

Cystic fibrosis center prioritizes screening for depression and anxiety

June 4 2021, by Ellen Goldbaum



Credit: University at Buffalo

Cystic fibrosis is a genetic, progressive disease that causes persistent lung infections and impacts the most basic physical processes. While recent breakthroughs have significantly extended the lifespan of patients with CF, the disease presents patients and their caregivers with significant, lifelong daily challenges.

The primary purpose of [cystic fibrosis](#) clinics is to treat the physical disease, but providers are well aware of the mental toll it takes on

patients and caregivers.

"It can be challenging for people with CF and their families to sustain daily therapies and to live with a life-limiting disease," said Danielle M. Goetz, MD, director of the Cystic Fibrosis Center of Western New York at UBMD Pediatrics and Oishei Children's Hospital, and clinical associate professor of pediatrics in the Jacobs School of Medicine and Biomedical Sciences at the University at Buffalo. "Our team began to feel that mental [health](#) screening was an important part of care to look at."

The Jacobs School/Oishei team effort was led by Goetz and Carla A. Frederick, MD, associate professor of medicine, with guidance from Drucy Borowitz, MD, professor emeritus of pediatrics, and Beth Smith, MD, professor of psychiatry and pediatrics.

In 2013, the Buffalo researchers began systematically using efficient tools for screening for anxiety and depression in patients and their caregivers, both of whom exhibit higher rates of these conditions than the general population. The researchers also developed an algorithm to determine which type of treatment would be necessary.

The screening process has been shared with other centers and was piloted at a larger CF center at the Ann and Robert H. Lurie Children's Hospital in Chicago.

These tools and the research it is based on are described in a paper published last month in the *British Medical Journal Open Quality*.

"CF is a disease that affects the whole body, including the ability to breathe and digest food," explained Goetz, who is also a pediatric pulmonologist with UBMD Pediatrics. "The burden of taking two to three hours per day to clear the airways of mucus and taking multiple

medicines can be so difficult and cause feelings of isolation." The disease also can cause diabetes and liver problems.

Impact on health outcomes

"It is a lot to think about and address," said Goetz, adding that previous studies have shown that depression in CF patients is linked with worse [health outcomes](#), including decreased lung function, lower body mass index, and increased exacerbations and hospitalizations.

Due to the grave risk of passing infections to each other, people with CF are also not supposed to gather, as depicted in the book and adapted Hollywood film "Five Feet Apart," which tells the story of a romance between two teens with CF. In reality, CF patients are advised to stay six feet apart from each other (even before the COVID-19 pandemic), a restriction that by itself can lead to feelings of isolation and depression.

At the same time, since most CF patients are diagnosed as young children, parents or caregivers of CF patients are intimately involved with their care.

"Parenting is hard, and parenting a child who has multiple medical and perhaps social needs is challenging," said Goetz. "It makes sense that depression and anxiety are more common in these parents and caregivers. Watching and helping their child go through multiple stressors is painful. We support the parents and caregivers, oftentimes talking to them about how they are dealing with their child or loved one's illness and how we can help them to seek help when needed."

Simple screening

In 2013, the center began to assess all of its 180 pediatric and adult CF

patients for depression. The center is now screening between 95% and 99% of patients and caregivers.

The first step was a simple screening questionnaire (the Patient Health Questionnaire-2, or PHQ-2), which asks about the degree to which the individual has experienced either depression or anhedonia (lack of pleasure in activities the patient used to find pleasurable).

A positive response to either question triggers a more detailed questionnaire (the Patient Health Questionnaire-9 or PHQ-9) or Generalized Anxiety Disorder-7 (GAD-7) questionnaire, which the center now uses as the initial screening tools. With these questionnaires, along with clinical assessments, the center assesses patients as having mild, moderate, moderately severe or severe depression or anxiety. Patients are then referred to mental health specialists or treated at the CF center by its own mental health coordinator. They receive follow-up assessments to determine effectiveness of treatment.

The researchers reported a higher prevalence of both depression and anxiety in the CF center than has been reported in the literature.

Suicidal thoughts

They also found that 5-10% of patients and caregivers had thought about committing suicide. The researchers had made the decision to include suicidal ideation in the screening process, and all clinic staff were trained to assess for this.

"We looked at it this way," said Goetz. "If we choose not to screen for suicidal ideation, it just means we may be missing it, not that suicidal ideation is not occurring. It is a challenging thing to screen for, though, if you don't know what to do with a positive screen. So, it is important for the whole team to understand how to do the screening and how to make

an emergency plan with patients. Anyone on the team can learn, especially nurses and providers, but really anyone, in case there isn't a social worker or psychologist on the team."

The center's emergency plans are tailored to each patient and may involve development of a suicide risk management plan, i.e., a "safety net" for the patient, or urgent or emergent referral to a mental health professional.

Goetz explained that the stepped process, beginning with the short questionnaire, allows for quick screening for all people with CF and their caregivers.

"A provider can then hone in on what needs to be done for each patient, with a focus on those who need more interventions," she said.

"It has been so meaningful to have a social worker and psychologist in our clinic who can help support the providers in providing the best mental health care or referrals for care," she added. "I can't say enough good things about this integrative approach and the importance of mental health and its impact on physical health."

CF Care Center teams also include nutritionists, respiratory therapists, nurse coordinators and research coordinators, all of whom play essential roles in quality improvement efforts.

The toolkit and related resources have now been disseminated on an international listserv for CF mental health and medical providers.

The CF Center of WNY at UB and Oishei Children's Hospital, a Cystic Fibrosis Foundation-accredited center that treats patients from eight counties, has been involved in the CF Foundation's Quality Improvement Network. Goetz noted that the [mental health screening](#) project

demonstrates a key premise of the quality improvement effort.

"We know now that people with CF should be involved with our projects from their inception," said Goetz. "That is an excellent aim for all teams looking to improve clinical care: The people who know best how to improve the process for disease assessment and management are likely the people living with the disease."

More information: Danielle Marie Goetz et al, Systematic depression and anxiety screening for patients and caregivers: implementation and process improvement in a cystic fibrosis clinic, *BMJ Open Quality* (2021). [DOI: 10.1136/bmjoq-2020-001333](https://doi.org/10.1136/bmjoq-2020-001333)

Provided by University at Buffalo

Citation: Cystic fibrosis center prioritizes screening for depression and anxiety (2021, June 4) retrieved 17 April 2024 from <https://medicalxpress.com/news/2021-06-cystic-fibrosis-center-prioritizes-screening.html>

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