Cystic Fibrosis Research News

Title:
Mobile Health Platform for Self-management of Pediatric Cystic Fibrosis: Impact on Patient-Centered Care Outcomes

Lay Title:
A mobile app for self-management of CF and improved patient-centred care

Authors:
Gabriela R. Oates, PhD[1]; Cathy Mims, RN, MSHQS[2]; Robin Geurs, BS[1]; Rikard Bergquist, MS[3,4]; Andreas Hager, LLM[4]; Jennifer S. Guimbellot, MD, PhD[1]; Anastasia M. Hartzes, PhD[5]; Hector H. Gutierrez, MD[1]

Affiliations:
[1] Pediatric Pulmonary and Sleep Medicine, University of Alabama at Birmingham, Birmingham, AL, USA
[2] Children's of Alabama, Birmingham, AL, USA
[3] Motivo Management, LLC, Reno, NV, USA
[4] Upstream Dream AB, Stockholm, Sweden
[5] School of Public Health, University of Alabama at Birmingham, Birmingham, AL, USA

What was your research question?
Previously, we adapted a CF app (Genia) to the needs of children and adolescents with CF, their families, and providers in a U.S. CF care centre. We now tested whether the use of Genia is feasible, acceptable, and beneficial for patient-centred care outcomes.

Why is this important?
Mobile apps allow users to track symptoms, behaviours, and events between clinic visits and share these data with their providers for coproduction of care and better disease management. Routine use of such patient-generated data has been linked to improved symptoms, quality of life, patient-clinician communication, and satisfaction with care in other complex conditions. Adoption in CF care has been limited.

What did you do?
We conducted a one-group study with 40 participants: 30 parents of children with CF (14 years and younger) and 10 adolescents with CF (15 years and older). Over the course of 6 months, study participants (1) used the app's functionalities as relevant to them based on

Cystic Fibrosis Research News

their own needs; (2) completed brief weekly check-ins; (3) generated a pre-visit report with standard questions and select app data before seeing their CF provider; (4) shared their experiences in an exit survey; and (5) completed baseline and 6-month surveys on shared decision-making, satisfaction with care, and CF-related quality of life.

What did you find?

Participants reported significant improvements in satisfaction with care and shared decision-making, and nominal improvements in the domains and symptom scales of CF-related quality of life. Improvements were sustained over 6 months despite the COVID-19 pandemic. The use of Genia was feasible, with participants recording more than 4,400 observations (mean 84) and submitting 496 weekly reports (mean 14) and 70 quarterly pre-visit reports (mean 2). The most useful app feature for participants was the pre-visit report (67%). The top symptom trackers were those for cough (24%), appetite (21%), energy (18%), and medicines (18%). The use of Genia was acceptable based on 95% retention rate.

What does this mean and reasons for caution?

The use of patient-generated health data collected and shared with a CF app (Genia) was feasible, acceptable, and associated with improved measures of patient-centred care. Study results support wider use of the app in clinical settings. Results are limited by the absence of a control group, the single-centre patient population, and the small sample size. The study did not assess clinical outcomes such as lung function, pulmonary exacerbations, or nutritional status, nor the potentially confounding effect of highly effective modulators. The study was conducted during the COVID-19 pandemic, which affected daily activities.

What's next?

This is the first study that assessed if patient-generated health data can be used to improve patient-centred care. Future studies need to use more rigorous study designs with larger samples that are representative of the larger CF population and evaluate clinical outcomes. The integration of the patient-generated health data in the process of CF care delivery should also be evaluated.

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