

physical symptoms after infection. These symptoms last from months to years and range from limited to debilitating. The SARS-CoV-2 pandemic has also affected mental health given the prolonged stress and uncertainty. In the United Kingdom, 54% of people with cystic fibrosis (PwCF) reported clinically significant anxiety, which is double the percentage before the pandemic. The mental health repercussions extended to family members, with mothers of children with CF reporting significantly higher anxiety scores than mothers of children without CF. There is a dearth of knowledge regarding the long-term effect of SARS-CoV-2 on the physical and mental health of PwCF and their caregivers in the United States.

**Methods:** A 17-question survey garnered 278 responses between December 16, 2021, and January 6, 2022. Respondents included 187 PwCF and 88 caregivers answering questions regarding the experienced of PwCF. Questions asked about demographic characteristics, experiences of acute SARS-CoV-2 infection and level of care required, mental health symptoms of depression and anxiety (Table 1), and physical symptoms lasting at least 1 month after having SARS-CoV-2.

**Table 1.**  
Mental health symptoms reported since start of COVID-19 pandemic

Symptom	PWCF n=187 (% Responding Affirmatively)	Caregiver n= 96
Feeling down, depressed, or hopeless		
Not at all	27	32
Several days	52	44
More than half of the days	14	14
Nearly every day	7	10
Trouble falling or staying asleep, or sleeping too much		
Not at all	27	34
Several days	43	35
More than half of the days	20	17
Nearly every day	10	14
Feeling tired or having little energy		
Not at all	17	23
Several days	53	44
More than half of the days	19	21
Nearly every day	11	13
Not being able to stop or control worrying		
Not at all	26	24
Several days	45	43
More than half of the days	19	22
Nearly every day	10	11
Eating and drinking as much as you normally would		
Not at all	30	23
Several days	20	23
More than half of the days	17	19
Nearly every day	33	35

Note: Survey question was “Since the start of the pandemic, how often have you been bothered by any of the following problems”? Caregivers were answering for themselves.

**Results:** Forty-five respondents reported having a positive SARS-CoV-2 test or symptomatic COVID since 2020, with more than 80% of those never requiring hospitalization for their acute infection. Of those who had acute infection, almost three-quarters had one or more new physical symptoms that persisted at least 1 month after their acute infection. The most common symptom was “fatigue that made it hard to do things [they] needed or wanted to do,” with 74% of PwCF and 24% of caregivers answering affirmatively for their PwCF. Commonly reported symptoms were “problems with memory” in 35% and “difficulty concentrating” in 26% of PwCF. Reports of muscle aches (19–35%), shortness of breath (10–26%), cough (17–29%), and loss of taste or smell (19–22%) were also described. Since the start of the pandemic, 52% of PwCF and 44% of caregivers have had several days of feeling down, depressed, or hopeless. Between 30% and

50% of PwCF and caregivers endorsed sleep-related symptoms and feeling tired or low energy since the start of the pandemic, and 33% to 36% reported uncontrollable worry the previous 2 weeks. Although mental health support has increased in CF care overall, one-third of respondents reported that they did not have regular access to a mental health provider.

**Conclusions:** We performed this pilot study to characterize mental health and post-COVID symptoms in PwCF and their caregivers in the United States during the SARS-CoV-2 pandemic. Although most of our respondents had mild acute illness, most had lingering physical symptoms 1 month after acute SARS-CoV-2 infection, most commonly significant fatigue. Mental health of PwCF and caregivers was significantly affected, with frequently reported anxiety and depressive symptoms. Many of the reported symptoms are not observable to others and can have significant effects on functioning. Additional studies are essential to facilitate comprehensive understanding of the long-term physical and mental health effects of SARS-CoV-2 in PwCF and their caregivers to inform timely screening and focused interventions.

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**A multi-center study of peripherally inserted central venous catheters: Predictors of difficult line insertion, malfunction, and soft tissue injury**

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**Background:** People with cystic fibrosis (PwCF) may have peripherally inserted central venous catheters (PICCs) placed for administration of intravenous antibiotics. Little has been published about factors associated with problematic line placement, subsequent catheter malfunction, and local soft tissue reactions in this population. We present data from PICC-CF, a prospective study of PICC practice patterns and complications in adult and pediatric PwCF at 10 U.S. centers.

**Methods:** Eligible PwCF were aged 6 and older and undergoing treatment via a hospital-placed PICC. Exclusion criteria included use of a totally implanted vascular access device or peripheral line for the full course of therapy and anticoagulant medication at the time of line insertion. We collected clinical and demographic data before catheter insertion. We made detailed assessments of line insertion, management, and subsequent function, along with patient signs and symptoms related to the indwelling catheter every 2 to 4 days until line removal. We used logistic regression models to evaluate the association between patient and catheter characteristics and line placement, subsequent catheter malfunction, and local soft tissue reactions. Analyses were conducted separately for adult and pediatric patients where appropriate. Analyses of catheter malfunction and local soft tissue reactions were adjusted for length of treatment. Analyses of outcomes in pediatric patients were additionally adjusted for patient age. *P* < 0.01 was considered significant in the context of multiple comparisons.

**Results:** We screened 429 individuals and enrolled 260 (n = 123 female (47%); median age 20 (interquartile range 13, 28); n = 103 children (40%)), totaling 4,705 catheter-days for 375 lines. Three hundred forty-two of the catheters (91%) were single lumen, 334 (89%) were less than 5 Fr, and venue of line placement was bedside in 90 (24%), dedicated vascular access suite

in 76 (20%), and interventional radiology in 209 (56%). Despite a low frequency of blood stream infections (0%) and venous thrombosis (1.6%), less-serious adverse events were noted in 147 cases (39%). In 24 cases (6.4%) line placement was problematic, usually due to difficult guidewire advancement (22/24). We found no significant predictors of difficult line placement. Local soft tissue reactions were noted in 94 (25%), with proportions similar in adults and children, although reactions leading to line removal tended to be more frequent in adults (5.5% vs 1.4%,  $p = 0.05$ ). Predictors of local reactions included larger catheter size (OR 3.85, 95% CI, 1.53–10.44,  $p = 0.006$  for 4 Fr vs 3 Fr; OR 4.53, 95% CI, 1.44–14.72,  $p = 0.01$  for 4.5 Fr vs 3 Fr) in children and multilumen catheter use (OR 3.11, 95% CI, 1.32–7.24,  $p = 0.008$ ) in adults. Catheter malfunction was observed in 59 cases (16%) and resulted in line removal in 10 cases (2.7%), both in similar proportions of adults and children. Predictors of catheter malfunction in adults included history of difficult wire passage (OR 6.09, 95% CI, 2.33–15.7,  $p < 0.001$ ) and venous stenosis or anatomy preventing access on one side (OR 6.91, 95% CI, 2.02–23.8,  $p = 0.002$ ). Adverse events other than venous thrombosis led to early line removal in 11 cases (2.9%).

**Conclusions:** Despite practice variation across sites, instances of venous thrombosis were rare, although we identified several factors predictive of catheter malfunction and soft tissue reactions.

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### Cystic fibrosis in West Virginia: Is higher body mass index target desirable?

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**Background:** Malnutrition in people with cystic fibrosis (PwCF) is associated with worse pulmonary function and greater morbidity and mortality. Nutritional intervention and introduction of modulator therapy has led to increase in overweight (body mass index (BMI) = 25–29.9 kg/m<sup>2</sup>) and obesity (BMI >30 kg/m<sup>2</sup>) in PwCF, although the advantage and impact of higher BMI is understudied. We aim to study the effect of higher BMI in PwCF on clinical outcomes.

**Methods:** We conducted a retrospective cross-sectional study of PwCF aged 18 and older followed at the Mountain State CF Center. Information on demographic variables, BMI, lung function (percentage predicted forced expiratory volume in 1 second (FEV<sub>1</sub>pp)), and number of exacerbations from January 1, 2020, to December 31, 2020, was collected from the CF Registry, as well as number of reported exacerbations from January 1, 2015 to December 31, 2019. Outcomes of underweight/normal (BMI ≤24.9 kg/m<sup>2</sup>) and overweight/obese (BMI >24.9 kg/m<sup>2</sup>) individuals were compared.

**Results:** Of 86 patients included in the study, 36 (41.8%) were overweight or obese. Mean age of the total cohort was 33.3 ± 13.3, and mean BMI was 25.1 ± 6.5 kg/m<sup>2</sup>. FEV<sub>1</sub>pp was higher in the overweight/obese group (78.5 ± 26.7%) than in the underweight/normal group (67.4 ± 25.8%). Sixty (69.8%) patients were on modulator therapy, with half of these on triple modulator therapy; 25 patients (69.4%) in the overweight/obese group and 35 (70%) in the underweight/normal group were on modulator therapy. Pulmonary complications (asthma, allergic bronchopulmonary aspergillosis, bronchiectasis) were similar in both groups (8 (16.0%) vs 8 (22.2%);  $p = 0.5$ ). Hyperlipidemia was more common in the overweight/obese group than in underweight/normal group ( $p = 0.04$ ). Rates of all other comorbidities, including hypertension, diabetes, and cardiovascular events, were similar ( $p > 0.05$ ). CF exacerbations in 2020 were similar in the two groups ( $p > 0.05$ ), whereas there were fewer exacerbations between 2015 and 2019 in the overweight/obese group, although this was not statistically significant.

**Conclusions:** Higher BMI may be associated with fewer CF exacerbations, although it may increase risk of cardiovascular comorbidities. Therefore, the risks and benefits of higher BMI in PwCF should be studied in further detail.

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### Factors contributing to successful retention of people with cystic fibrosis in a 3-month daily symptom-tracking study

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**Background:** Retention of research participants is critical for studies to provide useful results. Failure to meet retention goals can compromise a study's statistical power and the conclusions that can be drawn. Recommendations for optimizing retention include engaging stakeholders, mitigating potential barriers, and minimizing burdens while returning value for participants [1]. We applied these strategies to a study investigating the relationship between cystic fibrosis (CF) symptoms and the menstrual cycle using a smartphone app to record daily symptoms and online monthly surveys.

**Methods:** We developed study aims based on research priorities that people with CF identified as part of the Cystic Fibrosis Reproductive and Sexual Health Collaborative (CFReSHC) [2] and included a patient-partner on our research team. Study participation involved daily tracking of CF and menstrual symptoms and four monthly surveys. To standardize tracking, we customized a period-tracking smartphone app to list all symptoms of interest. Participants had access to their own app data throughout the study. We built our online database to fully automate the sending of email reminders and monthly survey links. We recruited 74 women aged 18 to 45 with CF and regular menstrual cycles from June 1 to October 30, 2021. Participants were able to enroll and start tracking on any day of their menstrual cycle. Before tracking, participants attended a one-on-one, 45-minute video conference orientation. Research staff walked participants through downloading the app, recording symptoms, setting phone reminders for daily tracking, and next steps. Participants received an electronic gift card after each online survey.

**Results:** Of the 74 participants who completed a virtual orientation, 99% ( $n = 73$ ) completed the baseline survey, which was the next step in study participation. Completion rates for the four monthly surveys were 97% ( $n = 72$ ), 95% ( $n = 70$ ), 89% ( $n = 66$ ), and 89% ( $n = 66$ ), respectively. One participant was withdrawn while completing the month 4 survey, so the overall study completion rate was 88% ( $n = 65$ ). Of the nine participants who did not complete the study, six were withdrawn because they failed to complete the online surveys. Three participants were withdrawn because of other study criteria.

**Conclusions:** Several factors contributed to successful retention of research participants in this study. We designed the study based on research priorities that the patient community of interest identified. We minimized barriers to participation by allowing participants to enroll during any phase of their cycle and by selecting mobile technology that required minimal time and effort for tracking. Showing participants how to track in the app mitigated potential technology challenges. Participants could see their symptom data in the app and were compensated every few weeks. Daily reminders and automated survey invitation emails streamlined study efforts for participants and research staff.

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