

Cystic Fibrosis Research News

Title:

Sharing decisions on reproductive goals: A mixed-methods study of the views of women who have cystic fibrosis.

Lay Title:

Sharing decisions about family goals: A study exploring women's experiences and needs for support.

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What was your research question?

To understand to what extent women with Cystic Fibrosis (CF) felt their information and support needs in relation to decisions about starting/expanding their family had been met. To understand experiences of discussing options for having a family with their healthcare providers and to find out what type of support and information would be most useful to support decisions.

Why is this important?

Since the introduction of Cystic Fibrosis Transmembrane Conductance Regulator (CFTR) modulator therapies, people with CF are living longer healthier lives. More people with CF are now considering having families of their own. There are complex medical, psychological, social and financial aspects to becoming a parent with CF. Providing useful and timely support

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to people with CF with their decisions about their reproductive goals is important in enabling them to make informed decisions that are in-line with their individual values and preferences.

What did you do?

An international questionnaire for women who have CF and are between 18-49 years old was advertised through social media in the United Kingdom, Ireland, New Zealand, Australia, Canada and United States of America. In total 189 women took part. From the women who completed the survey, 21 also took part in interviews which enabled a more in-depth understanding of their experiences and decision support needs. The 21 women who took part in the interviews were from different countries, backgrounds and had different preferences for wanting/not-wanting to start or grow their families.

What did you find?

Women often felt that they did not have enough information about starting a family or opportunities to discuss their preferences for having a family within healthcare consultations. Women who felt more confident in decisions about having a family were more satisfied with the communication they experienced with healthcare professionals. Interviews showed that women wanted to discuss family decisions with their healthcare professionals but their ability to do so was reduced because of a lack of information about options and lack of opportunity to have conversations focusing on planning a family with healthcare professionals.

What does this mean and reasons for caution?

Women with CF are keen to engage in conversations with healthcare professionals about reproductive health, but currently there is not enough information and support to enable them to do so. Changes need to be made including more information about having a family when living with CF, training for healthcare professionals to have conversations about preferences for family and the organisation of healthcare in general to better support women's ability, motivation and opportunity to have preference based discussions with their health professionals. The participants in the study were mainly from the UK and USA and more of the participants had children.

What's next?

There is a need to provide support with these complex and emotive decisions. More research is needed which looks at the views of women from different countries and backgrounds.



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Original manuscript citation in PubMed

<https://pubmed.ncbi.nlm.nih.gov/36863947/>

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