METHODS FOR MONITORING PULMONARY HEALTH IN CYSTIC FIBROSIS PATIENTS IN A REMOTE-FIRST CARE ENVIRONMENT - A SURVEY

A.PITTMAN[1], N.M.LUO[1]

1. Folia Health, Boston, MA

INTRODUCTION

The COVID-19 pandemic has disrupted many important routines, including the quarterly inperson 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.

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 study 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.

AIM

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.

METHOD

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. The survey was reviewed by an outside researcher in CF, to gauge relevance and patient sensitivity.

RESULTS (N = 43)

- Pulmonary Symptoms
  - 67% felt comfortable tracking symptoms at home
  - 77% already had a plan in place
- Adding new monitoring items
  - 84% were interesting in adding something new
- Improving home monitoring
  - 88% wanted more or better communication methods
- Home Spirometry
  - 26% own a home spirometry device
  - 81% would be interested in adding one
  - 96% would use one at least monthly
  - Wide cadence range
- About half of respondents would track guide symptoms

Table 1. Response Breakdown

	Responses (N)
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%)

CONCLUSIONS

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.

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.

ACKNOWLEDGEMENTS

CONTACT INFORMATION

Adam Pittman ScM adam@foliahealth.com