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## Financial impacts of the COVID-19 pandemic on cystic fibrosis care: lessons for the future<sup>☆</sup>



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### ABSTRACT

**Background:** Chronic care delivery models faced unprecedented financial pressures, with a reduction of in-person visits and adoption of telehealth during the COVID-19 pandemic. We sought to understand the reported financial impact of pandemic-related changes to the cystic fibrosis (CF) care model.

**Methods:** The U.S. CF Foundation State of Care surveys fielded in Summer 2020 (SoC1) and Spring 2021 (SoC2) included questions for CF programs on the impact of pandemic-related restrictions on overall finances, staffing, licensure, and reimbursement of telehealth services. Descriptive analyses were conducted based on program type.

**Results:** Among the 286 respondents (128 pediatric, 118 adult, 40 affiliate), the majority (62%) reported a detrimental financial impact to their CF care program in SoC1, though fewer (42%) reported detrimental impacts in SoC2. The most common reported impacts in SoC1 were redeployment of clinical staff (68%), furloughs (52%), hiring freezes (51%), decreases in salaries (34%), or layoffs (10%). Reports of lower reimbursement for telehealth increased from 30% to 40% from SoC1 to SoC2. Projecting towards the future, only a minority (17%) of program directors in SoC2 felt that financial support would remain below pre-pandemic levels.

**Conclusions:** The COVID-19 pandemic resulted in financial strain on the CF care model, including challenges with reimbursement for telehealth services and reductions in staffing due to institutional changes. Planning for the future of CF care model needs to address these short-term impacts, particularly to ensure a lack of interruption in high-quality multi-disciplinary care.

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## 1. Introduction

Over the past several decades, the approach of center-based cystic fibrosis (CF) clinical care has become well-established throughout the world [1]. In the United States, the CF Foundation (CFF) supports a model of CF center accreditation with periodic reviews of centers to aid local institutions in supporting guideline-driven multi-disciplinary approaches to CF care [2,3]. In general, CF

care models include a varied group of clinical providers, including physicians (pulmonary and other subspecialties), advanced practice providers, nurses, dietitians, social workers, physical and respiratory therapists, pharmacists, and psychologists. With the rapid growth of the adult CF population, more adult-focused CF centers have also been developed, often at institutions that previously did not support a CF care program. Given the complex care needs of the CF population, the vast majority of accredited CF centers are housed within academic medical centers. The organization of CF care has enabled innovation in care delivery, quality improvement, and research contributing to improvements in population health outcomes. Reports of patient experience with this multi-disciplinary care model have been positive [4].

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In general, providing population-level chronic CF health care results in high rates of health care utilization and annual costs, with the largest cost drivers being hospitalization and pharmacy expenditures [5,6]. In the US, the vast majority of people with CF have either private or government-funded health insurance, and payment for CF care is supported by health insurance through fee-for-service or negotiated contracts between providers and payors [7]. For individual institutions, financing a multi-disciplinary CF care team can be a challenge, requiring multiple funding sources including reimbursements from health insurance companies as well as structural and financial support for non-reimbursable services such as social work.

The COVID-19 pandemic presented an unprecedented challenge to the existing CF center-based care model. At the onset of the pandemic, health systems were forced to pivot clinical operations to focus on COVID surges, leading to cancellation or delay of elective services as well as re-deployment of clinical staff. As lockdowns spread, in-person healthcare delivery rapidly shifted to telehealth. Throughout the US, the majority of routine CF care visits, particularly in the early months of the pandemic, were conducted virtually [8]. Ancillary clinical staff, including many core members of multi-disciplinary CF teams, were asked to conduct work remotely. This rapid shift in care delivery uncovered potential challenges with respect to licensure and reimbursement for services, particularly for clinicians that previously had not supported a telehealth model of care [9,10].

As part of the CFF sponsored State of Care (SoC) surveys during the COVID-19 pandemic, an evaluation of the financial impact of the pandemic on CF care was conducted. This paper reports on data from CF care centers on the impact of the pandemic on financial aspects of CF care delivery.

## 2. Methods

The CFF distributed two online surveys to all care centers within its accredited care network. The surveys were designed to assess the state of CF care delivery at two timepoints during the COVID-19 pandemic. The initial survey (SoC1) was distributed between July 29 to September 18, 2020, and a second, modified version (SoC2) was released between April 19 to May 19, 2021. Survey distribution methods and respondent characteristics are reported separately [8].

Each survey included specific questions on the perceived financial impact of the pandemic (Supplemental Tables S1–S4). In SoC1, program directors were first asked: “Have members of your program been impacted by actions that your institution/hospital has taken? (yes/no)”. Those that responded “yes” received a follow-up question asking: “Do you believe your CF program is delivering the same level of quality care despite actions that your institution/hospital took to respond to COVID-19? (yes/no)”. Other general questions asked whether the existing structure of the CF care team was financially affected during the pandemic for reasons including layoffs or staff redeployment and about whether the level of financial support from the institution was expected to change in the future. Additional questions were focused on staff licensure and reimbursement for services, with a particular focus on reimbursement of telehealth services.

Descriptive statistics were analyzed using SPSS (Version 26), and program size (small (0–70 patients), medium (71–140 patients), and large (>140 patients)) and type (adult, pediatric, affiliate) were used to compare responses based on center characteristics. Differences in the proportions of cohorts with a specific categorical response were compared using Chi-square ( $\chi^2$ ) tests and differences in continuous variables were compared using Anova or Kruskal-Wallis h tests. Comparisons between survey time points were conducted using McNemar and McNemar-

Bowker tests for categorical data and Kruskal-Wallis h tests for continuous variables. Human-subjects approval was granted by a central institutional review board (Advarra) after review of protocol Pro00045302 (Marshall, P.I.).

## 3. Results

### 3.1. Overall financial impact on CF care programs in the US due to COVID-19 pandemic

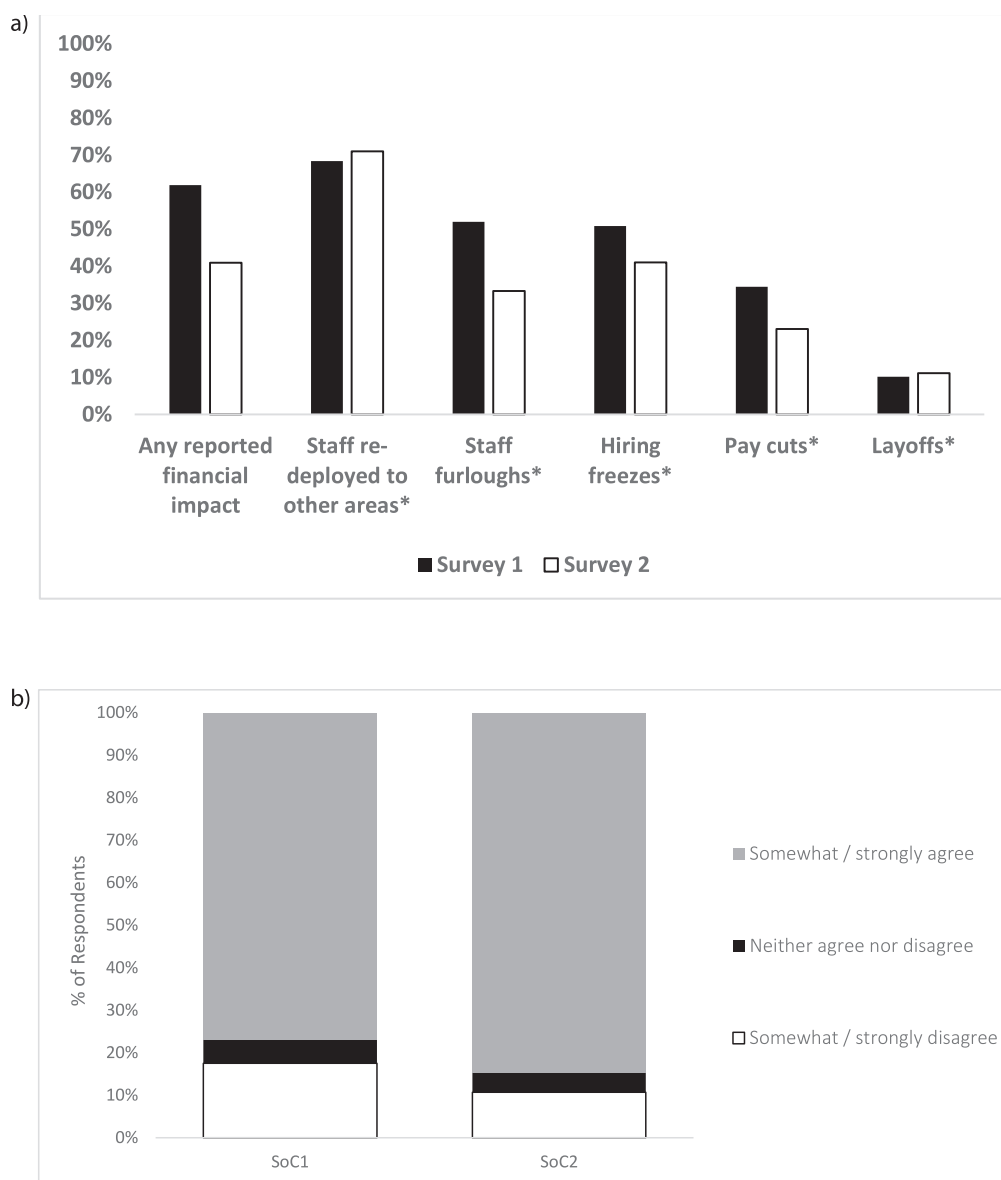
Among the 286 program directors who responded to SoC1 (128 pediatric; 118 adult; 40 affiliate), 177 (62%) reported that the pandemic had led to detrimental financial actions taken by their institution or hospital (Fig. 1a). There were no differences among those who reported any financial impacts compared to those that did not (n=109) based on program type, size, or geographic location. Among the respondents reporting a detrimental financial action, the most common impacts were redeployment of clinical staff to other areas within the institution (68%, n=121), furloughs (52%, n=92), hiring freezes (51%, n=90), decreases in salaries (34%, n=61), and layoffs (10%, n=18). In general, there were few observed differences in responses based on program type or size (Supplemental Table S1). However, directors at larger programs were more likely to report both hiring freezes and pay cuts, and affiliate program directors were more likely to report layoffs and furloughs. Seventy-two percent of program directors that reported detrimental financial actions still felt that their program was delivering the same quality of care despite institutional changes. Directors of large programs were less likely to report that their care quality was at the same level as a result of institutional financial actions (58.3% vs. 82.5% (medium size) vs. 71.2% (small size), p=0.019).

In SoC2, significantly fewer program directors (41.8%, n=117, p<.001 comparing to responses in SoC1 (n=177 (62%)) reported that members of their program were impacted by institutional-level actions (Fig. 1a). Interestingly, a higher percentage of these program directors (80.3%, n=94) reported that their program care quality was at the same level despite institutional changes, with directors at larger programs still less likely to report that their program was delivering the same quality of care (58.1% vs. 87.8% (medium size) vs. 88.9% (small size), p<0.001).

In anticipating future financial strains on their program, a majority (77%, n=220) of program directors in SoC1 felt that future financial support from their institution would continue at pre-pandemic levels (Fig. 1b). There was no difference in anticipated level of future financial support by program size or type (Supplemental Table 1). In SoC2, a larger percentage (84.6%, n=237) agreed that future financial support would continue at the pre-pandemic level.

### 3.2. Licensure

Seventy percent of care program directors (n=199) reported that their program provides care for patients located in a state other than where the program is located (Supplemental Table S2). Within these programs, a median of 6% of patients were out-of-state, with an inter-quartile range of 3–15%. The majority of programs (57%, n=114) did not report obtaining any out-of-state licenses for any of their clinical staff to deliver telehealth services for patients residing in any other state. One-fifth (21%; n=43) of programs had obtained out-of-state licenses for some states, 7% (n=14) had obtained licenses for all states in which their out-of-state patients live, and 14% (n=28) did not know whether they had obtained out-of-state licenses to deliver telehealth services. Among the 56 programs reporting that members of their clinical team obtained out-of-state licensures to deliver telehealth services to patients, the majority received out-of-state licensures for physicians,



**Fig. 1.** a: Financial Impact on CF Program Based on Institutional Action During the COVID-19 Pandemic b: Anticipation that CF Program financial support will continue at the pre-pandemic level \*Among those reporting any financial impact.

with a smaller proportion obtaining out-of-state licensures for clinicians from other disciplines.

SoC1 assessed whether cross-state licensure issues resulted in challenges for patients accessing telehealth care. Among the 184 programs reporting licensing waivers in some or all states, 80% (n=147) reported no limitations to patient access, while 20% (n=37) indicated that some out-of-state patients were not able to access telehealth services due to issues related to licensure of their clinical team members. Among the programs that indicated limitations in telehealth access, three-fifths suggested that 10% or fewer of their out-of-state patients could not access services (62%, 26/37), while nearly one-fifth suggested that 90-100% of their out-of-state patients couldn't access telehealth services (19% (n=7/37)). Larger programs were more likely to report limitations in access to telehealth for out-of-state patients (p<.001). There were no differences by program type.

### 3.3. Reimbursement of telehealth services

In SoC1, 86 (30%) program directors reported lower reimbursement of telehealth services (Table 1). Sites reporting lower re-

**Table 1**  
Reported differences with telehealth reimbursement.

	SoC1 (n=283)*	SoC2 (n=274)*
<b>How does reimbursement for telehealth services compare to equivalent in-person services (e.g., routine visit with physician)?</b>	N (%)	N (%)
Somewhat more	1 (0.4)	1 (0.4)
About the same	141 (49.8)	123 (44.9)
Somewhat less	54 (19.1)	87 (31.8)
Much less	32 (11.1)	28 (10.2)
Unable to answer	55 (19.2)	35 (12.8)

\* Analyses limited to programs currently providing telehealth services

imbursement rates estimated that telehealth services were reimbursed a median of 25% (Inter-quartile range: 18%-46%) lower than in person services (average: 33% ± 21%). Reported reimbursement differences between telehealth and in-person visits did not differ based on center-level characteristics, such as center size or program type. Among those programs reporting some telehealth

**Table 2**  
Availability to provide telehealth services (SoC2: Spring 2021).

	Yes, provides and reimbursed (n, %)	Yes, provides but not reimbursed (n, %)	No, neither provides nor reimbursed (n, %)	Unable to answer (n, %)
Physician (MD)	268 (97.8)	1 (0.4)	1 (0.4)	4 (1.5)
Registered nurse (RN)	40 (14.6)	137 (50.0)	70 (25.5)	27 (9.9)
Registered dietitian (RD)	95 (34.7)	132 (48.2)	21 (7.7)	26 (9.5)
Social work (SW)	38 (13.9)	170 (62.0)	37 (13.5)	29 (10.6)
Respiratory therapist (RT)	57 (20.8)	127 (46.4)	59 (21.5)	31 (11.3)
Pharmacist	17 (6.2)	101 (36.9)	85 (31.0)	71 (25.9)
Mental health coordinator	85 (31.0)	89 (32.5)	55 (20.1)	45 (16.4)

reimbursement limitations (n=145), availability of reimbursement varied based on discipline, with highest availability reported for physicians (98%) and dietitians (72%) (Supplemental Table S3). Telehealth services were reported as non-reimbursable for approximately one quarter of programs with respect to nursing (28%), respiratory therapy (28%), and social work (25%).

In SoC1, over one quarter reported that lower reimbursement led to their program not being able to see some patients (27%, n=23) or resulted in clinicians spending less time with patients (26%, n=22) (Supplemental Table S4). One-sixth had furloughed staff due to lower reimbursement rates (16%, n=14). Other reported impacts of lower telehealth reimbursement included compensation reduction (n=5) and financial loss to the organization, including billing at a lower level (n=5); increasing the volume of visits required for the care team (n=3); or reducing the number of clinical hours (n=2).

In SoC2, nearly all program directors (97.8%) reported that physicians provided and were reimbursed for telehealth services (Table 2). Other members of the multi-disciplinary care team were reported to be providing telehealth services, but with a much lower percentage of those services eligible for reimbursement (Table 2). Additionally, in SoC2 a higher number of program directors (n=115, 42.0%, p=0.05 compared to SoC1) reported that reimbursement for telehealth services was lower than for in-person services (Table 1), with no differences based on program characteristics.

At the time of SoC1, only 5% of programs (n=14) reported receiving any reimbursement for remote monitoring services. Six of these programs reported being able to receive reimbursement for device set up, nine for patient education, and eight for physician services related to remote monitoring. In SoC2, 10.7% (n=30) reported receiving any reimbursement for remote monitoring services. Of these, most (n=25) were able to receive reimbursement for physician activities related to remote monitoring, and a small number (n=5) were able to receive reimbursement for respiratory therapist activities.

#### 4. Discussion

The COVID-19 pandemic resulted in rapid shifts in health care delivery impacting CF care programs throughout the U.S. In these nationwide surveys of CF care program directors administered at two distinct timepoints during the pandemic, the majority reported some degree of financial impact on their program's ability to deliver CF care. These impacts included changes in staffing in multi-disciplinary care teams, differential availability of clinical care teams to provide telehealth, and challenges with licensure and reimbursement for telehealth services. Importantly, despite these challenges and financial risks, many program directors felt increasing confidence that services to their CF programs would be maintained in a post-pandemic era.

For decades, CF care centers have evolved to include numerous clinicians from multi-disciplinary backgrounds. In the U.S., CFF care guidelines and accreditation standards have increased access to

highly specialized clinical teams. In many ways, the CF care model is unique in its approach given the overall small patient population. Financial support comes through combinations of institutional / hospital-based sources as well as overall reimbursement from insurance companies for clinical services. As such, it was not surprising that our surveys identified potential adverse financial ramifications due to disruptions in routine health care delivery during the COVID-19 pandemic. With these disruptions, particularly for smaller programs, return of staff that may have been lost or re-deployed could serve as a challenge, and in fact, two affiliate CF care programs were closed as a result of the pandemic (CFF, personal communication). Fortunately, our survey data suggests that most of the program directors in the US are hopeful that financial impacts will be minimized moving into the future.

Among the many changes in health care delivery that resulted from widespread societal changes during the COVID-19 pandemic, the rapid shift to telehealth may have the longest lasting impacts. In CF care, clinicians and people with CF have reported overall positive experiences with telehealth during the pandemic [11,12], with a clear interest amongst both groups for continuing telehealth services into the future. The expansion of telehealth in 2020 also came soon after the more widespread introduction of CFTR modulator therapies in the US in late 2019. This resulted in a rapid decrease in the number of hospitalizations reported in the US CFF Patient Registry, a decline that preceded the onset of the COVID-19 pandemic [13]. As inpatient care is one of the largest cost drivers in CF care [5], a reduction in hospitalizations at the population level also could lead to financial changes for an institution to support a CF care program. Simultaneously, an improvement in health outcomes resulting from modulator therapy could result in changes to the ambulatory care models as well, wherein individuals and clinicians may not find quarterly, routine visits to be as necessary. Taken together, it is clear that the CF care model needs to transform, and telehealth is now clearly positioned to remain an important part of chronic CF care. In such a model, efforts to sustain the multi-disciplinary approach to CF care remain critical.

In our surveys, reimbursement for telehealth was perceived as somewhat lower, particularly in the second survey fielded later in the pandemic. By that time, most programs had experiences with a telehealth model, so the report that reimbursement is lower for telehealth services poses a potential challenge for the future. Reasons for lower reimbursement for telehealth are multifactorial, including differences in payor policies for telephone or video visits, state regulations around telehealth reimbursement, lack of testing such as routine spirometry or cultures, and overall loss of hospital-based facility fees which may not be accounted for in telehealth care provision. These issues are not unique to the CF care model, as health care systems throughout the world are now grappling with implications of telehealth in terms of licensure, regulatory concerns, and payment [14–16]. There is a real opportunity for innovation in the CF care model to incorporate telehealth and home monitoring in a meaningful value-based approach. Attention to funding models and reimbursement for telehealth, particularly across state



lines, will be essential to ensure that telehealth-based innovation would be financially viable and sustainable.

As with any survey, our study has limitations. Most importantly, the data are based on self-reported perceptions of program directors. Actual data on reimbursement and financial support of CF programs would be obtainable from other sources not included in our surveys. It is possible that respondents would over-estimate or perhaps under-estimate some of the potential financial impact of the pandemic on their programs. Additionally, institutional, regional, and national policies on health care delivery and payment changed frequently during the pandemic, and thus re-assessing the overall impact on care program finances will be essential in the future.

## 5. Conclusion

The 2020–2021 CFF State of Care (SoC) surveys identified several areas of potential financial impact on the CF care delivery model in the U.S. In general, despite potential challenges of financial strains and limited reimbursement to the multidisciplinary care team, U.S. CF program directors identified resiliency in the CF care model. The experiences of care programs during the COVID-19 pandemic, particularly around sustained implementation of telehealth and reimbursement of such services, will shape ongoing changes in the CF care model. Reimbursement and financial considerations, coupled with a commitment to team-based multi-disciplinary care, will need to be addressed in order to maximize value, quality, and outcomes for individuals with CF well into the future.

## Declaration of Competing Interest

None

## Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:[10.1016/j.jcf.2021.09.008](https://doi.org/10.1016/j.jcf.2021.09.008).

## CRedit author statement

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draft, Writing review & editing. **Olivia Dieni:** Conceptualization, Writing review & editing. **Kathryn A. Sabadosa:** Conceptualization, Funding acquisition, Project administration, Supervision, Writing review & editing. **Anne Willis:** Conceptualization, Writing review & editing. **Debbie Benitez:** Conceptualization, Writing review & editing. **Thida Ong:** Conceptualization, Writing review & editing. **Elliott C. Dasenbrook:** Conceptualization, Investigation, Writing review & editing.

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