Perspectives of People with CF and Caregivers Regarding Medication Access,

Self-Reported Adherence, and Telehealth in CF Care During The COVID-19 Pandemic

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Abstract

Background: In the context of an international pandemic, social distancing and quarantine have unknown and possibly substantial effects on medication and care delivery. In this study, adult persons with CF (PwCF) and CF caregivers (CG) were surveyed regarding changes in medication access and adherence, as well as telehealth care before and during the COVID-19 pandemic.

Methods: The electronic de-identified survey was disseminated to CFF Community Voice and CysticLife communities from 6/24/2020 to 7/15/2020. This survey included PwCF and CG ages 18 years and older, within and outside of the U.S.. The survey items included multiple choice and Likert scale questions focused on perceptions of medication access and use before and during the pandemic; telehealth service availability and use; and demographics. Data were analyzed using descriptive statistics.

Results: The 342 respondents who attempted the survey included 57.6% were PwCF and 42.4% were CGs. Seventy-five percent of CGs cared for a PwCF under 18 years old. Forty US states were represented and 3% were from outside the US. Reported access to 60 or 90-day medication supply was not different before and during the pandemic. Most (90%) shared availability of at least one service encouraging minimal/no contact (e.g., drive thru, delivery) at their local pharmacy; while only 40.5% observed in-pharmacy precautions (e.g., limited people inside, spacing, special hours). When asked about medication use, 8.6% reported taking less of their medications while 33.6% were taking medications more regularly. Of those taking less, dornase alfa (25%), hypertonic saline (13.5%), and inhaled antibiotics (19.2%) were most common. Similarly, of those taking them more regularly, dornase alfa (19.3%) and hypertonic saline (18.5%) in addition to pancreatic enzymes (19.3%) were most common. Top reasons for taking medication less often included concern for possible medication shortages (11.1%) and cost (33.3%). Worry about contracting COVID-19 (26.3%) and having more time from “safe at home” orders (53.4%) were common reasons for respondents taking medications more

regularly. For laboratory blood draws and respiratory cultures, 40% and 65% of respondents shared that they were postponed, respectively. Most felt that video visits and phone visits were convenient, effective, and sufficient in place of in-person visits.

Conclusion: The COVID-19 pandemic had wide reaching effects on CF care, with positive changes in available pharmacy medication pickup and delivery options. A small number of participants reduced their medication use due to worries about medication shortages and being able to pay for medications. A larger percentage made efforts to improve adherence due to worries about COVID. Participants appreciated the telehealth visits while laboratory tests and respiratory cultures were postponed. Although this pandemic is far from over, our results offer a new lens from which to view the potential opportunities and challenges in CF care for PwCF and their caregivers.

Introduction

The coronavirus 2019 (COVID-19) pandemic has caused a significant shift in the daily life of people worldwide with changes to access to routine and necessary services such as healthcare as a result of social distancing, staffing shortages, and other factors. The socioeconomic effects of the COVID-19 pandemic are currently being researched, but a recent survey study found that one in ten patients with cystic fibrosis (CF) reported concerns related to insurance security and access to medications[1]. Another study of health care professionals (HCPs) aimed to identify the impact of COVID-19 on routine care for chronic diseases. It was found that most of the HCPs (84%) reported their patients being affected by medication shortages to some degree[2]. Access to guideline recommended medications can be challenging in general; however, in the setting of an international pandemic, such as COVID-19, information about possible changes in medication adherence, access, and perception are lacking. Further understanding of the potential challenges in medication access, the perceptions of possible medication shortages, and adherence to medications in a widespread pandemic may help inform stakeholders such as care teams, clinicians, payers, and public health officials to prepare for future possible scenarios.

Patients with CF, among others with underlying health conditions, are at higher risk of severe disease due to COVID-19 than healthy peers[3]. Thus, experts encourage these individuals to engage in social distancing and other preventative measures. Telehealth appointments have been used during the COVID-19 pandemic to maintain continuity of care while minimizing risk of exposure. A survey conducted by Horell and colleagues showed that among the respondents with CF, 70% indicated using telehealth within 4 months compared to 49% of all respondents[4]. Another study by Jaclyn and colleagues showed that most respondents, which included both adult and pediatric patients with CF, rated their telehealth visits the highest level of convenience and satisfaction[5]. Achieving more insight about the

various perceptions and preferences of telemedicine may help care teams expand how patient care can be delivered and maintained.

The purpose of this study was to describe perspectives of persons with cystic fibrosis (PwCF) and their caregivers with regards to cystic fibrosis (CF) medication access before and during the COVID-19 pandemic, including types of pharmacies used, services offered by pharmacies used, and access to 60 or 90 days supply of CF guideline recommended medications. The study also aimed to evaluate the perceptions of possible medication shortages, adherence to medications before and during the COVID-19 pandemic, and the perspectives of utilizing telemedicine as part of CF care.

Methods

Study design and population

From June 24, 2020 to July 15, 2020, an anonymous survey was distributed electronically (Qualtrics) to members of the CF community through CysticLife and the CF Foundation Community Voice listservs and social media platforms. A survey reminder was disseminated to participants after week 2 and before the end of the survey period. The intended population included persons with CF age 18 years and older, and caregivers (CG) of persons (all ages) with CF, within and outside of the U.S. All who were asked to consider participation in the survey had the opportunity to be entered in a raffle for the chance to win one of 25, $40 electronic gift cards. Participation in the survey was not required to be eligible for the raffle. Information collection for the raffle (name, email) was separate from the survey and not linked to a given participant's responses.

Survey development and measures

The survey was developed by an interprofessional team representing pharmacy, psychology, public health and a member of our local CF Family Council. The electronic survey

was developed using Qualtrics survey software (Qualtrics Labs, Inc. 2013) and included multiple choice and Likert scale items. Participants were not required to answer every question and all responses to questions were included. Branch and skip logics were used to prevent the presentation of irrelevant questions to participants. Survey items regarding medication access and adherence included types of pharmacies used and services offered by local pharmacies in light of the COVID-19 pandemic, access to extended medication supply (60 or 90 day fills), medication adherence and reason for adherence change (if any). Items regarding telehealth modalities included the accessibility and availability, respondent's perspectives of the convenience, effectiveness, and comfort with phone and video visits, as well as, preference for future use with quarterly/routine and sick CF clinic visits.

Other survey items included accessibility and availability of laboratory draws, respiratory cultures, and remote home spirometry. Respondents were also asked to identify which care disciplines were present during telehealth visits as well as describe their out of pocket costs associated with telehealth visits. The final section of the survey included items pertaining to demographics. U.S. Census regions were based on the U.S. Census Bureau Regions and Divisions, and the median household income was based on the 2020 Income & Poverty U.S. Census Bureau[5,6].

Analysis

Descriptive data analysis was completed using STATA 16.0 (College Station, TX) and Microsoft Excel(™). Non-response to individual questions were not included in the analysis.

Results

Demographics

The respondents of the survey included 197 persons with cystic fibrosis (PwCF) and 145 caregivers of persons with cystic fibrosis (CG). Of the CG's who responded, 73.1% (N=87/119)

reported caring for a PwCF under 18 years old. Of those who answered the item pertaining to sex, most PwCF and CG's were female (61.9% N=122/197) and 77.2% N=112/145 respectively) while most PwCF as reported by CG were male (53.6% N=67/125). A majority of respondents who answered the item pertaining to ethnic/racial background were white/caucasian (92.6 % of PwCF N=162/175, 91.3% of CG N=116/127 and 84.6% of PwCF as reported by CG N=115/136). Of the respondents who answered the item pertaining to residency, a majority reported residing in suburban areas (54.0% N=157/291). Thirty-five percent (N=97/280) of respondents reported having CF care centers located in the Southern region of the US. Of the total participants who responded to the survey item regarding total household income, 28.4% (N=81/285) reported having a total household income less than the median household income per the 2020 U.S. Census ($\leq$ $59,999/year)[5]. Private insurance through an employer was the most common form of insurance across both groups (34.8%, N=130/374). A summary of these and other demographic variables can be seen in Table 1A, Table 1B and Table 1C.

The five most common comorbidities for PwCF and PwCF as reported by CG's included: pancreatic insufficiency, gastroesophageal reflux/gastroesophageal reflux disease, asthma, diabetes, and anxiety disorder. An estimated baseline lung function of 70% or greater was reported in 71.2% (N=200/281) of PwCF and PwCF as reported by CG's at the time of the survey. A summary of comorbidities and lung function can be found in Table 2.

Access and adherence

Reported access to 60 or 90-day medication supply appeared similar both before and during the COVID-19 pandemic. It was reported that 8.0% (N=26/327) of participants were taking less of their CF medications and 33.6% (N=110/327) reported taking their CF medications more regularly. Of those taking them less regularly, dornase alfa (25% N=13/52), hypertonic saline (13.5% N=7/52), and inhaled antibiotics (19.2% N=10/52) were most common. Similarly, of those taking CF medications more regularly dornase alfa (19.3% N=48/249), hypertonic

saline (18.5% N=46/249) and pancreatic enzymes (19.3% N=48/249) were most common. Top reasons for taking CF medication less often included concern for possible medication shortages (11.1% N=3/27) and cost (33.3% N=9/27). Worry about contracting COVID-19 (26.3% 31/118) and having more time from “safe at home” orders (53.4% 63/118) were common reasons for respondents taking medications more regularly.

Figure 1 shows the most common types of pharmacy used for CF and non-CF related medications were local pharmacies (39.6% N=286/723) and specialty pharmacies (38.6% N=279/723). According to the respondents, the service most commonly offered at local pharmacies during COVID was Drive-Thru pick-up for medicines (34.9% N=35/580) (Figure 2). Twenty-one percent (N=119/580) of respondents reported that their local pharmacy offered in-store protective measures such as required masks, marked customer spacing, limited number of customers in the building at one time, etc. Only 1.9% (N=11/580) of respondents reported that their local pharmacy did not offer services to optimize social distancing during COVID.

Table 4 summarizes that 37.5% (N=110/293) of respondents had a travel time of 31-60 minutes to their CF care center from home and 36.2% (N=106/293) reported it being more than an hour, and most respondents reported a travel time of less than 30 minutes to their pharmacy (85.2%, N=276/324). Survey respondents were asked to describe their access to lab draws, respiratory cultures, and home spirometry during the pandemic. About forty percent (N=125/313) of respondents reported having laboratory draws postponed and approximately 65% (N=204/315) reported having respiratory cultures postponed. About thirty-eight percent of respondents reported having access to at-home spirometry (N=121/319).

Perspectives and Preferences Regarding Telehealth

When asked to rank preference for both routine, quarterly and sick CF clinic visits, a higher percentage of respondents ranked in-person CF clinic visits as their most preferred

option. The type of CF clinic visit ranked most oftenly as least preferred was telephone clinic visits. A summary of the responses is presented in Figure 3.

Respondents were asked to describe the convenience, comfort, and effectiveness of telephone and video visits, Figure 4 summarizes the following results. A higher percentage of respondents indicated that they agree and/or strongly agree that telephone and video conference clinic visits are a convenient way to receive care from their CF care team (71.7%, N=226/315 and 82.3%, N=261/317 respectively). Forty-one percent (N=129/315) of respondents agreed and/or strongly agreed that telephone visits are an effective way to receive care from their CF care team. A greater percentage of respondents indicated that video conference visits are an effective way to receive care from their CF care team (56.3%, N=178/316). When asked to describe whether or not they were comfortable with telephone clinic visits in place of in-person CF clinic visits, only 32.3% (N=102/315) of respondents agreed and/or strongly agreed. A greater percentage of respondents felt more comfortable with video conference clinic visits in place of in-person CF clinic visits (57.1%, N=181/317). A large percentage agreed and/or strongly agreed to wanting video conference visits (63.7%, N=202/317) as an option for future CF clinic visits and a lesser percentage for telephone visits (47.1%, N=148/314).

When asked to describe the copay or out-of-pocket cost for video conference and telephone clinic visits compared to in-person clinic visits, a majority of respondents were unaware of the costs (51.6% N=16/31 and 60% N=18/30, respectively). Only 5.3% (N=4/76) of respondents reported a pharmacist present during a video conference visit and 9.0% (N=6/67) reported a pharmacist present during telephone clinic visits.

Discussion

The COVID-19 pandemic may have caused a shift in the way outpatient healthcare is provided. Individuals with diseases requiring multiple medication regimens and therapies, like CF, likely experienced challenges in medication and clinical diagnostic access and adherence

first-hand. Regarding adherence, 8.6% of respondents reported taking less of their CF medications, with dornase alfa, hypertonic saline, and inhaled antibiotics reported as the three medications most commonly taken less regularly. The top reasons for taking CF medications less often included: concern for possible medication shortages (11.1%) and cost (33.3%). This may be due to the fear that medication production and distribution would be suspended during the pandemic. Additionally, income may have been negatively affected depending on employment status, transition, and other factors. To combat this, patients may have halted their therapies in an attempt to preserve their medications to “stretch” their supply and save money. This is also observed in a cross-sectional survey by Bhatnagar and colleagues, involving persons with cystic fibrosis and their difficulty in medication access during the pandemic. Of the 119 PwCF respondents, 24.4% reported finding access to CF medications challenging and 5.9% reporting having to find alternatives in accessing their CF medications[8].

A greater percentage of patients (33.6%) reported taking their CF medications more regularly with worry about contracting COVID-19 (26.3%) and having more time from “safe at home” orders (53.4%) as common reasons. One CF center found that their CF patients had significantly improved pulmonary function parameters during the post-lockdown phase compared to pre-lockdown[9]. These changes in pulmonary function may be partially explained by the reported increase in medication adherence as well as stay at home or quarantining which decreased exposure to pathogens leading to pulmonary exacerbations.

The COVID-19 pandemic may have had an impact on patient access to CF-related medications, routine monitoring procedures, and clinical care. The most common types of pharmacies used for CF and non-CF related medications were local and specialty pharmacies (39.6% and 38.5%, respectively). Most respondents reported a travel time of less than 30 minutes to their local pharmacy. The most commonly offered service at the local pharmacies during the pandemic included Drive-Thru pick-up for medicines (35%), with enhanced in-store protective measures like required masks, marked customer spacing, and limited number of

customers in the building at one time (21%). Only 1.9% of respondents reported that their local pharmacy did not offer services to optimize patient safety/distancing during COVID-19. These results may indicate that pharmacies remained open and accessible to the public during these times, minimizing medication access interruptions expected with complete closures related to the pandemic.

Survey respondents also reported having laboratory draws and respiratory cultures postponed during the pandemic, and only 38% percent reported having access to at-home spirometry. This is also observed in a study by Compton and colleagues, where only 37% (N=49/131) of eligible patients from a CF adult clinic at the University of Virginia had received a home spirometry (HS) device at the beginning of the COVID-19 pandemic. It is important to recognize the importance of providing access to home spirometry, but also the need to overcome the potential utilization barriers in providing the home spirometry. This includes ensuring adequate patient education, training, and adherence[10]. Given the importance of routine monitoring in CF, there is room for improvement to prevent the delay of these measures and efficacy of provided services.

Virtual modalities were adopted during the pandemic in order to minimize infection risks and ensure social distancing, but many long-term benefits of standardizing it exist. One study, conducted by Hendra and colleagues, demonstrated that 80% of CF patients and 88% of providers surveyed at the University of California San Francisco Benioff Children's Hospital were satisfied with the conducted telemedicine visits. Both groups also preferred to have 50% of the recommended annual CF visits via telemedicine modality[11]. Adopting virtual consultations as an alternative to in-clinic consultations reduces barriers to healthcare such as travel time to clinics, transportation availability, and scheduling conflicts. Jaclyn and colleagues observed in a cross-sectional survey conducted across 11 CF centers that 77% of adults and 72% of pediatric respondents were highly satisfied with their telehealth visit, and overall 85% found the visits to be highly convenient[5]. The pandemic prompted research assessing the implementation, utility,

and efficacy of telemedicine as a standard practice is still ongoing – however, it is still very limited.

Overall, our study shows that in-person CF clinic visits were most preferred for both types of CF clinic visits (quarterly/routine and sick). The least preferred type of telehealth CF clinic visit was telephone. Of note, patient preference varies between individuals, including what aspects constitute as 'convenient,' 'effective' or 'comfortable.' However, overall respondents reported that both telephone and video visits were convenient ways to receive care from their CF care team. This may be due to reduced costs in travel to clinic visits, scheduling conflicts, and time constraints. We observed that 37.5% of respondents reported having to travel 31-60 minutes to their CF care center from home, and 36.2% reported traveling more than one hour. In total, for a large proportion of patients, at minimum an hour of time can be saved from travel to/from clinics with the use of telehealth services. These long travel times are physically taxing on patients, and eliminating this could result in more comfort and relaxation at home and utilizing telehealth.

Preference for video consultations was evident, with more than 50% of respondents indicating that video visits are an effective way to receive care and felt more comfortable with video visits in place of in-person CF clinic visits. This may be because individuals value a more traditional consultation, allowing face-to-face interaction that can be replicated via video conference versus audio only over telephone. However, it is important to note that hesitation for complete transition to telemedicine exists due to a number of concerns. Non-verbal cues and fear of being overheard are difficult to overcome via telephone or video conference. Discussions regarding sensitive and personal issues, both in adult and pediatrics, are difficult to safeguard in an environment outside of the clinic as well[12].

Having pharmacists as part of the care team during clinic visits are becoming more prominent and as such have also been involved in telehealth visits. Certain CF care centers, such as the Michigan Medicine Pediatric Cystic Fibrosis Center, have clinical pharmacists

(PharmD) as part of the interdisciplinary care team. Pharmacists at the clinic regularly conduct telehealth visits via video visit or telephone prior to MD visits[13]. Implementation of pharmacists as part of CF telehealth may increase access to pharmacists' care. In our study, only 5% of respondents reported having a pharmacist present on their care team during video conference visits and 6% during telephone clinic visits; however the survey was conducted during the Summer of 2020 when telehealth was likely still in its earlier stages. This overall low percentage of reported pharmacists present during telemedicine clinics suggest that there is room to integrate pharmacists in routine clinic visits beyond in-person, as demonstrated in a larger study conducted by Young, et al. The study showed that of the 666 respondents recorded, 54% reported that a pharmacist was involved in their (in-person) CF clinic visit and further stratified as "full access" or "limited access" to the pharmacist. Those clinics with "full access" to a pharmacist were significantly more likely to get their medications refilled on time (78% vs 63%)[14]. Pharmacist involvement in-person, as demonstrated by Grant et al, provides many benefits such as improving access to medication, providing prompt medications-refill authorization, and promoting adherence. With the adoption of telemedicine, certain barriers to healthcare access are eliminated and opportunities for multidisciplinary involvement (like pharmacists) can be further incorporated[15].

This study had several limitations which involved the electronic nature of the survey. There was an unknown total possible respondent count, so a response rate could not be determined. Additionally, the survey was conducted electronically and shared via known CF community listservs and social media platforms. However, given the rare disease status of CF and the value of perspectives from PwCF and CF on a larger scale, we elected to distribute the survey in this non-traditional fashion with the hope to learn from the broader CF community. Summarized findings may not necessarily be fully representative of the U.S. population of PwCF, given not all states and local communities were represented and those with limited or no access to technology may have different perspectives and preferences compared to those with

access. Additionally, CG responses are on behalf of the PwCF they care for and thus may be biased or based on recall. Self reported medication adherence is also not ideal given possible bias and recall inaccuracies. This was a pilot, survey study and thus its findings are intended to provide clinicians perspectives of a proportion of members of the CF community; thus, future qualitative and quantitative research are needed to further evaluate the implications of COVID-19 pandemic on medication access, adherence, and telemedicine perspectives and preferences.

Conclusions

The COVID-19 pandemic had wide-reaching effects on CF care, with positive changes in available pharmacy medication pickup and delivery options. A small number of participants reduced their medication use because of worries about medication shortages and being able to pay for medications. A larger percentage made efforts to improve adherence because of worries about COVID. Participants appreciated the telehealth visits, while laboratory tests and respiratory cultures were postponed. Although this pandemic is far from over, our results offer a new lens through which to view the potential opportunities and challenges in CF care for PwCF and their caregivers.

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Table 1A. Demographics - Persons with Cystic Fibrosis (PwCF), Caregivers of Persons with Cystic Fibrosis and Persons with Cystic Fibrosis as reported by caregivers

Demographic Categories	Persons with Cystic Fibrosis	Caregivers of Persons with Cystic Fibrosis	Persons with Cystic Fibrosis as reported by caregivers
Age group, N, %	**N=170**	**N=125**	**N=119**
< 1 years	-	-	0 (0)
1-5 years	-	-	15 (12.6)
6-11 years	-	-	39 (32.8)
12-17 years	-	-	33 (27.7)
18 years+	-	-	32 (26.9)
18-25 years	22 (12.9)	1 (0.8)	-
26-35 years	71 (41.8)	16 (12.8)	-
36-45 years	41 (24.1)	57 (45.6)	-
46-55 years	20 (11.8)	37 (29.6)	-
56-65 years	8 (4.7)	12 (9.6)	-
66+ years	8 (4.7)	2 (1.6)	-
Sex, N, %	**N=197**	**N=145**	**N=125**
Male	45 (22.8)	12 (8.2)	67 (53.6)
Female	122 (61.9)	112 (77.2)	57 (45.6)
Prefer Not to Answer	1 (0.5)	21 (14.4)	0 (0)
Prefer to Self Describe	2 (1.0)	0 (0)	1 (0.8)
Ethnic/Racial Background, N, %	**N=175**	**N=127**	**N=136**
Hispanic/Latinx	2 (1.1)	6 (4.7)	11 (8.0)
White/Caucasian	162 (92.6)	116 (91.3)	115 (84.6)
Black/African American	0 (0)	0 (0)	1 (0.7)
Asian/Pacific Islander	2 (1.1)	1 (0.8)	4 (2.9)
Native American/Native Alaskan	4 (2.2)	0 (0)	1 (0.7)
Other	1 (0.6)	2 (1.6)	2 (1.5)
Prefer not to answer	4 (2.2)	2 (1.6)	2 (1.5)

Percents may not equate to 100 due to rounding
Those who did not respond to an individual question were not included in the analysis

Table 1B. Demographics – Caregiver Relationship to Persons with Cystic Fibrosis

Demographic Categories	Caregivers of persons with Cystic Fibrosis
Caregiver Relationship to Person with Cystic Fibrosis, N, %	**N=125**
Mother	104 (83.2)
Father	10 (8.0)
Spouse/Partner	8 (6.4)
Other	3 (2.4)
Number of Persons with Cystic Fibrosis Cared for, N, %	**N=145**
1	120 (82.8)
2+	25 (17.2)
Age of Persons with Cystic Fibrosis that requires the most care, N, %	**N=25**
<1 years	0 (0.0)
1-5 years	3 (12.0)
6-11 years	6 (24.0)
12-17 years	12 (48.0)
18 years and older	4 (16.0)

Percents may not equate to 100 due to rounding
Those who did not respond to an individual question were not included in the analysis

Table 1C - Demographics- Residential and Socioeconomic Variables

Demographics Categories	Total	Persons with Cystic Fibrosis	Persons with Cystic Fibrosis as reported by Caregivers
Residence, N, %	**N=291**	**N=169**	**N=122**
Urban	81 (27.8)	56 (33.1)	25 (20.5)
Suburban	157 (54.0)	82 (48.5)	75 (61.4)
Rural	53 (18.2)	31 (18.3)	22 (18)
Number of household members, N, %	**N=299**	**N=170**	**N=123**
1	25 (8.4)	25 (14.7)	0 (0)
2	85 (28.4)	74 (43.5)	11 (8.9)
3	75 (25.1)	36 (21.2)	39 (31.7)
4	62 (20.7)	17 (0.1)	45 (36.6)
5+	41 (13.7)	14 (0.8)	27 (22.2)
Prefer Not To Answer	5 (1.7)	4	1 (0.8)
CF center location, N, %	**N=280**	**N=164**	**N=116**
West	72 (25.7)	42 (25.6)	30 (25.9)
Midwest	61 (21.7)	40 (24.4)	21 (18.1)
South	97 (34.6)	49 (29.9)	48 (41.3)
Northeast	50 (17.9)	33 (20.1)	17 (14.7)
Other US Territories	0 (0)	0 (0)	0 (0)
Outside of the US	8 (2.9)	5 (3.0)	3 (2.9)
Total Household Income (US Census 2020 Median Household Income), N, %	**N=285**	**N=169**	**N=123**
≤ $59,999/year (median household income)	81 (28.4)	51 (30.2)	30 (24.4)
$60,000 - $105,000/year	80 (28.1)	47 (27.8)	33 (26.8)
>$105,000/year	77 (27)	40 (23.7)	44 (35.8)
Prefer not to answer	47 (16.5)	31 (18.3)	16 (13.0)
Insurance Type, N, %	**N=374**	**N=228**	**N=146**
No Insurance	4 (1.1)	3 (1.3)	1 (0.7)
Private (through parents or spouse)	83 (22.2)	51 (22.4)	32 (21.9)
Private (through Health Insurance Marketplace)	2 (0.5)	0 (0)	2 (1.4)
Private (through employer)	130 (34.8)	71 (31.1)	59 (40.4)
Private (purchased on own)	8 (2.1)	7 (3.1)	1 (0.7)
Government (Medicare/Medicaid)	117 (31.3)	79 (34.6)	38 (26.0)
Military (Tricare)	8 (2.1)	6 (2.6)	2 (1.4)
Children's Health Insurance Program (CHIP)	5 (1.3)	1 (0.4)	4 (2.7)
Other	11 (2.9)	6 (2.6)	5 (3.4)
Prefer Not To Answer	3 (0.8)	3 (1.3)	0 (0)
Unknown	3 (0.8)	1 (0.4)	2 (1.4)

Percents may not equate to 100 due to rounding
Those who did not respond to an individual question were not included in the analysis
Cystic Fibrosis Center Location regions determined by the U.S. Census Bureau Regions and Divisions
Median household income based on the 2020 Income & Poverty U.S. Census Bureau

Table 2 - Reported Comorbidities and Lung function of Persons with Cystic Fibrosis

Categories	Total	Persons with Cystic Fibrosis	Persons with Cystic Fibrosis as reported by Caregivers
Number of comorbidities, N, %	**N= 284**	**N=165**	**N=117**
None	28 (9.9)	7 (4.3)	21 (17.9)
1-3	136 (47.9)	72 (43.6)	64 (54.7)
4-6	88 (31.0)	59 (35.8)	29 (24.8)
7+	30 (10.6)	27 (16.4)	3 (2.6)
Most common comorbidities, N, %	**N=284**	**N=165**	**N=117**
Anxiety disorder	78 (27.5)	61 (37.0)	17 (14.5)
Asthma	91 (32.0)	67 (40.6)	24 (20.5)
Diabetes	89 (31.3)	69 (41.8)	20 (17.1)
Gastroesophageal Reflux/Gastroesophageal Reflux Disease	95 (33.4)	67 (40.6)	28 (23.9)
Pancreatic Insufficiency	222 (78.2)	138 (83.6)	84 (71.8)
Estimated Baseline Lung Function (FEV1), N, %	**N=281**	**N=169**	**N=122**
≥70% or greater	200 (71.2)	96 (56.8)	104 (85.2)
40-69%	54 (19.2)	45 (26.6)	9 (7.3)
<40%	22 (7.8)	21 (12.4)	1 (0.8)
Unknown	8 (2.8)	7 (4.1)	1 (0.8)
Not applicable	7 (2.5)	0 (0)	7 (5.7)

Percents may not equate to 100 due to rounding
FEV1- Forced Expiratory Volume in the 1st second
Those who did not respond to an individual question were not included in the analysis

Table 4 - Travel time to CF Care Center and Pharmacy

Categories	Total	Persons with Cystic Fibrosis	Persons with Cystic Fibrosis as reported by Caregivers
Time to CF care center from home (minutes), N, %	**N=293**	**N=170**	**N=123**
< 30 minutes	75 (25.6)	48 (28.2)	27 (22)
31-60 minutes	110 (37.5)	55 (32.4)	55 (44.7)
61-120 minutes (1-2 hours)	57 (19.5)	36 (21.2)	21 (17.0)
>120 minutes (2 hours)	49 (16.7)	30 (17.6)	19 (15.4)
Unknown	2 (0.7)	1 (0.5)	1 (0.8)
Time to Pharmacy, N, %	**N=324**	**N=185**	**N=139**
<30 minutes	276 (85.2)	162 (87.6)	114 (82)
31-60 minutes	18 (5.6)	10 (5.4)	8 (5.8)
61-120 minutes (1-2 hours)	2 (0.6)	0 (0)	2 (1.4)
>120 minutes (2 hours)	6 (1.9)	4 (2.2)	2 (1.4)
Unknown	22 (6.8)	9 (4.9)	13 (9.4)

Those who did not respond to an individual question were not included in the analysis

Figure 1. Pharmacy Type Used for Cystic Fibrosis and Non-Cystic Fibrosis Medications During COVID-19 Pandemic

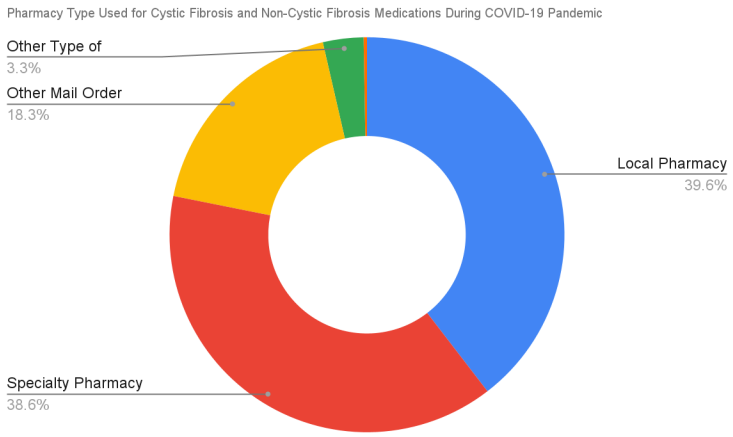

Figure 2. Local Pharmacy Services Offered During COVID-19 Pandemic

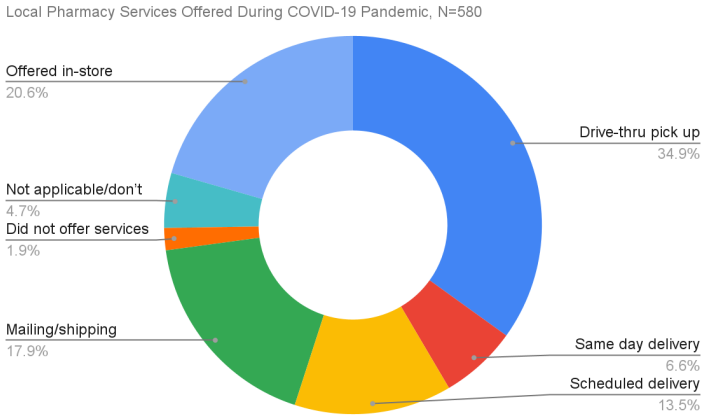

Figure 3. Preference for Quarterly, Routine and Sick Cystic Fibrosis Clinic Visits

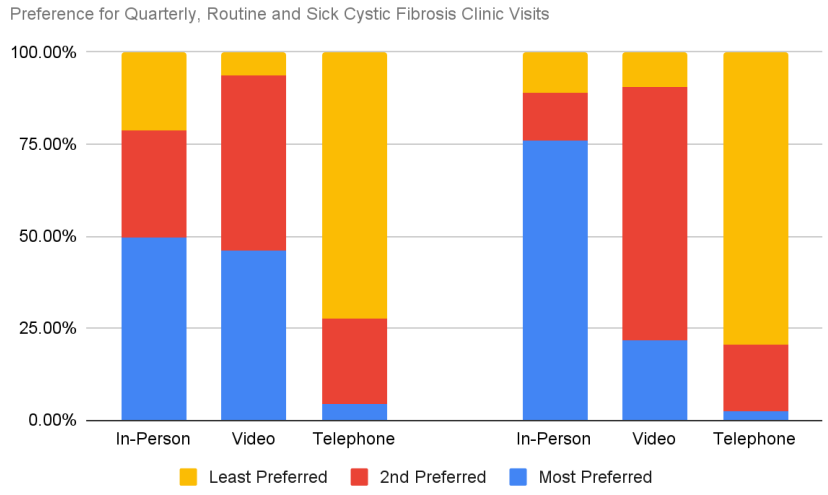

Figure 4. Perspectives regarding convenience, effectiveness, comfort and future option of video (VV) or phone (PV) visits in CF care