Methods for monitoring pulmonary health in cystic fibrosis patients in a remote-first care environment - a Survey

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Abstract

Recent social distancing practices due to the COVID-19 pandemic have caused the cystic fibrosis (CF) community to transition to remote routine care. As a result, several important measures of pulmonary health, including FEV1, are not currently possible to collect through traditional in-clinic methods, requiring the substitution of new remote methods for pulmonary health monitoring. This survey was conducted to develop an updated understanding of how people with CF and their care teams can effectively monitor and communicate changes to pulmonary health in a remote setting, while maintaining high levels of care. The questions focused on how people with CF or their parents are now tracking their pulmonary symptoms, their access to home spirometry devices, their preferences for future pulmonary health monitoring, and how they would prefer to communicate symptomology and spirometry results to their care teams. We received 43 responses and found a majority of participants felt comfortable tracking pulmonary symptoms at home and had a plan already in place, but were interested in adding new symptom and FEV1 monitoring and communication methods as remote routine care becomes standard. About a quarter of respondents owned a home spirometry device, and currently use this as their primary monitoring method. Most respondents without home spirometers would be interested in adding a home spirometry device, and would be willing to use it on a weekly or monthly basis. Nearly half of respondents were also interested in adding guided pulmonary symptom tracking to their current monitoring routine. Finally, we found respondents would prefer more ways to communicate changes in pulmonary health to care teams outside of quarterly remote visits, especially in an automated, asynchronous manner.

Introduction

The COVID-19 pandemic has disrupted many important routines, including the quarterly in-person clinic visits practiced by much of the cystic fibrosis (CF) community. Social distancing measures have significantly reduced the practicality of in-person clinic visits, requiring a shift toward at-home approaches to routine care. In order to continue this shift without sacrificing hard-won patient health gains, it is imperative we establish a clear understanding of how best to facilitate home-based care decision-making.

One of the primary objectives of a routine clinic visit in CF is a pulmonary health update. Patients and caregivers (PCG) report on experienced symptoms and lung function tests are performed. Transitioning to home-based care will require new methods for collecting and communicating these important data-points.

Pulmonary health in CF is commonly assessed using the maximal amount of air you can forcefully exhale in one second (FEV1) or the amount of air that can be forcibly exhaled from your lungs after the deepest breath possible (FVC) scores, which are measured using a spirometry device.

This aspect of pulmonary health assessment can present challenges in the transition to home-based care. Home spirometry devices have been shown to be just as valid and reliable as a "gold standard" clinic device in experimental conditions[1,2]. However in "real-world" situations capturing spirometry measurements can be difficult even in a clinical setting[1], as devices are highly sensitive to use protocol, and can register inaccurate readings when tests are administered incorrectly[1]. Home spirometry devices are also expensive, rarely covered by insurance[3,4], and require a prescription. A majority of previous home spirometry research has focused on using home spirometry to capture patients' health on behalf of a trial or research study, instead of patients using spirometry devices organically as part of their care routine. Finally, no strong guidelines exist on how to communicate home spirometry results back to the care team in an actionable manner, to drive care decisions. Studies suggest most people with CF do not routinely measure lung function at home[5].

These barriers to home spirometry, and the new necessity for measuring pulmonary health outside of the clinic, have created a friction point in CF care. The goal of this report is to use the results of a recent survey administered by Folia Health to describe the current methods being used by the CF community to collect and communicate pulmonary health information to providers, and to explore potential new methods for pulmonary health updates as part of remote routine care.

Methods

Survey design

To capture perspectives of PCG, we drafted a 27-question survey for administration to a cohort of existing Folia users in the CF community. Folia users can be either self-managed patients or family caregivers who respond on behalf of a patient. The survey focused on (1) understanding the methods currently used by respondents to monitor and communicate changes in pulmonary health, and (2) measuring sentiment toward potential additions to current methods, including home spirometry.

Nominal questions were utilized where possible, with answer options designed to be inclusive of many potential home-monitoring methods. All ordinal questions used a 1-5 scale, with 1 associated with very easy, not important, or 'no anxiety', and 5 associated with very hard, very important, or 'high anxiety'. Any question pertaining to difficulty used the phrasing, "Overall, how easy or difficult is X" in an attempt to reduce response priming.

The survey first asked about current monitoring and communication methods, then transitioned to questions on attitudes toward other options that could be used to facilitate remote routine care. This section included questions on the difficulty level of measuring pulmonary health at home and communication of this information to care teams. The final section of the survey focused on home spirometry access and attitudes. Branching logic was used based on the response to certain question such as home spirometry access. Prior to administration, the survey was reviewed by an outside researcher in CF, to gauge relevance and patient sensitivity.

A list of all survey questions and distribution of responses can be found in the appendix.

Going forward, we would like to include the results of a provider companion survey. If you are a cystic fibrosis provider, please visit LINK to participate or go to https://nellmeoskyluo.typeform.com/to/pnmo2w.

Administration

The survey was created using Typeform, and administered via an email request to PCG users of the Folia platform. No exclusion criteria were placed on participants, except that they be a patient or caregiver of someone with CF. The survey was intended for 40 participants, and was closed after 43 responses had been collected (approximately 72 hours after launch). All participants were given the option to receive a $10 Amazon gift card in recognition of time spent.

The survey took approximately 5 minutes to complete. The welcome page explained the purpose of the survey and included a confidentiality assurance. All questions except email

address (used only for compensation) were required. Participants were able to change the answer to any question until final submission of the survey.

Analysis

We performed descriptive analysis, response frequency analysis, and average values analysis for survey questions based on three themes: Experiences with tracking pulmonary health at home; current use of home spirometry and attitudes toward prospective use; and patient-provider communication of information on pulmonary health measures. The main stratifications used were age groups (0-17, 18-34, 35-64, 65+) and home spirometry access (Yes/No).

Results

We received a total of 43 PCG responses. **Table 1** breaks down the participants by age, spirometry access, and patient/caregiver status. We received a wide range of age values, ranging from <1 year to 66, and 58% of respondents reported on behalf of patients in the 0-17 age bracket. Nearly all respondents for patients in the 0-17 age bracket (96%) were caregivers, and nearly all respondents for patients in the 18+ age brackets (94%) were self-managed patients. Approximately one out of four survey respondents owned a home spirometry device.

Table 1. Response Breakdown

	Number of responses (%)
AGE GROUPS	
0-17	25 (58%)
18-35	9 (21%)
36-64	6 (14%)
65+	3 (7%)
SPIROMETRY ACCESS	
No access	32 (74%)
Has access	11 (26%)
PATIENT/CAREGIVER	
Patient	18 (42%)
Caregiver	25 (58%)

Tracking pulmonary health at home

Survey questions: 5, 7-10, 13

Overall, the majority of respondents (67%) felt comfortable tracking pulmonary health at home, and most (77%) have not made significant changes to how they monitor their pulmonary health due to coronavirus. The most popular methods for at-home monitoring were 'making a mental note of changes' (65%), 'tracking changes in coughing' (61%), and 'tracking changes in other symptoms' (42%). About one in four respondents used home spirometers to monitor pulmonary health, and a similar number used pulse oximeters with 5 participants (12%) owning both a home spirometer and pulse oximeter device. For those who have made changes in monitoring due to coronavirus, the most common changes reported were introduction or more frequent use of home spirometry (40%, 30%) and recording respiratory symptoms more frequently or adding to the symptoms they're tracking (30%, 20%). Interestingly, no respondents have added pulse oximetry in response to coronavirus.

Although respondents felt tracking pulmonary health at home was not very difficult, most felt access to an affordable, easy-to-use spirometry device (47%) and guided respiratory tracking on Folia (47%) would make home tracking of pulmonary health easier. Introduction of pulse oximetry or help from a respiratory therapist were not as popular. Of four proposed factors that may be considered in deciding on methods of home-tracking (recommendation by care team, ease-of-use, accuracy of measurement, and affordability), participants felt that accuracy of measurement was the most important with 76% of participants claiming this is "very important". However, all four decision factors were rated as at least 'somewhat important' by the majority of respondents.

We found variation in preferred pulmonary health monitoring methods by age bracket. Caregivers of children and teenagers with CF rely mainly on monitoring changes in coughing, while all three respondents in the 65+ age bracket use home spirometry as their primary method of tracking. This difference may be partially attributable to the difficulty of using home spirometry devices with young children, and highlights the importance of age-appropriate recommendations for at-home monitoring.

Respondents who own a home spirometry device reported spirometry as their main method of pulmonary symptom tracking, and also reported a greater level of ease with monitoring pulmonary symptoms. These participants also watched their symptoms at a lower rate than those without a spirometer. For example, in those who own a spirometry device, only 46% made a "mental note" of changes and 36% tracked changes in coughing. However, in the non-spirometry group, these numbers are almost double as 72% of this group makes a "mental note" of changes, and 69% tracked changes in coughing.

Age and spirometry access status did not seem to play a significant role in the importance of our four proposed factors for home-monitoring decision-making.

Tables 2 and 3 show a more in-depth stratification of participant responses' by age and spirometry access.

Table 2. Pulmonary symptom responses

	Top method for tracking Symptoms (% in group)	Percent of people who made changes	Most common change (% among those who changed)	Average difficulty of tracking symptoms	Top method that would make tracking easier (% in group)
OVERALL (N=43)	Making a mental note of changes (65%)	23%	Introducing home spirometry (40%)	2	Affordable home spirometry device, Easy-to-use home spirometry device, Guided respiratory tracking on Folia (47%)
AGE GROUPS					
0-17 (N=25)	Tracking changes in coughing (68%)	16%	Addition to respiratory symptoms that I'm watching, Recording respiratory symptoms more frequently (50%)	2.1	Affordable home spirometry device, Easy-to-use spirometry device, Guided respiratory tracking on Folia (48%)
18-35 (N=9)	Making a mental note of changes, Tracking changes in coughing (78%)	33%	Introducing home spirometry (66%)	2.1	Guided respiratory tracking on Folia (55%)
35-64 (N=6)	Making a mental note of changes (66%)	17%	Recording respiratory symptoms more frequently, Using a home	1.8	Easy-to-use home spirometry device, Affordable

			spirometer more frequently (100%)		home spirometry device (66%)
65+ (N=3)	Home spirometry, Pulse oximetry (100%)	66%	Introducing home spirometry (100%)	1.0	Guided respiratory tracking on Folia (66%)
SPIROMETRY ACCESS					
No access (N=32)	Making a mental note of changes (72%)	16%	Addition to respiratory symptoms that I'm watching, Recording respiratory symptoms more frequently (40%)	2.2	Affordable home spirometry device (60%)
Has access (N=11)	Home spirometry (91%)	45%	Introducing home spirometry, Using a home spirometer more frequently (60%)	1.4	Guided respiratory tracking on Folia (73%)

Table 3. Average importance score for home-monitoring decision factors*

	Recommended by care team	Easy-to-use	Accurate measurement	Affordability
OVERALL	4.3	4.3	4.8	4.4
AGE GROUPS				
0-17	4.3	4.3	4.8	4.4
18-34	4.6	3.9	4.9	4.2
35-64	4.0	5.0	4.7	4.7
65+	4.3	4.7	4.7	4.0
SPIROMETRY ACCESS				
No access	4.4	4.4	4.6	4.3
Has access	4.3	4.3	4.8	4.5

*Scale of 1-5. 1 = “Not important”, 5 = “Very important”

Home spirometry

Survey questions: 14-20, 22-25

We now shift our focus to home spirometry, with questions pertaining to device ownership and attitudes towards home spirometry use.

Only 26% of respondents currently have access to a home spirometry device; however, 82% of the remaining respondents are interested in obtaining one. There was significant variability in reasons for not using a home spirometry device in the past; top reasons included ‘never saw the need’ (40%), ‘too expensive’ (37%), and ‘haven’t thought of it’ (25%). Only 6% of respondents had avoided starting home spirometry because it would cause anxiety.

There were six different spirometry devices owned across the 11 respondents with home spirometers; the most common were Microlife PF (27%) and Spiro PD (27%). (See **Table 4** for additional detail.) Approximately half of all home spirometry users received their device from their clinics or as a result of participating in research (54%); the rest purchased their own devices. The vast majority of respondents reported using their home spirometry devices at least once per month (91%), with 27% reporting once per month, 36% reporting once per week, and a surprising 27% reporting more than once per week.

Interestingly, these reported usage rates are very similar to expected usage rates by respondents who are interested in starting home spirometry. The latter group expected to use their new devices relatively frequently, with 97% expecting use at least once per month, including 23% expecting once per month, 53% expecting once per week, and 19% expecting once per day.

Most home spirometry users felt the device was easy to use, with 82% reporting the device was “very easy” or “somewhat easy” to use, however, only about half (55%) felt “very confident” or “somewhat confident” the device provided accurate results. These results stay very similar when stratifying participants by whether they received any coaching or not. It is worth noting however, that the only person to report using the device is “very hard” and did not receive any coaching.

Finally, home spirometry users reported low levels of anxiety associated with performing pulmonary tests at home (81% reported little or no anxiety).

Table 4. Spirometry device breakdown (for those with spirometry)

Spirometry device	N	Top acquiring method (% in group)	Average Ease / Difficulty*	Average Perceived Accuracy **	Number who received coaching	Most common use Frequency (% in group)	Average Anxiety ***
OVERALL	11	I purchased it (46%)	1.8	3.8	6	Once per week (36%)	1.8
BY DEVICE							
Microlife PF	3	My clinic gave it to me (66%)	1.7	4.7	2	More than once per week (66%)	1.3
Spiro PD	3	I received it for participating in research (66%)	2.0	3.7	2	Once per week, More than once per week, Once per month (33%)	2.3
GoSpiro	2	I purchased it, I received it for participating in research (50%)	3.0	3.5	1	Once per week, A couple times per year or less (50%)	1.0
MIR Smart One	1	I purchased it (100%)	1.0	4.0	0	Once per month (100%)	2.0
Piko Electronic Health Meter	1	My clinic gave it to me (100%)	1.0	3.0	1	Once per week (100%)	3.0
Vitalograph Lung Monitor	1	I purchased it (100%)	1.0	3.0	0	Once per week (100%)	2.0

* Scale of 1-5. 1 = “Very easy”, 5 = “Very difficult”
**Scale of 1-5. 1 = “Not confident”, 5 = “Very confident”
***Scale of 1-5. 1 = “No anxiety”, 5 = “High anxiety”

Communication between patient and provider

Survey questions: 6, 11-12, 21, 26

While most (84%) of respondents reported current patient-provider communication methods were relatively easy to navigate, we found substantial interest in employing additional methods of communication between virtual visits.

The most common reported patient-provider communication methods reported were phone calls (51%), patient portal messages (51%), video telemedicine visits (44%), and emails or text messages (42%). The common combination of communication methods was using both phone calls and patient portal messages for communication. Those who used either the phone or patient portals for communication were much less likely to use email or text messages, while those utilizing video telemedicine visits engaged in higher rates of emails/text communication.

Among suggested additions to current communication practices, the most popular methods were 'more ways to communicate between remote visits' (41%), 'having my clinic automatically notified if my Folia data changes significantly' (30%), and 'regularly updating the care team with automated Folia report' (27%). Interestingly, improvements to remote visits received slightly fewer votes than additions to asynchronous communication outside of visits. In all, 81% of respondents would like to see more automatic, asynchronous communication of pulmonary health information between visits. One respondent suggested that it would be helpful to have a 'point-person' to contact at the clinic.

For home spirometry results, current spirometry users differ in their top choice for results communication. Nearly half (45%) of respondents preferred to discuss the results personally with their care teams, either at the next remote visit (36%) or by phone (9%). The rest preferred asynchronous communication of results, either with results automatically sent to providers in a report like the Folia Appointment Guide (36%), or discussed via patient portal or other remote communication (18%). Notably, all of the home spirometry users were comfortable sharing results with their clinics. Prospective home spirometry users favored remote check-ins for communication of spirometry results (53%), followed by communication in a report like the Folia Appointment Guide (23%). Only 14% favored discussion at the next appointment or by phone call.

Table 5 provides a breakdown of communication method responses broken down by age groups and spirometry access.

Table 5: Communication method responses by age and spirometry access

	Top method of communication (% in group)	Avg difficulty of communication	What would make communication easier (% in group)
OVERALL	Call with clinic, Patient portal messages (51%)	1.8	More ways to communicate between remote visits (42%)
AGE GROUPS			

0-17	Patient portal messages (68%)	1.7	More ways to communicate between remote visits (40%)
18-34	Video telemedicine visits (55%)	1.9	More ways to communicate between remote visits (55%)
35-64	Call with clinic, Video telemedicine visits (83%)	2.0	More ways to communicate between remote visits (50%)
65+	Emails or text messages (66%)	2.0	Having my clinic automatically notified if my Folia data changes significantly (66%)
SPIROMETRY ACCESS			
No access	Call with clinic, Patient portal messages (53%)	1.7	More ways to communicate (47%)
Has access	Video telemedicine visits (55%)	2.1	Better technology for remote visits (36%)

Discussion

Overall, most respondents already have a strategy in place to monitor their pulmonary health at home, and do not experience significant difficulty with either monitoring or communicating changes to their care teams. (As one respondent stated in the survey comments, “It seems pretty easy [to monitor] if you know your body and have the tools.”) The most common monitoring method used by respondents was to keep an eye on symptoms, using a combination of digital tracking and making mental notes of changes. Home spirometry was only available to one in four respondents, but for these individuals, it was a primary method of pulmonary monitoring.

Respondents seemed to feel there is room to grow in both monitoring and communication methods. Most are interested in expanding at-home pulmonary health measurement to include home spirometry and guided respiratory symptom tracking, with results communicated not only during telemedicine visits but via remote, asynchronous communication methods like patient portal messages or automatic reports sent to clinicians.

So far, only 23% of our respondents have made a change to their tracking routine due to COVID-19, but those with access to home spirometry were much more likely to make a change, and were also more likely to report a high degree of ease in monitoring pulmonary symptoms. Only 16% of participants without a spirometry device changed their tracking behavior, primarily becoming more vigilant in tracking respiratory-related symptoms.

In considering the introduction of home spirometry, we found there is no clear ‘favorite’ device, and that additional guidance is required for the community to agree upon standards of

measurement frequency. Although there is broad consensus among respondents that home spirometers are used at least once per month, there is significant variation in actual and expected use frequency (ranging from once per day to once per month). Even at once per month, this cadence is significantly greater than the usual in-clinic measurement of once per quarter.

Despite some reports of very frequent home spirometry use, we were interested to find both current and prospective home spirometry users seem relatively unconcerned about anxiety related to performing pulmonary function measurements at home. Some research suggests cystic fibrosis patients may experience higher rates of anxiety[6], and measuring lung function in the home could cause stress if measurements showed any deterioration in performance[7,8].

Previous research covering home spirometry use is a bit limited, possibly due to expense or feasibility, but has shown using home spirometry to monitor pulmonary function can lead to a decrease in dangerous exacerbations[5] and provide useful clinical information[6]. However, it is yet to be determined how regular use of home spirometry affects long-term health outcomes, as these limited studies found disease progression to be relatively unchanged.

Through this survey, we have found that the COVID-19 crisis has provided the cystic fibrosis community with an impetus for experimentation with home spirometry and home-reporting of respiratory symptoms, as nearly all routine care for cystic fibrosis has become remote. We have also found a need for a greater degree of guidance from the provider community regarding home spirometry use frequency, and the most important symptoms to track at home and frequency of tracking suggested. Finally, it is important to note that patients and caregivers cannot currently decide to use home spirometers without a prescription - and so collaboration between patients and providers will be paramount in expanding home spirometry use.

We would like to encourage the community to be proactive in designing studies to test the effectiveness of new monitoring and communication methods, to use this time of natural experimentation to ultimately improve the efficiency and effectiveness of the care that people with cystic fibrosis receive.

Limitations

This survey is subject to sample bias, as all participants came through the Folia Health platform. Patients who use Folia Health to help manage their care may be more active in symptom monitoring and decision-making. Therefore, it is possible participants in the study engage in more activities to monitor and maintain their health status than those in the general population.

Additionally, the answer choices reflected in this survey were not exhaustive to all possibilities for monitoring and communication methods in cystic fibrosis pulmonary health management.

Conclusion

Based on these findings Folia will be adding to its platform to better meet the needs of remote routine care

Conflicts of Interest

The authors declare that there are no conflicts of interest.

Data Availability

The data used to support the findings of this study can be found here

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