

Outcomes That Matter to Adolescents With Continuous Headache Due to Chronic Migraine and Their Parents

A Pilot Survey Study

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Study Question

What are the outcomes that matter to adolescents with continuous headache due to chronic migraine and their parents?

What Is Known and What This Paper Adds

Despite representing up to 20% of patients presenting with chronic headache disorders to pediatric headache specialty clinics, patients with continuous headache have often been excluded from migraine prevention trials. The typical outcome measure in clinical trials for migraine prevention is the reduction in the number of headache days per month, which does not hold as much value or applicability in this patient population. The results of this study show that >60% of adolescents felt it was more important to measure decrease in frequency and intensity of headaches in terms of severe headaches/spikes rather than total headache days. By assessing the outcomes that matter to these patients, this article identifies relevant outcomes for trials of interventions to prevent continuous headache due to chronic migraine.

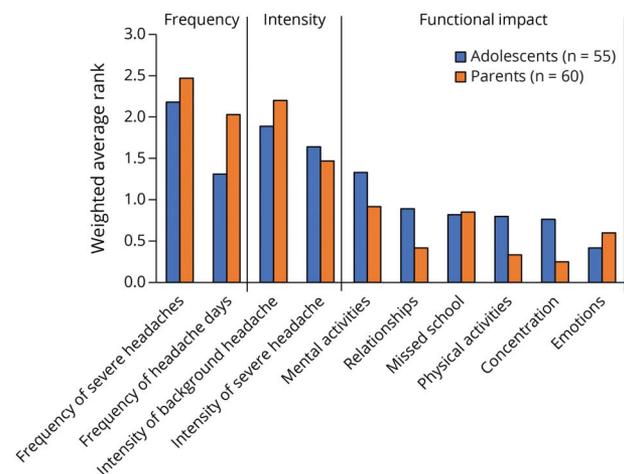
Methods

For this survey study, 55 adolescents and 60 parents of adolescents with continuous headache due to chronic migraine were recruited from the University of California, San Francisco Child & Adolescent Headache Program. Inclusion criteria included age of 12 to 17 years, a diagnosis of chronic migraine, and having experienced a continuous headache for a minimum of 3 months before enrollment. Participants were asked to complete a 78-question multiple choice survey on their headache history, features of their headaches, and their opinion on the importance of a variety of different treatment outcomes, including the broad categories of headache intensity, headache frequency, functional impact, associated symptoms, and acute interventions. For ranked responses, a weighted average rank was calculated for each option across the participants. No statistical analysis was performed due to a low number of highly variable participants.

Results and Study Limitations

The mean age of adolescent participants was 16 years, with 82% being female. Median adolescent-reported duration of

Figure Most Important Treatment Outcomes



continuous headache was 24 months (interquartile range 12–39 months). Overall, the most valued individual outcome measure among both adolescents and their parents was a decrease in frequency of more severe headaches; however, outcomes reflecting headache intensity were most valued by adolescents, while outcomes reflecting functional impact were most valued by parents. More than 60% of adolescents felt that it was more important to measure decrease in frequency and intensity of headaches in terms of severe headaches/spikes rather than total headache days. Among associated symptoms, improvement in brain fog was most highly valued by both adolescents and parents. Other outcomes are shown in the Figure. Generalizability of results may be limited by participants being recruited from a single subspecialty pediatric headache clinic.

Study Funding and Competing Interests

This study received funding from Amgen. The authors report no competing interests. Go to [Neurology.org/N](https://www.neurology.org/N) for full disclosures.

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