Pediatric Team ‘Shakes Up CF’ for Better Patient Care

Last year, the BBCH pediatric team led a clinical transformation project with the aim of improving cystic fibrosis (CF) treatment and engaging patients and their families to better adhere to medication and therapy, both in and out of the hospital. The project was successful; 89 percent of patients liked participating in the program, 86 percent of parents felt their child was more compliant with their treatment plan, and 90 percent of staff felt patients were more compliant.

“We knew we could make meaningful change that would affect the lives and lung function of children across the state with this life-shortening disease,” says Ana Cairns, M.D., the physician lead on the CF project.

Cystic fibrosis is a genetic disease that causes lung infections and limits the ability to breathe. In people with CF, a defective gene causes a thick, buildup of mucus in the lungs, pancreas and other organs. CF patients can have a variety of symptoms, including coughing, lung infections, weight loss, wheezing, or shortness of breath.

The team brought in focus groups that included patients and their families, all disciplines involved in CF inpatient care, and pediatric residents. Each group was asked to identify what they thought could be improved and how. The team used this invaluable input and looked at more than 200 variables from the national CF Foundation to narrow their focus to three areas for improvement: communications, therapy, and adherence to medication.

Communications for CF patients can be complex. When patients come to the hospital for treatment they work with multiple caregivers, including residents, therapists, dieticians, social workers, and child life specialists, in addition to physicians and nurses. The regimens and instructions from each require careful coordination, so the team introduced interdisciplinary rounding, afternoon huddles, and schedule boards. Families are given the brochure “What to Expect During Hospital Stay” before they arrive. An enhanced menu for CF patients was created to com

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Mending Hearts One Patient at a Time at MMC

Mended Hearts Volunteer Bob McLean has been recognized as a Healthcare Hero for his work with MMC cardiac patients. Mended Hearts volunteers offer support to cardiac patients. Many of the volunteers have themselves had cardiac issues and they all provide understanding, compassionate care.

Here’s what a patient’s wife wrote about Bob: “One of the things the wonderfully helpful Mended Hearts volunteer Mr. McLean shared was that his wife had an awareness of things related to his hospital experience that he didn’t as a patient. I think this was true of our experience as well. Even with the distance of time and intensity from my husband’s medical situation, we continue to be thankful for the staff and volunteers of Maine Medical Center and their great care and concern.”

Bob visited with 931 patients last year. Thank you for your dedication to our patients, Bob.
Children with CF have to do 2-3 hours of therapy a day, including chest physical therapy, exercise, and up to 12 nebulizer treatments, plus multiple oral medications. They get many blood draws and have central lines placed for prolonged antibiotics. It can be difficult for them to comply with therapy, even in the hospital. To increase adherence to medications and treatment, the team introduced the “Shake Up CF” program. Patients earn stickers and prizes for taking medication and completing therapy. The initiative is so successful that some parents have asked for sticker boards to use at home.

“The surveys for families from the adherence project have shown that families have felt that their children are more adherent and that the teams are communicating better about their child’s care,” Cairns says.

To further improve adherence, Fitbits — wearable exercise tracking devices — are given to all CF patients over the age of 11. In addition, a dedicated respiratory therapist has been assigned to the BBCH.

The CF team plans to maintain these improvements as the standard of care. They also plan to begin improving bone health in kids with CF and will participate in a national collaborative to try to increase the rate of sufficient sweat samples (used to diagnose CF in newborns).