Impact of the SARS-CoV-2 pandemic on cystic fibrosis centres and care: survey results from US centres

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To the Editor:

The COVID-19 pandemic has affected patients with cystic fibrosis 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 cystic fibrosis that began in 2019, we assessed how large US cystic fibrosis centres adapted to and perceived effects of the COVID-19 pandemic on care delivery options. The IP&C parent study included two or three centres from each US census region, which followed >300 adult and paediatric patients.

Electronic surveys (Qualtrics) were sent to 10 paediatric and 10 adult cystic fibrosis directors in 10 states. At nine institutions, paediatric and adult centres were colocated in the same institution. To capture changes in care practices over time, surveys were sent on 24 June, 26 August and 9 October 2020. Survey topics included potential closure of the cystic fibrosis centres, 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 Microsoft Excel (Office 365).

The response rate was 18 out of 20 centres for survey 1, and the same 19 out of 20 centres for surveys 2 and 3. Closure of routine in-person care occurred between 16 and 31 March, 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 (interquartile range 2–12.5 days) at both paediatric and adult centres.

In survey 1, 50% of centres reported obtaining respiratory cultures. In surveys 2 and 3, 61% and 67%, respectively, obtained cultures. In survey 3, 75% of adult *versus* 60% of paediatric centres collected cultures (p=0.03, Fisher's Exact test). Often, cultures were limited to patients with increased symptoms. At survey 1, only 30% of centres that collected samples made cultures available to all patients, which increased to 63% and 67% of centres by surveys 2 and 3. Among the various, overlapping options, 40–60% of centres across the surveys reported that patients or parents collected samples at home and brought these to the hospital or cystic fibrosis centre laboratory for processing. ~20% of centres had specimens brought to a nonhospital laboratory. Four centres (paediatric and adult in two states) offered the mailing of home-collected specimens to the cystic fibrosis centre laboratory. Most sites (83%) created instructions for patients and parents for obtaining specimens; two paediatric centres included instructions for obtaining throat swabs. Challenges reported with remote culture collection included unwillingness of patients to travel to the centre to drop off specimens or difficulties mailing specimens.

Spirometry was increasingly available, as 44%, 72% and 100% of centres reported the ability to perform spirometry in surveys 1, 2 and 3, respectively. Three of the centres limited spirometry to patients with increased symptoms (one centre) or those with negative SARS-CoV-2 tests (two centres). Options included conducting spirometry in the cystic fibrosis clinic, in an off-site clinic and/or at home. In survey 1, patients at five adult and three paediatric centres had home spirometers available from prior studies. By survey 3, all centres 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,

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and, especially for children, concerns about reliability of results due to lack of coaching during the manoeuvres. Changes to spirometry in clinic included portable spirometers in the examination room and spirometry in the pulmonary function laboratory with newly installed high-efficiency particulate-absorbing filters. Two sites had pre-existing negative pressure in their pulmonary function laboratories. Healthcare personnel at all centres wore gloves, gowns, eye protection and masks (eight sites, only N95 respirators; eight sites, only surgical masks; three sites, either) while performing spirometry.

Most sites reopened in May and June 2020 (range 15 April to 14 September, 2020). By survey 3, 84% (16 out of 19 centres) had reopened for in-person visits. In open-ended questions, several sites reported special IP&C requirements (*e.g.* no waiting room and closing examination 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 surveys 2 and 3, but two adult centres estimated no changes over time. Figure 1 shows survey 3 responses.

Lay-offs occurred at two (11%) centres and furloughs occurred over time in 16–32% of centres, but hiring freezes were reported by 74%, 63% and 53% of centres in surveys 1, 2 and 3, respectively. Open comments from the sites mentioned that cystic fibrosis team members (respiratory therapists, dieticians and social workers) were temporarily reassigned to other hospital areas and/or conducted visits remotely from home. The cystic fibrosis centre space was reassigned temporarily at one centre.

Our surveys of geographically dispersed US cystic fibrosis centres showed nearly simultaneous closure to routine clinical care but variable reopening dates. Presumably, the rapid start of the pandemic stimulated consensus across the country, while regional factors influenced decisions to reopen for routine care. Of note, a limitation is generalisability, as the study included only large cystic fibrosis centres and smaller centres may have had different experiences. The majority of centres retained all their staff and transitioned rapidly to telehealth. Thus, patients were able to maintain urgently needed multidisciplinary care. However, performing cystic fibrosis-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 Cystic Fibrosis Foundation. Yet, the proportion of patients actually performing spirometry was affected by extrapandemic related factors and could not be reliably measured. Training and education for home spirometry had to be performed remotely, no comparative values to clinic spirometry were available and the costs of additional software was not supported by all cystic fibrosis centres, 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 centres still reported lack of cultures 7 months into the pandemic (figure 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, and because processing of cystic fibrosis respiratory cultures requires special expertise and family members may be uncomfortable obtaining throat swabs. Furthermore, the pandemic began 4 months after approval and widespread prescription of highly effective triple cystic fibrosis transmembrane conductance regulator modulators, which probably reduced the number of patients able to produce sputum, further reducing 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

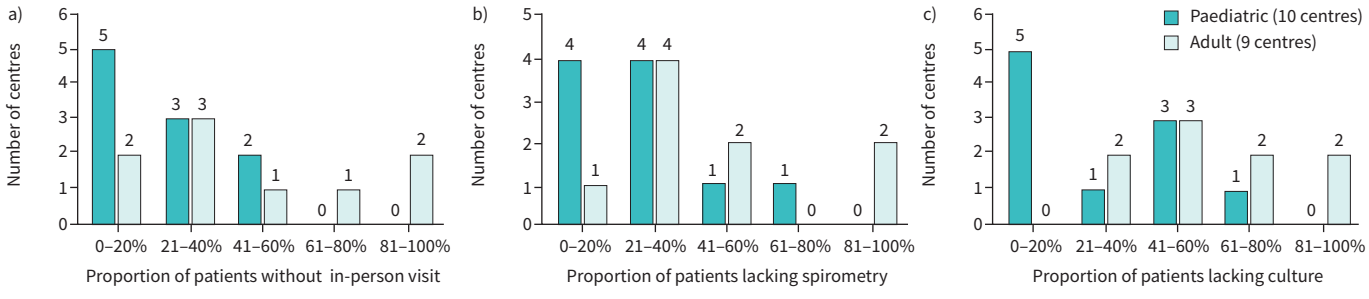

FIGURE 1 Each panel shows the number of centres who estimated the given proportion of patients still lacking a) in-person visits, b) spirometry and c) respiratory culture at the time of survey 3. The five categories of proportions were predefined in the survey.

microbiological monitoring and potentially lower transmission/acquisition risks may become evident in the 2021 Cystic Fibrosis Foundation Patient Registry data.

In conclusion, we found rapid uptake of video/telehealth, yet the centres we surveyed here reported challenges with uptake and quality of home spirometry, in contrast to prior studies [3, 4]. These centres also reported more challenges with microbiological monitoring *via* telehealth compared to spirometry (open comments and figure 1). Based on the comments that several centres 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 cystic fibrosis care remained functional and most patients with cystic fibrosis cared for at our study sites were able to access cystic fibrosis-specific care.

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