

Cystic Fibrosis Research News

Title:

Olfactory Loss in People with Cystic Fibrosis: Community Perceptions and Impact

Lay Title:

Loss of the Sense of Smell in People with Cystic Fibrosis: Community Perceptions and Impact

Authors:

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What was your research question?

We investigated how changes in sense of smell impact quality of life in the cystic fibrosis (CF) community, and we explored the CF community's interest to engage in research on sense of smell. To achieve this, we constructed and utilized a survey distributed via the CF Foundation Community Voice program.

Why is this important?

Loss of sense of smell is widespread in the CF community and can negatively affect quality of life, but it remains a relatively unexplored area of research. This study delves into the community's perspectives on loss of sense of smell, examines the effects of altered smell on daily life, and gauges interest in participation in research. These insights will guide potential future studies and interventions.



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What did you do?

This study evaluated sense of smell in the individuals with CF, exploring community perceptions of their sense of smell and quality of life. A 21-question survey was distributed through the CF Foundation Community Voice program to adults with CF or parents of children with CF. This questionnaire incorporated questions from a survey to assess smell-specific quality of life and gathered insights on changes in sense of smell and interest in future research in this area.

What did you find?

Greater than 90% of survey participants reported problems in their ability to smell and believed their sense of smell had changed over time. Quality of life impairments, assessed by the validated survey, were evident with over one-third of respondents reporting their sense of smell problems made them feel angry, altered their eating preferences, and worsened isolation. The majority of respondents reported that sense of smell should be investigated further and expressed willingness to participate in future studies aimed at understanding and addressing this topic.

What does this mean and reasons for caution?

This research underscores that a subset of people with CF experience loss of smell problems that noticeably affect their quality of life. A majority of respondents reported that having a good sense of smell was important to them; however, CF-related sense of smell issues remain not fully understood and may be underreported. The cohort's expressed willingness to engage in research on loss of smell reflects a strong demand for better understanding and management of this condition. Nevertheless, this study's results should be interpreted considering its limitations, such as the modest survey response rate which may not fully represent the broader CF population.

What's next?

These findings signal to CF clinicians and researchers that improving olfaction is a priority for many individuals with CF. Understanding the timing of onset and progression of loss of smell in CF and the effectiveness of early interventions are future areas of research.

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