

Cystic Fibrosis Research News

Title:

Implementation and Evaluation of Fertility Preservation Telehealth Counseling for Males with Cystic Fibrosis

Lay Title:

Evaluating Fertility Preservation Telehealth Counseling for Males with Cystic Fibrosis

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What was your research question?

This study assessed the feasibility, acceptability, and potential effectiveness of telehealth counseling to increase knowledge about fertility preservation (FP) as a reproductive option for males with cystic fibrosis (CF), satisfaction with CF reproductive care, and confidence to seek reproductive and FP care.

Why is this important?

Although males with CF usually produce sperm, most are infertile because they do not have a vas deferens (tube that carries sperm) and need medical help to have biological children (CFF, 2019; 2022). Unfortunately, many males with CF have limited knowledge about how CF affects sexual/reproductive health (Kazmerski et al., 2021). Persons with CF should receive sexual/reproductive health and FP education early in life. Specifically, conversations about preserving (freezing and storing) sperm, eggs, and/or embryos should occur before lung transplantation due to potential harmful effects of post-transplant medications on sperm, possibly limiting a person's reproductive options (De Pinho & Sauer, 2014; Semet et al., 2017).



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What did you do?

We provided FP telehealth counseling to males with CF in the U.S. ages 18 or over with no history of lung transplant. Participants completed surveys immediately before and two months after counseling to measure knowledge about CF-specific fertility and FP, satisfaction with their reproductive care, and self-confidence in seeking fertility care. One week after counseling, we measured how acceptable and appropriate the counseling was to participants and how feasible it was to complete. We interviewed participants one week after counseling to learn about their experiences with the counseling and get feedback for improvement.

What did you find?

Thirty males with CF (ages 22-49 years) completed counseling. Most were in a relationship (70%) and White (86.7%). Despite wanting providers to introduce education, wanting children (81%), and identifying the CF team as their primary care provider (97%), 44% reported not receiving information about infertility by their CF team. Participants found FP telehealth counseling acceptable, appropriate, and feasible. FP knowledge, satisfaction with care, and confidence to seek fertility care improved at two months post-counseling. Participants were satisfied with the length, educational materials, and topics discussed during the counseling session, but stated that education should begin earlier and more regularly.

What does this mean and reasons for caution?

Sexual/reproductive health and FP are important topics for all persons with CF. These discussions are critical for patients to understand reproductive options and make informed decisions. Findings suggest telehealth counseling can be included in CF care and may improve FP knowledge, care satisfaction, and self-confidence. Although ethnic and racial distribution of our participants, particularly lower percentages of White/Hispanic males, is not representative of the US population with CF, participants included mixed ages, U.S. regions, and fertility experiences. Additionally, counseling was done by one provider from an academic institution with an active FP program. Wider implementation may change acceptability and effectiveness because of differences in provider training and communication.

What's next?

This was the first study assessing FP telehealth counseling for males with CF. Next steps include larger studies to make sure results can be reproduced. Studies on sexual/reproductive health and FP counseling for females, younger males with CF, and other transplant populations may be warranted.

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Original manuscript citation in PubMed

<https://pubmed.ncbi.nlm.nih.gov/38942720/>

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