primary studies - published RCT

Providing Mobile Patient Access to Their Electronic Secondary Care Patient Record in Adults With Cystic Fibrosis: Results of a Prospective, Parallel, Randomized Open-Pilot Quantitative Study.

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Study design (if review, criteria of inclusion for studies)

Parallel, randomized, open, pilot study

Participants

91 people with CFAB were recruited on a consecutive basis, from outpatient clinics or as inpatients on the regional Leeds adult CF unit.

Interventions

A modified primary care electronic health care record (EHR). This study aims to evaluate the feasibility, benefits, usability, and acceptability to patients of providing secure access to linked secondary care in CF. Intervention (EHR access; I) vs control group (no EHR access; C).

Outcome measures

At baseline and 6 months, paper-based self-report questionnaires were completed by participants to assess having access to EHR on psychological impact, patient satisfaction, quality of life (QoL), patient and physician relationships, and patterns and rates of adherence to treatment. Perceptions and engagement with Patient Access and computer literacy were also assessed.

Main results

A total of 91 people with CF completed the 6-month study (intervention n=45; median age 27.5, IQR 12.0 years; 22 male participants; control group n=46; median age 27.0, IQR 15.0 years; 29 male participants). Median number of logins was 9 (range 1-205). There was no effect of Patient Access on levels of anxiety (Generalized Anxiety Disorder-7; I=3.0, C=5.0), all symptom QoL scales and seven QoL domains (Cystic Fibrosis Questionnaire-Revised; respiratory I=63.89, C=55.56; weight I=100.00, C=66.67; digestion I=88.89, C=88.89; physical I=60.42, C=50.00; vitality I=54.17, C=41.67; emotional I=86.67, C=66.67; role I=75.0, C=75.0; body image I=77.78, C=66.67; eating disturbances I=88.89, C=100.0; treatment burden I=55.56, C=55.56), levels of depression (Patient Health Questionnaire-9; I=3.0, C=7.0), confidence in managing health care (Patient Activation Measure-13; I=66.67, C=60.63), level of trust in health care professionals (patient and provider perceived efficacy in patient-physician interaction; I=49.0, C=47.0), and computer literacy. Patient Access scored 86% for satisfaction, 82% for ease of use, and 80% for usefulness (Perceived Health Web Site Usability Questionnaire). Of those who had EHR access, 41 of 42 (98%) participants agreed that access to EHR should continue.

Authors' conclusions

This pilot study suggests that providing access to EHR in adults with CF does not appear to have a negative effect (increase levels of anxiety or decrease QoL), and uptake by patients has been very positive. Prospective studies are needed to investigate the long-term effect on objective health outcomes and how we can improve the functionality of such apps from the patient perspective.

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See also

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Keywords

non pharmacological intervention - devices OR physiotherapy;