cystic fibrosis experience of MTS; however, acute stress screeners such as the Acute Stress Checklist for Children can aid in the identification of MTS, thereby guiding providers on who to refer for further mental health assessments or support. One common concern regarding screening for MTS is managing the burden of time as well as supporting those PwCF who screen at-risk. Thus, in planning for MTS screening, teams ought to consider the time required for screening, appropriate training for those performing the screening, and the development of a clear workflow for management and referrals. While these barriers require a thoughtful approach to processes and care, the benefits outweigh the consequences of not screening. MTS is present for many regardless of if screening occurs and screening allows the medical team to optimize overall healthcare.

The second tier of the PPPHM recommends targeted approaches to MTS for those with risk factors or early symptoms. Possible MTS risk factors in PwCF include parent posttraumatic stress disorder, high daily medication burden, and emergency room and intensive care [1]. Interventions for PwCF who have MTS risk factors or early symptoms may include increasing support during potentially traumatic medical experiences (e.g. having a child life expert prepare a patient before a procedure); altering the medical care plan when possible (e.g. minimizing daily medication burden); educating family members on what to say to PwCF before, during, and after potentially traumatic medical experiences; and integrating patient-specific resilience factors into individualized coping and support plans. In some cases, brief therapeutic psychological interventions may help address specific symptoms (e.g., targeted CBT needle phobia interventions, behavioral sleep interventions, brief psychoeducation interventions).

The third tier of the PPPHM recommends treatment for MTS symptoms that impact medical care or impair daily functions. PwCF with significant MTS symptoms should be referred to a mental health provider with expertise in the treatment of trauma symptoms. Ideally, the provider should have familiarity with chronic medical conditions, and, ideally, cystic fibrosis specifically. While we do not yet have evidence-based MTS-specific interventions for PwCF, approaches may include cognitive behavioral techniques such as restructuring of hospital-related thoughts, behavioral activation, or trauma-focused cognitive behavioral therapy. Mental health providers could also collaborate with families and cystic fibrosis care teams to develop an individualized plan for minimizing re-traumatization and reducing the impact of MTS on medical care and quality of life.

In summary, given the substantial impact that MTS can have on PwCF, cystic fibrosis care teams should consider integrating trauma-informed approaches into the medical care of PwCF to optimize overall health (including mental health). Comprehensive approaches to MTS mitigation in PwCF include 1) universal awareness, prevention, and screening, 2) targeted interventions for those at high risk, and 3) individualized MTS treatment administered by mental health professionals. To optimize cystic fibrosis care with attention to MTS, future research should prioritize more definitive identification of MTS risk factors, the development of validated cystic fibrosis-specific MTS screening tools, the creation and dissemination of evidence-based MTS prevention programs, and the development of evidence-based MTS mental health interventions tailored to PwCF.

**Figure 1: Application of the Pediatric Psychosocial Preventative Health Model to Cystic Fibrosis.** Adapted with permission from the Center for Healthcare Delivery Science at Nemours Children’s Health System 2018-2019. All rights reserved[5].

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## Conflicts of Interest

Drs. Cuneo, Smith-Thomas, and Marsac declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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