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Early View

Research letter

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Impact of the SARS-CoV2 pandemic on cystic fibrosis centers and care – Survey results from U.S. centers

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To the editor

The COVID-19 pandemic has affected patients with cystic fibrosis (CF) in multiple ways including fear of becoming infected, the risk of severe disease from SARS-CoV-2, and the need to maintain medical care. As part of an ongoing infection prevention and control (IP&C) study in CF that began in 2019, we assessed how large U.S. CF centers adapted to and perceived effects of the COVID-19 pandemic on care-delivery options. The IP&C parent study included 2-3 centers from each U.S. census region which followed >300 adult&pediatric patients.

Electronic surveys (Qualtrics®) were sent to ten Pediatric and ten Adult CF center directors in ten states. At nine institutions, Pediatric and Adult centers were co-located in the same institution. To capture changes in care practices over time, surveys were sent on June 24th, August 26th, and October 9th, 2020. Survey topics included potential closure of the CF centers, alternative means of providing patient care during clinic closures, timing of and measures taken to resume in-person visits, and effects on staff. In Surveys 2 and 3, we asked directors to estimate the proportion of patients lacking culture or spirometry results since clinic closure (Survey available per request). Descriptive statistics were performed in Excel MS Office 365.

The response rate was 18/20 centers for Survey 1 and the same 19/20 centers for Surveys 2 and 3. Closure of routine in-person care occurred between March 16 and March 31, 2020 at 19 sites and 83% transitioned to video visits within 1-3 weeks. The median time from closure to initiation of telehealth was 7 days (IQR 2-12.5 days) at both Pediatric and Adult centers.

In Survey 1 50% of centers reported obtaining respiratory cultures. In Surveys 2 and 3 61% and 67%, respectively obtained cultures. In Survey 3, 75% of Adult versus 60% of Pediatric centers collected cultures ($p=0.03$, Fisher's Exact test). Often cultures were limited to patients with increased symptoms. At Survey 1, only 30% of centers that collected samples made cultures available to all patients, which increased to 63% and 67% of centers by Surveys 2 and 3. Among the various, overlapping options 40-60% of centers across the Surveys reported that patients or parents collected samples at home and brought these to the hospital/CF center laboratory for processing. About 20% of centers had specimens brought to a non-hospital laboratory. Four centers (Pediatric and Adult in two states) offered the mailing of home-collected specimens to the CF center laboratory. Most sites (83%) created instructions for patients/parents for obtaining specimens; two Pediatric centers included instructions for obtaining throat swabs. Challenges reported with remote culture collection included

unwillingness of patients to travel to the center to drop off specimens or difficulties mailing specimens.

Spirometry was increasingly available as 44%, 72% and 100% of centers reported the ability to perform spirometry in Surveys 1, 2, and 3, respectively. Three of the centers limited spirometry to patients with increased symptoms (1 center) or those with negative SARS-CoV-2 test (2 centers). Options included conducting spirometry in the CF clinic, in an off-site clinic, and/or at home. In Survey 1, patients at five Adult and three Pediatric centers had home spirometers available from prior studies. By Survey 3, all centers offered home spirometry. Reported challenges with home spirometry included variable uptake by patients, transmission of results due to extra costs for the software specific to the brand of spirometer, and, especially for children, concerns about reliability of results due to lack of coaching during the maneuvers. Changes to spirometry in clinic included portable spirometers in the exam room and spirometry in the pulmonary-function lab with newly installed HEPA filters. Two sites had pre-existing negative pressure in their pulmonary-function labs. Healthcare personnel at all centers wore gloves, gown, eye protection and mask (8 sites only N95-respirator, 8 sites only surgical masks, 3 sites either) while performing spirometry.

Most sites reopened in May and June 2020 (range April 15 to September 14, 2020). By Survey 3, 84% (16/19 centers) had reopened for in-person visits. In open ended questions several sites reported special IP&C requirements, e.g., no waiting room and closing exam rooms for an hour between patients. We inquired about estimated proportion of patients lacking in-person visits, spirometry, and/or cultures. This proportion decreased between Survey 2 and 3, but two adult centers estimated no changes over time. **Figure 1** shows Survey 3 responses.

Lay-offs occurred at two (11%) centers, furloughs occurred over time in 16-32% of centers, but hiring freezes were reported by 74%, 63% and 53% of centers in Surveys 1, 2, and 3, respectively. Open comments from the sites mentioned that CF team members (Respiratory Therapists, Dieticians, Social-workers) were temporarily reassigned to other hospital areas and/or conducted visits remotely from home. The CF center space was reassigned temporarily at one center.

Our surveys of geographically dispersed U.S. CF centers showed nearly simultaneous closure to routine clinical care, but variable re-opening dates. Presumably, the rapid start of the pandemic stimulated consensus across the country, while regional factors influenced decisions to re-open for routine care. Of note, a limitation is generalizability as the study included only large CF centers and smaller centers may have had different experiences. The majority of centers retained all their staff and transitioned rapidly to telehealth. Thus, patients were able to maintain urgently needed multidisciplinary care. However, performing CF-specific monitoring (spirometry and culture) was more challenging with a gap between availability and reported performance. Ability to obtain spirometry was enhanced by availability of commercial systems and provision of home spirometers by the CF Foundation. Yet the proportion of patients actually performing spirometry was affected by extra-pandemic related factors and could not be reliably measured. Training and education for home-spirometry had to be done remotely, no comparative values to clinic spirometry were available, and the costs for additional software was not supported by all CF centers leading to delays in data transmission. As noted in prior studies, uptake of the home monitoring varied between patients[1].

Obtaining cultures proved more problematic than obtaining spirometry; several centers still reported lack of cultures seven months into the pandemic (**Fig. 1**). The lack of cultures is especially concerning in patients without chronic infections who benefit from early detection and treatment of *Pseudomonas aeruginosa*[2]. Potentially, even collected specimens were suboptimal due to delays in shipping of specimens, processing of CF respiratory cultures requires special expertise, and family members may be uncomfortable obtaining throat swabs. Furthermore, the pandemic began four months after approval and wide-spread prescription of highly effective triple-CFTR modulators, which likely reduced the number of patients able to produce sputum which further reduced culture rates among teenagers and adults. In contrast, fewer healthcare encounters and enhanced attention to IP&C during the pandemic might decrease the number of new infections. The effect of reduced microbiological monitoring and potentially lower transmission/acquisition risks may become evident in the 2021 CF Foundation Patient Registry data.

In conclusion, we found rapid uptake of video/telehealth yet the centers we surveyed here reported challenges with uptake and quality of home spirometry in contrast to prior studies[3, 4]. These centers also reported more challenges with microbiologic monitoring via telehealth compared to spirometry (open comments and **Fig. 1**). Based on the comments that several

centers only obtained cultures from expectorating patients we speculate that microbiology assessment may become more difficult with decreasing numbers of patients who can expectorate. Our findings also highlight the need to develop or enhance methods for collecting respiratory cultures at home, for example during airway clearance, and to use clinic visits for home spirometry teaching. Reassuringly, the team structure for CF care remained functional and most patients with CF cared for at our study sites were able to access CF-specific care.

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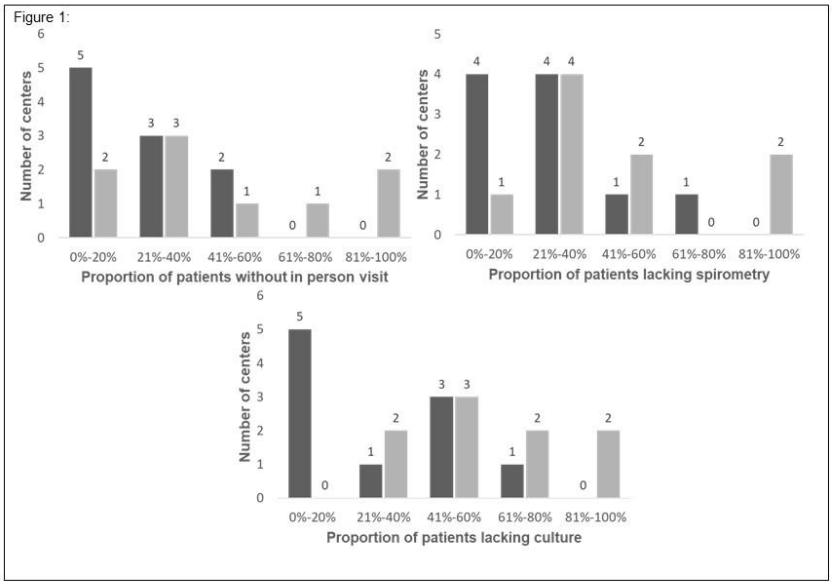
Legend Figure 1:



Each panel shows number of centers who estimated the given proportion of patients still lacking A) In person visit B) Spirometry C) respiratory culture at time of Survey 3. The 5 categories of proportions were predefined in the survey. Dark bars are Pediatric (total 10 centers); light bars Adult CF centers (total 9 centers).