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Cystic Fibrosis Research News

Title:

Pain in adults with cystic fibrosis – are we painfully unaware?

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Pain in adults with cystic fibrosis – are we painfully unaware?

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What was your research question?

Our research aimed to investigate pain in cystic fibrosis (CF) compared to the general population. Further, we also wanted to compare not only the significance of pain but also the frequency and severity of pain experienced by people living with CF.

Why is this important?

It is well known that pwCF live with pain; however, it has never been specifically measured and evaluated against the general population using pain measurement tools. Further, there is a lack of knowledge on pain medication and its perceived effectiveness in pain in CF and also on modulator therapies and any effects it may have on pain. We also wanted to investigate how pain is managed in the clinical setting and any barriers to receiving pain-specific treatment or care.

What did you do?

Our study was conducted by disseminating an online survey using social media such as Facebook and Instagram and via community-facing bodies such as Cystic Fibrosis Australia and CF Together. The survey itself, designed by a pain medicine specialist and the research team, consisted of four validated tools previously used in pain studies and areas to provide detailed lived experiences with pain. To compare people living with CF (pwCF) and the general population, two surveys were distributed online and analysed after nine months.

What did you find?

Over 200 people responded to the survey, with 117 of those pwCF. The findings of the survey described significantly more pain being experienced by pwCF and at a much greater frequency. Notably, nearly 70% of pwCF described daily pain at a much greater severity and also reported multiple areas or locations of pain, such as headaches, chest, back, abdominal and sinus pain. Our study, similar to other studies in America, also described unmet needs and poor management of pain in the clinic by their CF teams. When evaluating the effects of modulators on pain, there was no difference in those who were prescribed modulators and those who were not.

What does this mean and reasons for caution?

Whilst our study highlights the need for more studies on pain in CF, it also emphasises that pain is undermanaged and, in some cases, dismissed by CF Teams, meaning that clinical pathways specific to pain in CF are needed. Whilst our study had a great response, we acknowledge that a larger sample size and a more balanced mix of genders is needed in the future.

What's next?

Pain in CF is significantly understudied, and so future research is needed, particularly in pain profiling and potentially genetic research, allowing for more personalised pain management plans and therapies.

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