



Cystic Fibrosis Research News

Title:

Men's Sexual and Reproductive Health in Cystic Fibrosis in the Era Highly Effective Modulator Therapies: A Qualitative Study

Lay Title:

Men's Sexual and Reproductive Health in Cystic Fibrosis in the Era Highly Effective Modulator Therapies: A Qualitative Study

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What was your research question?

Our research aim was to explore the experiences and preferences of men with cystic fibrosis (CF) related to sexual and reproductive health (SRH) decision-making and care in the era of highly effective modulator therapies (HEMT) to provide evidence for improvements to SRH care provision and effective communication around these topics.

Why is this important?

This is important because the increasing use of HEMTs has led to improved health and life expectancy for many with CF. Due to this improvement, men with CF have been able to focus on SRH aspects of their CF, such as fertility and sexual functioning. Despite this shift of focus, past research has indicated insufficient discussion and care provision within CF health care regarding SRH, as indicated by both providers and patients.

What did you do?

We interviewed adult men recruited from around the United States through the CF Foundation Community Voice, a virtual CF forum, and locally through physician referrals. We interviewed them through telephone interviews and explored their experiences regarding their SRH in general and with their CF healthcare providers. Two researchers then analyzed

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the transcribed interviews and created a codebook to identify key themes. A codebook is a collection of ideas expressed throughout the interviews that are subsequently taken from the interviews and applied to see if they appear throughout other interviews. From this codebook, we determined common themes amongst men with CF.

What did you find?

We interviewed 24 men with CF and identified the following themes: 1) CF SRH concerns, specifically infertility, can have negative impacts on men's perception of masculinity, relationships, and mental health; 2) As life expectancy increases, addressing male SRH is increasingly important in CF care; 3) Men with CF experience lack of SRH counseling and care; 4) Conversations about SRH should begin in early adolescence and be addressed regularly by CF providers, addressing some, but not all aspects, at each meeting; 5) Men with CF value peer support and SRH information featuring the experiences of other men with CF.

What does this mean and reasons for caution?

Men with CF desire comprehensive SRH discussions initiated by the CF team beginning in early adolescence and they recognize the increasing importance of SRH being addressed in CF care due to the increased utilization of HEMT. Reasons for caution include bias of participants based on their increased engagement levels in the national CF community, homogeneity with regards to race and sexuality from a small sample size of men with CF, and discomfort with a female interviewer, which could affect participant responses.

What's next?

Future research is needed to better understand the impact of infertility and SRH concerns on the mental health and self-identity, especially regarding masculinity, of men with CF. Additionally, readily accessible SRH resources should be made and trialled with men with CF for their efficacy.

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