



Cystic Fibrosis Research News

Title:

Medical Traumatic Stress in Cystic Fibrosis: A Qualitative Analysis

Lay Title:

Understanding Medical Traumatic Stress in Cystic Fibrosis from the Viewpoints of Patients, Families, and Providers

Authors:

Addison A. Cuneo, MD^a, Simon Outram, PhD^b, Meghan L. Marsac, PhD^c, Siena Vendlinski^a, Melvin B. Heyman, MD^a, Ngoc Ly, MD, MPH^a, Emily von Scheven^a, MD, MAS, Emily R. Perito, MD^a

Affiliations:

- a. Department of Pediatrics, University of California San Francisco, San Francisco, CA
- b. School of Nursing, University of California San Francisco, San Francisco, CA
- c. Department of Pediatrics, Kentucky Children's Hospital, Lexington, KY

What was your research question?

In this study, we asked: 1) what kinds of illness-related events do people with CF find to be traumatic? 2) what psychological symptoms do they have from those events? and 3) what impact do those symptoms have on their lives?

Why is this important?

People living with CF face a lifetime of illness-related experiences, including those within the medical system (like medical visits, lab draws, and hospitalizations) and those outside of the medical system (like lifestyle restrictions and medication burden). CF patients, families, and care providers have been aware that some of these experiences can be stressful and even traumatic, causing symptoms of post-traumatic stress disorder. However, the characteristics and impact of those experiences had not been previously detailed.

What did you do?

We interviewed people with CF, family members of people with CF, and CF care team members to get insight into: 1) what kinds of illness-related events people with CF find to be traumatic, 2) what symptoms they had from those events and 3) what impact those symptoms had on their lives.

Cystic Fibrosis Research News

cfresearchnews@gmail.com



Cystic Fibrosis Research News

What did you find?

Traumatic illness-related events often involved the feeling of loss of control, the threat of physical harm, and/or a change in how the person with CF viewed themselves. Reported symptoms generally fell into the posttraumatic stress disorder symptom categories of *negative mood* (eg. depression, anger); *physiologic reactivity* (the body's unconscious responses to trauma); *intrusion* (eg. flashbacks); and *avoidance* of reminders of the event. *CF-specific* symptoms included shame, survivor guilt, burden guilt, germaphobia, and symptom panic. The impacts of these symptoms were broad, but importantly included altered health behaviors and strained relationships between people with CF and their medical care teams.

What does this mean and reasons for caution?

This is the first study to explore the experience of medical traumatic stress in people with CF. Now that we understand what types of events lead to medical traumatic stress, the symptoms people with CF have from these events, and the impact of those symptoms on daily life and medical care, we can work towards evidence-based approaches to medical traumatic stress screening, prevention, and treatment.

Despite efforts to recruit Black, Indigenous, and People of Color, our participants had limited racial and lingual diversity. There may be important differences in the experiences of these individuals, and future work should look at these.

What's next?

Since existing posttraumatic stress questionnaires do not capture several of the symptoms we identified, the first next step is developing a dedicated questionnaire to screen people with CF for medical traumatic stress. Once we can screen for medical traumatic stress, we can evaluate the impact of prevention strategies and treatments.

Original manuscript citation in PubMed

<https://pubmed.ncbi.nlm.nih.gov/36925385/>