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Cystic Fibrosis Research News

Title:

Actigraphic and Patient and Family Reported Sleep Outcomes in Children and Youth with Cystic Fibrosis: A Systematic Review

Lay Title:

Sleep in Children and Youth with Cystic Fibrosis: A Review of the Research

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What was your research question?

How can we better understand usual sleep in the home environment for children and youth, aged 0-25 years, with cystic fibrosis (CF)?

Why is this important?

Concerns about sleep are commonly reported by children and youth with CF. However, these concerns are often not well addressed in research or in clinical care. Poor quality of sleep has negative effects on quality of life, ability to fight infection, ability to regulate blood sugar, ability to concentrate at school/work, and ability to feel well emotionally. These negative effects can be further intensified for those with CF who are already at an increased risk of infection, increased risk of altered blood sugars and who face the daily emotional challenges of living with a chronic and life-limiting illness.

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What did you do?

This review provided a summary of the research conducted on usual or normative sleep in children and youth, aged 0-25 years, with CF. Five online health-related research databases were searched for relevant research articles. Two reviewers independently screened the articles and included only research articles that had participants aged 0-25 years with CF and measured sleep by questionnaire or actigraph. An actigraph is similar to a watch and is worn on the wrist and determines how long a person is sleeping and how long they are awake based on how much they move.

What did you find?

We found 31 relevant research articles. Analysis found that when sleep was measured by actigraph, the percentage of time actually asleep during the sleeping period was less, and the number of nighttime awakenings was greater in children and youth with CF when compared to healthy peers. Sleep quality, measured by questionnaires, was also poorer for children and youth with CF. This review further found thirteen factors that were related to poor sleep and these included disease severity, oxygen level, body mass index, blood sugar regulation, nighttime cough, new pulmonary exacerbation, CF related factors (e.g., frequent nighttime trips to the bathroom, overnight tube feeding), quality of life, mental health, behavioural issues, pain, family factors (e.g., secondhand smoke exposure, mood disorder in a parent) and sleep hygiene (e.g., screen time before bed).

What does this mean and reasons for caution?

In children and youth with CF, evidence exists of nighttime sleep disturbance and poor sleep quality. Understanding usual sleep in the home environment and as reported from the perspective of children and youth with CF and their parents, is a first step in responding to an important clinical concern and developing a sleep assessment and intervention strategy.

However, more research is needed in this area. The conclusions of this review were limited by the quality of evidence of the included research studies.

What’s next?

As treatments advance, individuals with CF are living longer than ever before, which stresses the importance of sleep assessment and sleep research. Clinically, sleep assessment should be an important part of routine CF care. Future research is needed to better understand sleep disturbance and its effect on sleep quality which could lead to targeted interventions to improve sleep, well-being and quality of life.

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