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Evaluating barriers to and promoters of telehealth during the COVID-19 pandemic at U.S. cystic fibrosis programs[☆]

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ABSTRACT

Background: Cystic fibrosis (CF) care programs in the United States rapidly adopted telehealth during the COVID-19 pandemic. Understanding factors that promote or impede telehealth will inform planning for future telehealth-enabled care models.

Methods: Adult, pediatric, and affiliate CF care programs in the United States (n = 287) were surveyed twice eight months apart in 2020–2021 about telehealth use. Programs were asked to describe barriers to and promoters of telehealth.

Results: Ninety-seven percent of programs provided telehealth services. In the first CF Care Program State of Care Survey (SoC1), programs estimated that 57% of patients exclusively received in-person care, 36% of patients received telehealth by phone/computer with video, and 8% of patients received telephone-only care. In the second CF Care Program State of Care Survey (SoC2), programs estimated that 80% of visits were in-person and 15% were via audio and video telehealth. Pediatric programs (21%) were less likely than adult (37%) or affiliate (41%) programs to recommend telehealth (p = 0.007). All programs ranked lack of internet access as the highest barrier to patient engagement with telehealth. Promoters of telehealth were increased accessibility and avoidance of infection transmission. Top ranked changes to improve telehealth were expanded provision of remote monitoring devices and technology access. Similar proportions of program types anticipated institutional telehealth expansion.

Conclusion: During the COVID-19 pandemic, CF programs in the United States identified factors to improve future care delivery via telehealth. Targeting specific barriers and promoters will improve the use and quality of telehealth throughout the care center network.

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1. Introduction

For decades, the CF care model has emphasized interdisciplinary collaboration among physicians, nurses, dietitians, social workers, respiratory therapists, pharmacists, and others, to address the complex health problems affecting people with cystic fibrosis (PwCF). The model has improved longevity [1] by establishing accreditation standards, emphasizing the value of continuous quality

improvement activities and partnerships among clinicians, PwCF, and their families, and implementing a peer benchmarking process [2,3]. Programs that follow practice guidelines achieve superior health outcomes [4,5]. A comprehensive survey of PwCF and their families found that most of these stakeholders had favorable opinions about the care model [6].

The COVID-19 pandemic abruptly and pervasively disrupted activities associated with the traditional CF care model, forcing programs to pivot to telehealth. Telehealth refers to the use of electronic and telecommunications technology to share health information and services [7]. Medical and surgical disciplines have used telehealth to manage acute problems like stroke [8] and heart attack [9], as well as chronic digestive [10], rheumatologic [11], and psychiatric [12] diseases. Before the COVID-19 pandemic, the CF

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Table 1

Types of visits held by CF programs that responded to the CFF SoC Surveys and reported that they provided telehealth services. Data displayed as median and (interquartile range). ^a Program type vs. type of visit (SoC1); ^b Program type vs. type of visit (SoC2); ^c SoC1 total vs. SoC2 total.

Survey Iteration (Number of Programs)	Total		Adult		Pediatric		Affiliate		P-value
	1(n = 278)	2(n = 271)	1(n = 117)	2(n = 113)	1(n = 123)	2(n = 122)	1(n = 38)	2(n = 36)	
Type of Visit									
In-Person Only (%)	57 (25-86)	80 (65-95)	48 (15-75)	75 (59-90)	75 (40-90)	90 (70-98)	65 (33-91)	88 (64-100)	<0.001 ^a <0.001 ^b <0.001 ^c
Telephone Only Telehealth (%)	0 (0-10)	0 (0-1)	5 (0-10)	0 (0-5)	0 (0-5)	0 (0-0)	0 (0-16)	0 (0-2)	<0.001 ^a <0.001 ^b <0.001 ^c
Audio + Video Telehealth (%)	30 (10-60)	15 (5-30)	45 (20-74)	20 (10-38)	20 (9-50)	10 (2-25)	20 (0-49)	10 (0-20)	<0.001 ^a <0.001 ^b <0.001 ^c

community had begun to use telehealth, but its role within the care model was not fully established. Nearly all CF care programs adopted telehealth shortly after the onset of the pandemic. Although several early adopters reported local experiences with telehealth use during the pandemic [13–16], perspectives from the entire United States CF care program network about barriers to and promoters of telehealth have not been presented.

Telehealth requires providers and patients to have high-speed internet and a common program through which to communicate. These elements could be viewed as barriers to or promoters of telehealth if absent or present, respectively. Telehealth also introduces unique technological and logistical challenges to engaging multidisciplinary care team members during visits. Data necessary for medical decision-making, such as findings from physical examination, cannot be ascertained by telehealth. Although insurance companies facilitated telehealth services by fully reimbursing healthcare institutions during the pandemic, those practices are subject to revisions that would tend to support or undermine telehealth. Recognizing a timely need to understand how CF programs cared for PwCF during the COVID-19 pandemic, the Cystic Fibrosis Foundation (CFF) commissioned two State of Care (SoC) surveys. Here, we report the manner in which adult, pediatric, and affiliate programs used telehealth during the pandemic and discuss factors that programs perceived as barriers or promoters of telehealth.

2. Methods

The SoC surveys were deployed to CF care programs between July 29 and September 18, 2020 (hereafter, SoC1), and again between April 19 and May 19, 2021 (hereafter, SoC2). Survey design and distribution methods are discussed elsewhere in this supplement [17]. Adult programs cared for PwCF ≥ 18 years of age, and pediatric programs primarily cared for PwCF < 18 years of age. Affiliate programs typically followed fewer total patients than adult or pediatric programs and cared for both pediatric and adult patients.

Programs were asked to rank eight potential barriers to telehealth access by their patients and families on a 1 (most significant) to 8 (least significant) scale. These potential barriers were specified as choices in the survey. Top-three ranked barriers were analyzed by program type (adult, pediatric, or affiliate) to elucidate common or disparate issues among programs. Promoters of telehealth were determined by asking programs to respond to open-ended questions about what changes might improve their rating of telehealth. Programs were asked to rate how likely they were to recommend telehealth on a scale of 0 to 10 with higher numbers corresponding to higher likelihood of recommending it. Programs with scores of 9–10 on this question were considered net promoters of telehealth.

Non-parametric analyses were applied after checking data for normality. Comparisons of proportions between SoC1 and SoC2 were conducted using Wilcoxon Signed Rank tests for continuous variables and McNemar tests for categorical variables. (SPSS Statistics for Windows, version 26, IBM Corporation, Armonk, NY, USA). Qualitative analyses were conducted with Atlas.ti (version 8.4.5). We used deductive thematic analyses to identify themes and sub-themes. All qualitative data were independently coded by two reviewers (AVC and PS) and differences between reviewers evaluated for consensus, and discrepancies resolved via conversation. Human-subjects approval was granted by a central institutional review board (Advarra) after review of protocol Pro00045302 (Marshall, P.I.).

3. Results

3.1. Use of Telehealth by CF Care Programs during the COVID-19 Pandemic

A total of 286 CF care programs (118 adult, 128 pediatric, and 40 affiliate) responded to SoC1, and 280 programs (115 adult, 127 pediatric, and 38 affiliate) responded to SoC2. By August 2020, 97% of programs (n = 277) provided some form of telehealth services. In SoC1, the median proportion of patients that programs evaluated exclusively in-person was 57% (IQR: 25–86%), and this proportion rebounded to 80% (IQR: 65–95%) by SoC2 (Table 1). The converse was true for telehealth, with programs reporting that the median proportion of patients seen exclusively in this manner was 30% (IQR: 10–60%) in SoC1 and 15% (IQR: 5–30%) in SoC2. Programs rarely used telephone only visits (TOVs) throughout the COVID-19 pandemic.

3.2. Acceptance of Telehealth by CF Care Programs and their Associated Institutions

Programs utilized multiple telehealth platforms during the COVID-19 pandemic (Suppl. Fig. 1). No platform was used preferentially by program type. Three-quarters of programs (n = 216, 77%) agreed or strongly agreed that all members of their care team were comfortable using the technology required to provide telehealth services. Most programs (75%) expressed that their health system made it easy to provide telehealth services. Similar proportions of adult (n = 47, 45%), pediatric (n = 43, 34%), and affiliate (n = 14, 36%) programs reported that their institutions planned to expand in-home options to augment and/or improve telehealth. Moreover, similar proportions of adult (n = 27, 27%), pediatric (n = 41, 35%), and affiliate (n = 8, 26%) stated that their institutions expected a certain fraction of clinic visits to occur in-person rather than via telehealth.

Table 2

Numbers of care programs and percentages of total program respondents that ranked a specific barrier in their top-three barriers to telehealth access by PwCF and their families. ^a Lack of internet access vs. all other barriers; ^b Pediatric and affiliate vs. adult; ^c Adult vs. pediatric and affiliate.

Program Type (number)	Total (n = 283)	Adult (n = 117)	Pediatric (n = 127)	Affiliate (n = 39)	P-value
Program-Reported Barrier					
Lack of internet access	246 (86.9)	101 (86.3)	114 (89.8)	31 (79.5)	<0.001 ^a
Financial barriers	126 (44.5)	56 (47.9)	57 (44.9)	13 (33.3)	NS
Health literacy	125 (44.2)	44 (37.6)	60 (47.2)	21 (53.8)	NS
Privacy concerns	120 (42.4)	55 (47.0)	47 (37.0)	18 (46.2)	NS
Language barriers	73 (25.8)	15 (12.8)	43 (33.9)	15 (38.5)	<0.001 ^b
Job loss/insecurity	69 (24.4)	33 (28.2)	27 (21.3)	9 (23.1)	0.015 ^c
Loss of insurance	66 (23.3)	34 (29.1)	24 (18.9)	8 (20.5)	0.003 ^c
Housing insecurity	24 (8.5)	13 (11.1)	9 (7.1)	2 (5.1)	NS

3.3. Program-Reported Experiences with Care Visits and Screening

Most programs (n = 161, 57%) agreed or strongly agreed that visit content changed due to the telehealth format. Nonetheless, around half (n = 146, 52%) of programs could better understand patients' concerns about barriers to care using telehealth. Most programs felt that they could make healthcare decisions with patients (n = 272, 96%), create a care plan with patients (n = 270, 95%), and discuss what mattered most to patients (n = 249, 88%). A total of 108 programs (38%) thought that physicians and/or other team members spent more time with PwCF during telehealth visits compared to other types of visits.

Programs continued to screen for mental health (MH) problems and food insecurity via telehealth during the pandemic. A total of 209 programs (73%) used telehealth to screen PwCF ≥12 years old for depression and anxiety. This was accomplished by a social worker in 124 programs (59%), a MH coordinator in 47 programs (23%), or a psychologist in 24 programs (12%). Additional details about the use of telehealth to provide MH care during the pandemic are available elsewhere in this supplement [18]. A total of 155 programs (55%) were able to screen PwCF and their families for food insecurity, predominantly using the Hunger Vital Sign™ tool.

3.4. Program-Reported Barriers to Telehealth Access by PwCF

Descriptive statistics pertaining to how programs ranked barriers to telehealth access by PwCF data are provided in (Table 2). All programs ranked lack of internet access as a top-three barrier to telehealth engagement by PwCF, followed by financial and health literacy challenges (Table 2). Pandemic-related financial strains on CF programs are discussed elsewhere in this supplement [19]. Higher proportions of adult programs than pediatric and affiliate programs identified job loss and/or insecurity (p = 0.015) and lack of insurance coverage available to PwCF (p = 0.003) as barriers to telehealth use by PwCF. In distinction to adult programs, pediatric and affiliate programs more frequently cited language differences (p <0.001) between providers and PwCF and/or families of PwCF as a barrier to telehealth utilization (Table 2).

3.5. Care Program Opinions about Quality of Care Delivered by Telehealth

Nearly half of programs (n = 132, 47%) thought that the quality of care delivered by telehealth was less than that which was delivered in-person. Programs espousing this belief reported that they could improve quality of telehealth if they could distribute home monitoring devices to PwCF (n = 104, 79%), access better technology (n = 84, 64%), include multidisciplinary team members in telehealth visits more easily (n = 57, 43%), and change billing

and reimbursement policies and/or practices (n = 47, 36%). Similar proportions of adult, pediatric and affiliate programs endorsed these strategies to improve the quality of telehealth.

3.6. Willingness of Care Programs to Recommend Telehealth

Across all programs, 30% (n = 86) were narrowly defined as net promoters of telehealth, as previously defined. Pediatric programs (n = 28, 22%) were significantly less likely to recommend telehealth services than adult (n = 43, 37%) or affiliate programs (n = 15, 39%) (p = 0.014). Using open-ended questions, programs were asked to identify changes that would make them more likely to recommend telehealth as an option for care delivery (Table 3). Key drivers for recommending telehealth were expanded provision of remote monitoring devices to obtain measures such as weights and other physical exam assessments and better processes for blood and sputum collection. Programs often cited access to the interdisciplinary care team as another factor that would lead them to recommend telehealth with an emphasis on increasing the ability for all team members to join during the scheduled visits. There were no statistically significant distinctions between programs based on their thematic responses (Table 3).

4. Discussion

The SoC surveys provided a unique account of how adult, pediatric, and affiliate CF programs in the United States incorporated telehealth into a long-standing multidisciplinary care model threatened by the COVID-19 pandemic. We learned that programs of different sizes, types, and geographic locations rapidly initiated telehealth using a variety of platforms. Comparing visit type data between surveys suggested that in-person visits started to supplant telehealth visits. This shift back to in-person visits could have coincided with higher vaccination rates, fewer restrictions on sizes of public gatherings, and/or other unmeasured factors that allowed PwCF, their families, and care teams to feel more comfortable with in-person visits. Although most care teams felt comfortable using telehealth and thought that their institutions supported their efforts, they also perceived multiple barriers to patient and family engagement with telehealth, especially lack of internet access, limited financial resources, and challenges with health literacy. Nearly half of programs thought that the quality of telehealth was inferior to in-person care, and pediatric programs were less likely than adult and affiliate programs to recommend telehealth as a mode of care delivery.

It is notable that CF care programs, particularly pediatric ones, were somewhat skeptical about the quality of telehealth. This impression differs substantially from that of respondents to the PF-SoC Survey [20]. We cannot readily explain this difference of opinion between stakeholder groups. It could reflect different priorities

Table 3
Themes identified in responses to the open-ended SoC survey question: “What changes would need to be made to telehealth for your program to give it a higher rating?”

Number of Programs	Total n = 281	Adult n = 115	Pediatric n = 127	Affiliate n = 39
Theme				
Remote monitoring/physical exam	137 (49%)	59 (51%)	61 (48%)	17 (44%)
Technology or platform limitations	72 (26%)	30 (26%)	34 (27%)	8 (21%)
Participation of multidisciplinary team in visit	49 (17%)	18 (16%)	25 (20%)	6 (15%)
Internet access (speed/availability)	47 (16%)	19 (17%)	23 (18%)	5 (13%)
Reimbursement	40 (14%)	15 (13%)	23 (17%)	2 (5%)
Model of care (telehealth, in-person, visit frequency)	37 (13%)	17 (15%)	15 (12%)	5 (13%)
Logistics of telehealth (scheduling)	17 (6%)	7 (6%)	10 (8%)	0

about the content and execution of outpatient visits and highlights an area for future research. A possible explanation for lower ratings of telehealth quality by pediatric programs than adult programs is that pediatric teams follow guidelines for increased visit frequency for infants [21] and young children [22] with CF and/or that information from physical examinations factors more prominently into their medical decision making than it does for adult programs. The SoC Surveys were not written in a way that allowed us to correlate skepticism about telehealth quality with the higher proportion of pediatric than adult and affiliate programs that would not recommend telehealth.

The finding that programs ranked lack of internet access as the biggest obstacle to telehealth utilization by PwCF is consistent with other descriptions [23,24]. Broadband infrastructure tends to be scarcer and/or slower in rural America [25], which negatively associates with numbers of TH visits [24]. Nonetheless, poverty remains a formidable barrier to telehealth use by urban residents [26] despite widespread presence of high-speed internet service in metropolitan areas. Several authors have described the effects of geography and economic disparities on telehealth access during the pandemic as a widening of the “digital divide” [27–29]. Curiously, lack of internet access was an uncommon problem encountered by respondents to the Patient and Family CF SoC (PFSoc) survey [20]. However, that observation could reflect ascertainment bias if respondents to the PFSoc Survey were more likely than non-respondents to have internet access in the first place.

Additional questions about telehealth use by CF care programs during the pandemic cannot be answered by the surveys and must be acknowledged as limitations and potential avenues for future inquiry. First, we do not know if programs changed telehealth platforms between surveys and for what reasons. The multiplicity of telehealth platforms used by programs could have simply reflected the extent to which programs were satisfied or dissatisfied with specific platforms and/or institutional limitations on platform selection. Second, the surveys did not ask programs whether and in what ways they thought the rollout of triple combination CFTR modulator therapy for most PwCF [30,31], which coincided with the COVID-19 pandemic in the United States, influenced their perspectives on telehealth. The separate impacts of modulators, telehealth, and the pandemic on clinical outcomes are not fully known and may be challenging to disentangle. Regardless, if telehealth remains part of the CF care model, it is safe to assume that all stakeholders will want to optimize its usability and value.

In summary, comprehensive surveys of adult, pediatric, and affiliate CF care programs in the United States during 2020–21 revealed that telehealth is a feasible, scalable, and potentially useful option to care for PwCF and their families. Programs identified several barriers to telehealth use, all of which could be remedied by expanding access to broadband internet services, promoting health and technology literacy, distributing devices that enable remote monitoring of physiologic and psychologic parameters, and optimizing telehealth platforms to preserve the multidisciplinary

approach to CF care. The CF community may need to explore novel approaches to evaluate success or failure as it works to mitigate barriers to telehealth and optimize telehealth implementation. A long history of quality improvement activities, robust clinical and research networks, and the CF Foundation Patient Registry [32] should facilitate those efforts.

Declaration of Competing Interest

The authors have no conflicts of interest to declare pertaining to this work.

CRediT author statement

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Supplementary materials

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