

Cystic Fibrosis Research News

Title:

Intimacy and sexual life of females with cystic fibrosis

Lay Title:

What is the intimate quality of life of women with Cystic Fibrosis?

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What was your research question?

As a psychologist and sexologist working in a CF adult centre in France, I heard discreetly that women with CF experienced issues frequently in their sexual life. It was then important to characterise those issues, to quantify them, to understand and evaluate the quality of the sexual life of these women.

Why is this important?

The topic of sexual quality of life was somewhat absent from CF management, putting aside themes such as urinary incontinence, genital yeast infections, fertility, pregnancy, and access to medically assisted procreation. Women with CF were implicitly considered to be sexually active and to have no more issues with their sex lives than the general population. They did not complain to caregivers because sexual issues are intimately stigmatising and that women didn't identify these problems as linked to their CF illness; the recent social uncovering of female's sexual issues made this topic more visible and easier to express for women with CF.

What did you do?

The investigator of the study was a clinical psychologist and sexologist woman with 18 years' experience in a specialised unit for adults with CF; she was physically present on sites in 11 CF centres and available for discussion with each participant. Conditions for inclusion in the study was to have or have had sexual relationship; women were individually informed of the aims and confidentiality of the study. We collected data from a questionnaire adapted to CF issues and got a sample of 212 responses. Qualitative data were analysed from 15 one-to-one audio-recorded interviews to understand impact of issues on their personal life.

What did you find?



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We found that sexual disorders are more prevalent in women with CF than in the general population. Unlike presumed causes such as pulmonary exacerbation, coughing, repeated yeast infection or incontinence, a great majority of women reported that problems during intercourse were mainly related to a lack of vaginal lubrication resulting in discomfort or pain. The qualitative part of this study showed that these issues were psychologically costly for them who felt “*punished twice*” with negative outcome on their intimate relations, avoidance of intercourse, feeling of being different and not understanding a problem that is rarely talked about in their referral centre. They expressed a sadness difficult to share.

What does this mean and reasons for caution?

These results mean that sexual issues of women with CF are poorly known and poorly understood, that intimate concerns should be more discussed in CF centres as women with CF expressly wish. The study took place at a time when triple combination of CFTR modulators was progressively made available to people with CF: these new treatments also seem to have effects on sexual quality of life of women with CF: timing of this study is to be considered as conducted before widespread use of CFTR modulators who changed the face of CF.

What's next?

Next step is to conduct a study to assess effects of CFTR modulators on women's sexual life.

Original manuscript citation in PubMed

<https://pubmed.ncbi.nlm.nih.gov/39183126/>