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Cystic Fibrosis Research News

Title:

Use of a mobile application for self-management of pancreatic enzyme replacement therapy is associated with improved gastro-intestinal related quality of life in children with Cystic Fibrosis

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What was your research question?

Will patients and parents report a better quality of life and fewer gastro-intestinal symptoms whilst using a mobile application that can calculate the dose of pancreatic enzymes needed per meal?

Why is this important?

Most patients with Cystic Fibrosis (CF) suffer from pancreatic insufficiency, in other words the fat they eat is not well digested and absorbed. For many patients this leads to abdominal pains, fatty stools and poor weight gain. Taking supplements of pancreatic enzymes with every fat-containing meal is a well-known, efficient treatment for CF, but there is no right way to optimize their dose. Low doses of enzymes do not address the abdominal pain and poor weight gain.

The MyCyFAPP project is a large European project to assist nutritional interventions in CF and one of the aims was to develop a mobile application, to support patients in optimizing their pancreatic enzyme treatment.

What did you do?

First, a mathematical model of fat digestion was established based on laboratory data in a CF context. This mathematical model was integrated in a mobile app, the MyCyFAPP. Also in the app were a diary for food intake, a table to report abdominal symptoms, an online connection with the health care professionals (doctor, dietician) to provide personal feedback, and educational material including a CF handbook and games. All app content was available in 6 languages (Dutch, English, Flemish, Italian, Portuguese, Spanish). Participants used the MyCyFAPP in a 6-months study, where we evaluated the association between their use of the MyCyFAPP and their abdominal symptoms and quality of life. Four questionnaires on general and gastro-intestinal specific quality of life were used to evaluate self-reported changes after both 3 and 6 months, as well as parental observations.

What did you find?

We recruited 171 children aged between 2 and 18 years from 6 European CF centers.
We observed that the gastro-intestinal specific quality of life score was improved from a median (the value separating the top half of score from the bottom half) of 84.3 at the start to 89.4 after 6 months of using the APP. A similar improvement was observed in the median score of the parental survey (80.1 to 85.7). Patients reporting more symptoms at start reported more improvement in their symptoms compared to patients with fewer symptoms

at the start. The median percentage of app use was 46%, which represents use every second day and in line with the anticipated use. Patients and parents enjoyed using the app, and memorized which dose was needed for frequently consumed meals.

What does this mean and reasons for caution?

We are positive that the MyCyFAPP is a useful tool to help children with CF and their parents to optimize pancreatic enzyme treatment, especially for those children with more abdominal symptoms and poor weight gain.
Unfortunately, we were not able to compare the results with a 'control' group, which would be a group of patients receiving normal care and not using the app. Because of this we cannot be sure that the improvement in quality of life is the result of using the app and not from having their use of pancreatic enzymatic treatment closely studied. Moreover, the study also showed contradictory changes in height (increase) and weight (decrease).

What's next?

Further confirmation of the promising results is needed, the effect on growth must be clarified, and a CE mark (Certification Mark for products sold within the European Economic Area) must be obtained before the app can be safely and efficiently used in the clinic.

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