Patient and Family Perspectives Regarding the Use of Telehealth For Cystic Fibrosis Care

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The traditional model of cystic fibrosis (CF) care revolves around regular (usually three monthly) in person appointments with the multidisciplinary CF team at specialised CF care centres. At a typical appointment, in addition to seeing multiple professionals, people with CF perform spirometry, and have an airway sample and anthropometric measurements taken. This model of care has been crucial in helping to drive the significant improvements in outcomes for people with CF. However, there are several drawbacks associated with these in-person appointments which represent barriers to effective care. People with CF, and their families, often have to travel significant distances to a specialised CF centre and appointments result in interruption to daily activities such as work and study. In addition, the risk of cross-infection at in-person clinics is a significant issue. For example, infections which are potentially transmitted at CF clinics, such as non-tuberculous mycobacteria, are associated with significantly poorer outcomes.

Telehealth clinics hold many potential benefits for people with CF and their families which could address the negative aspects of in-person clinics. Attending appointments from home or work would result in less interruption to daily life and reduced travel time, with associated financial savings. In addition, the risk of cross-infection at the time of clinic visits would be eliminated. Conversely, given the complexity of CF care and the importance of multidisciplinary input as well as lung function, microbiology and anthropometric assessment it may be less amenable to telemedicine. While these interventions are possible via telehealth, the added complexity of attaining them is a potential barrier to its success.

Limited data exist regarding telehealth in CF multidisciplinary clinics, and these studies have focused on feasibility. For example, our centre demonstrated the
feasibility of telehealth spirometry.\textsuperscript{1} However, patient and family satisfaction with a telehealth model of care has received limited attention. Prior to 2020, the only assessment of this was a study of adult patients from regional Australia, and the majority (94\%) of participants supported a telehealth model.\textsuperscript{3} This leaves large knowledge gaps regarding the views of paediatric patients and their families, as well as those from metropolitan settings who do not share the same travel burden when attending for assessments. Given the importance of patient engagement in CF care, prior to incorporating telehealth into routine practice, it is essential to ascertain consumer support for this model.

The COVID-19 pandemic has led to many CF clinics transitioning to telehealth clinics. This is reflected by the numerous abstracts presented on this topic at the 2020 North American Cystic Fibrosis Conference (NACFC-2020).\textsuperscript{4} While the majority of these abstracts focused on feasibility, a number examined patient and family satisfaction with telehealth. Alongside the work presented at NACFC-2020, we have conducted a survey of satisfaction with telehealth clinics at our CF centre. Collectively, these studies provide a unique opportunity to assess what people with CF and their families think about telehealth and whether they would like it to continue into the future.

At the Royal Children’s Hospital, Melbourne, Australia (RCH) in response to COVID-19, we transitioned our CF clinics to a telehealth model. The new telehealth multidisciplinary appointments involved consultations with each member of the multidisciplinary team via a web-based video call platform called ‘HealthDirect’ (Health Direct, Australia). In addition, prior to the appointment, families were sent kits for obtaining airway samples including written instructions and a link to video demonstrations, and were asked to complete anthropometric measurements. Based on
the success of the previous pilot study\textsuperscript{1}, home spirometers were allocated to selected patients. Home spirometry assessments were supervised by a respiratory scientist as previously described.\textsuperscript{1} To assess family satisfaction with telehealth clinics, a specifically-designed survey was distributed to families electronically 3.5 months after the transition to telehealth clinics. Ethical approval was obtained from the hospital institutional review board, who deemed that completion of the survey indicated informed consent to participate.

The survey response rate was 38.5\% (79/205). Responses were received from families where the median age of the person with CF was 10 years (range 1-19 years). Only one respondent (1.3\%) did not have the necessary equipment. The findings were very similar to the other studies. Nearly all respondents (97.5\%) reported being able to speak to all the clinicians they wanted to, and 98.7\% responded that all questions were answered satisfactorily. Respondents were predominantly satisfied (46.8\%), or very satisfied (44.3\%) with telehealth clinics, with others neutral (7.6\%) or very dissatisfied (1.3\%). Just over half (51.7\%) of patients aged 6 years or older had access to a home spirometer. The majority were able to obtain an airway sample at home (88.6\%). Regarding anthropometrics, 92.4\% were able to weigh their child and 88.6\% were able to measure their height. In terms of the future role of telehealth clinics, the majority (87.3\%) of respondents wanted to consider telehealth clinics beyond the COVID-19 pandemic. Just over half (58.2\%) identified potential limitations with ongoing telehealth clinics (see table 1).

Along with these data from our centre there were ten abstracts presented at the NACFC 2020 that primarily assessed patient and family satisfaction with telehealth clinics instituted during the COVID-19 pandemic. The majority (8/10) of these were from the United States of America, and the remainder were from the United
Kingdom. All of the telehealth clinics utilised a web-based video call platform whereby patients were able to see the entire CF multidisciplinary team.

Seven of the ten studies assessed the satisfaction of adult patients (abstract number 492, 679, 704, 724, 742, 797, 814). The sample sizes of the abstracts ranged from 20-90 patients, with response rates between 33.3%-63.3%. The consistent themes from the adult studies were of high satisfaction with telehealth clinics. In most studies patient satisfaction with telehealth clinics was >95%, with the lowest reported satisfaction of 71%. Respondents reported that telehealth clinics addressed some of the current barriers to care via reduced time spent travelling, reduced time away from work and reduced cross-infection risk. Funnell et al (abstract number 492) quantified the time saving at a median of 180 minutes per clinic, and 59% of participants reported avoiding having to take half a day or more of leave from work. Concerns regarding telehealth included the lack of pulmonary function assessment, airway sample collection and physical examination. Despite this in several studies, patients reported they received an equivalent assessment via telehealth. NeSmith et al (abstract number 797) specifically asked how telehealth should be used in the future and the response ranged from using it for all visits (7%), most visits (35%), some visits (50%), and not at all (8%).

Three studies assessed satisfaction of pediatric patients (abstract number 770, 799, 815), with sample sizes ranging from 26-95 patients. The findings in pediatric patients parallel those in adults as well as those from our local centre, with high overall satisfaction and the same identified benefits and concerns.

Together the data from the ten recent abstracts and the survey at our centre show widespread support for future use of telehealth in CF multidisciplinary clinics. These data are novel, as they include patients from several countries, include patients from
metropolitan settings and specifically assess the experience of paediatric patients and their families. Limitations of this body of evidence primarily relate to the potential bias introduced by the survey response rates that ranged from 33.3%-63.3%.

However, these are in keeping with a previous study which demonstrated an average response rate of 32% (range 11-55%) in surveys of satisfaction with outpatient care.\textsuperscript{5}

In addition, our centre observed a reduction in clinic non-attendance and did not receive any formal complaints regarding telehealth clinics external to this survey, which supports user satisfaction with the model of care. Another limitation relates to the fact these data were generated during the COVID-19 pandemic. This would likely bias respondents to give a more positive review of telehealth clinics, as during a pandemic the benefits of receiving care at home and correspondingly the potential risks of attending hospitals are increased. The only study conducted prior to the COVID-19 pandemic reported 94% of participants being satisfied with telehealth clinics\textsuperscript{3}, which is reassuring that the positive results seen in the other studies will still be relevant post pandemic.

Future work will need to assess the effect of telehealth clinics on CF health outcomes. This should include the effect on lung function (forced expiratory volume in one second), microbiology (detection of infections such as \textit{Pseudomonas aeruginosa}, and non-tuberculous mycobacteria), pulmonary exacerbation detection, nutrition (weight and body mass index), and quality of life (using a CF specific measure).

Multidisciplinary CF teams have a track record of assessing these outcomes via participation in quality improvement studies and CF registries.

The consistent concerns raised across studies regarding the lack of lung function assessment, airway sample collection, and physical examination should also be addressed in the design of telehealth clinics. Potential solutions include the use of
home spirometry, wearable devices and digital stethoscopes, as well as using a mixture of telehealth and in person appointments.

However, what these studies demonstrate is the overwhelming support of people with CF and their families for telehealth. As such, these studies provide a mandate for incorporating telehealth clinics into CF care beyond the COVID-19 pandemic.

Conflicts of Interest;
The authors have no conflicts of interest to declare.

Data Availability
The corresponding author can be contacted to supply raw data regarding the survey undertaken at RCH.

References:

Table Captions
Table 1. Reported concerns regarding ongoing use of telehealth for CF multidisciplinary clinics

<table>
<thead>
<tr>
<th>Concern</th>
<th>Number of Respondents (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Physical Exam</td>
<td>20 (25.3%)</td>
</tr>
<tr>
<td>No Lung Function assessment</td>
<td>8 (10.1%)</td>
</tr>
<tr>
<td>Less Engagement with CF team</td>
<td>5 (6.3%)</td>
</tr>
<tr>
<td>No staff collected airway sample</td>
<td>4 (5.1%)</td>
</tr>
<tr>
<td>Need to travel to hospital anyway</td>
<td>1 (1.3%)</td>
</tr>
<tr>
<td>Privacy Concerns</td>
<td>1 (1.3%)</td>
</tr>
</tbody>
</table>
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