



Cystic Fibrosis Research News

Title:

Characterization of sleep in emerging adults with cystic fibrosis on elexacaftor/tezacaftor/ivacaftor

Lay Title:

Understanding sleep in young adults with cystic fibrosis (CF) taking elexacaftor/tezacaftor/ivacaftor (ETI)

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What was your research question?

We asked young adults with and without CF: How common are sleep disorder symptoms? What medications are being used to promote sleep? Has sleep changed since starting ETI? How is your sleep-related quality of life? How is your sleep associated with other health-related quality of life measures?

Why is this important?

Young adulthood is a time of both identity development, and major life changes, including education, work, and relationships. In addition, young adults commonly do not get enough sleep, have poor quality sleep, and take longer to fall asleep than other age groups.

ETI is a highly effective modulator therapy that has had profound health benefits for people with CF, including improved lung function, decreased hospitalizations and extended life span. However, little is known about the effects of ETI on sleep, and in particular sleep among young adults.

What did you do?

We asked young adults with and without CF to complete a questionnaire about their sleep and use of sleep aids.

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What did you find?

Over 88% of people with CF reported no change or improvements in sleep since starting ETI. However, people with CF reported using more sleep aids and having poorer quality sleep. Further, a stronger association between poor sleep and poor health-related quality of life was seen in people with CF than peers without CF. While over-the-counter sleep aid use was similar between people with and without CF, 75% of people with CF reported using marijuana or CBD for sleep compared to 44% of people without CF. Finally, people with CF reported more sleep disturbances and pain than peers without CF.

What does this mean and reasons for caution?

This study highlights that ETI may improve sleep in young adults with CF. Nonetheless, sleep remains a significant concern in this young adult population. Study limitations include the use of surveys, but no objective measures of sleep, recall bias which may have been influenced by the length of time people were taking ETI (up to 2.5 years), and the overall transformative health improvements frequently experienced by people taking ETI.

What's next?

Our data suggest more research is needed to understand sleep among people with CF in order to develop clinical practice guidelines. Standard evaluations and treatment guidelines can be used to better address sleep disturbances in people with CF.

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