Cystic Fibrosis Research News

Title:
Feasibility Testing of a Web-Based Reproductive Decision Support Tool for Cystic Fibrosis

Lay Title:
Testing the Usability, Acceptability, and Appropriateness of a Web-Based Reproductive Decision Support Tool for Cystic Fibrosis

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What was your research question?
Is the MyVoice:CF reproductive decision support tool acceptable, usable, and appropriate for women with cystic fibrosis (CF) who are trying to make decisions about their reproductive goals, including parenthood, pregnancy, and/or birth control choice.

Why is this important?
New treatments are leading to longer and healthier lives for people with CF. Because of this, more people are considering whether and how to become parents. We designed an online, interactive tool for people with CF called MyVoice:CF. This tool is designed to provide information on if and how CF and CF medications affect fertility, pregnancy, parenting, breastfeeding, and birth control. The tool also has activities to help people reflect on their reproductive goals and plan how to have conversations with their healthcare providers and family. We needed to see if women found the tool helpful and informative.

What did you do?
We recruited women with CF between ages 18 and 44 years from a single CF center in the United States to take part in a study to test whether the MyVoice:CF tool was acceptable,
usable, and appropriate for people with CF. Participants completed four surveys and one interview. We also recruited members of the adult CF center team to complete a survey and participate in a focus group to give feedback on if and how the tool impacted clinic operations and conversations with women with CF.

What did you find?
Forty-three women completed the first survey and 40 rated the MyVoiceCF tool. They rated MyVoice:CF’s acceptability as 4.48/5, appropriateness as 4.61/5, and usability as 82.25/100. Participants reported they felt significantly more prepared to discuss reproductive health with their care team after using the tool, and significantly more reported having had a conversation about their reproductive goals with their CF team. Ten CF providers also participated in the survey and rated MyVoice:CF as a highly feasible tool and reported no negative impacts on clinic operations.

What does this mean and reasons for caution?
MyVoice:CF is acceptable, appropriate, and usable for people with CF. Based on study results, the tool seems to improve their ability to discuss reproductive health with their care teams. Due to the small number of participants and lack of a comparison group, the results may not be applicable to the general CF population. Our study was only able to examine the impact of the tool over the course of three months and may have greater or lesser impact over a longer period of time.

What’s next?
Future studies should study the impact of MyVoice:CF on reproductive health communication, plans, and outcomes in greater detail.
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MyVoiceCF
A reproductive health tool for women with CF

Original manuscript citation in PubMed

Cystic Fibrosis Research News
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