

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

A Pilot Survey Study

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Abstract

Background and Objectives

Children and adolescents with chronic migraine who have continuous headache may have high levels of headache-related disability but have largely been excluded from clinical trials. Understanding patient-valued treatment outcomes may facilitate future study design. The aim of this work was to identify patient-valued outcome measures for headache preventive treatments among adolescents with continuous headache due to chronic migraine and their parents.

Methods

Adolescents with an International Classification of Headache Disorders, 3rd edition diagnosis of chronic migraine, who had continuous headache and who were being cared for at a tertiary pediatric headache clinic, and their parents were surveyed to query the value of treatment outcomes in the domains of headache frequency, intensity, functional impact, and associated symptoms. Individual outcomes and categories of outcomes were ranked in order of preference using weighted average rank. Results were rounded to the degree of precision with which they were measured.

Results

The survey was completed by 55 adolescents and 60 parents of adolescents with continuous headache due to chronic migraine. Mean age of adolescents was 16 (SD 1, range 12–17) years. Median adolescent-reported duration of continuous headache was 24 (interquartile range [IQR] 12–39) months, and adolescents had tried a median of 2 (IQR 0–5) preventive medications, only 13% of which were perceived as helpful. Overall, the most valued individual outcome measure among both adolescents and 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.

Discussion

The results of this study provide important information about which preventive treatment outcomes are valued by adolescents with continuous headache due to chronic migraine and their parents. Results suggest that adolescents value a decrease in frequency of severe headaches over a decrease in frequency of headache days overall. Generalizability may be limited because the surveyed population was being cared for at a tertiary pediatric headache clinic and generally had headache disorders that were refractory to treatment. These results may help guide future trial design in this population with continuous headache due to chronic migraine.

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Glossary

ICD-10 = *International Classification of Diseases, 10th revision*; **ICHD-3** = *International Classification of Headache Disorders, 3rd edition*; **IQR** = interquartile range; **PedMIDAS** = *Pediatric Migraine Disability Assessment*; **UCSF** = *University of California, San Francisco*.

Children and adolescents with continuous daily headache represent up to 20% of patients presenting with chronic headache disorders to pediatric headache specialty clinics,¹ with the majority of these attributed to chronic migraine.^{1,2} Historically, patients with continuous headache have often been excluded from both pediatric and adult migraine prevention trials.³⁻⁵ While studies have not specified the rationale for excluding these patients, it seems plausible that researchers anticipate that this population will not see significant improvement within the 3- to 6-month time frame of most treatment trials, particularly when the standard outcome measure of reduction in number of headache or migraine days per month is used.⁴⁻⁸

Excluding children and adolescents with continuous headache from treatment trials is problematic for numerous reasons. First, this population experiences a high degree of headache-related disability and therefore has an increased need for novel and effective headache treatments.^{2,9} Second, because recent literature suggests that most adolescents with migraine will improve with established treatments,^{7,10} it is essential for future studies to focus on those whose headaches are refractory to existing treatment options. Given the potential challenges in measuring improvement in this population, the first step in designing trials for continuous headache due to chronic migraine is to determine meaningful and valued outcome measures specific to this population.

The goal of this study was to identify outcome measures of value to adolescents with continuous headache due to chronic migraine and to their parents/caregivers to optimize selection of primary and secondary endpoints for future treatment trials in this patient population. We hypothesized that treatment outcome measures identified as important by adolescents with continuous headache would differ from those typically used in migraine preventive trials (e.g., number of headache days per month) and that adolescents may value different outcome measures from their parents.

Methods

Standard Protocol Approvals, Registrations, and Patient Consents

This study was approved by the University of California, San Francisco (UCSF) Institutional Review Board (19–27040). Parents provided written informed consent and adolescents provided written informed assent before participating. Electronic consent for participation was included at the beginning of each survey.

Participants

Participants were recruited from the UCSF Child & Adolescent Headache Program from July 29, 2019, to December 15, 2020. Eligibility criteria for adolescents were (1) age from 12 to 17 years, (2) diagnosis of chronic migraine as per *International Classification of Headache Disorders, 3rd edition (ICHD-3)* criteria,¹¹ and (3) continuous headache (i.e., some degree of head pain present during all waking hours) for a minimum of 3 months before enrollment. Eligibility for parents/caregivers (referred to hereafter simply as parents) was caring for an adolescent who met the above criteria.

Survey Development

The survey was developed in Research Electronic Data Capture.¹² The initial draft of the survey was generated by pediatric headache neurologists (A.G. and K.G.) and a pediatric headache psychologist (A.R.). The survey was revised iteratively over a series of meetings that included these same experts and other members of the UCSF Child and Adolescent Headache Team (3 pediatric headache registered nurses and a pediatric headache nurse practitioner). The survey was then sent to 5 pediatric headache neurologists and 5 pediatric pain/headache psychologists from other institutions for feedback. The survey was also reviewed by members of the UCSF Teen Advisory Council, a group of teens with chronic migraine or other chronic primary headache disorders, for quality, developmental appropriateness, readability, and comprehensiveness of questions. Patients who were noted to have a cause of continuous headache other than chronic migraine (including new daily persistent headache or persistent posttraumatic headache) were excluded. All diagnoses were made by pediatric headache specialists using *ICHD-3* criteria.

The final questionnaire (available in eAppendix 1, links.lww.com/WNL/B963) contained 78 multiple choice questions covering demographics, headache history (e.g., duration and intensity [scale of 0–10] of background headache and severe headaches/spikes), number of previous preventive medication treatment trials (either tried for >6 weeks or stopped after <6 weeks due to side effects), school attendance, and questions on participants' preferences for measuring treatment outcomes. Previous preventive treatment trials of non-pharmacologic interventions such as cognitive behavioral therapy or use of neuromodulation devices were not queried. Parents were asked to report their perceptions of their child's headache and its associated symptoms and disability. Throughout the survey, background headache was defined as the headache that was continuous and present at all times, and severe headache was defined as an increase in intensity over

the background headache of any severity or duration. The following categories of outcome measures were included:

- Headache characteristics: frequency of severe headaches, duration of background headache and severe headaches, and intensity of background and severe headaches;
- Functional impact of headaches (impact of headache on school attendance, peer and family social relationships, sleep, physical activities, mental activities, and emotional functioning);
- Associated symptoms, including nausea/vomiting, photophobia, phonophobia, vertigo, concentration impairment (i.e., brain fog), sleep, and vision changes; and
- Need for medical interventions (frequency and effectiveness of acute medications, frequency of contact with medical providers, and frequency of emergency room visits).

Participants were also asked about side effects of medication, preferred study duration, preferred time periods for assessment of severe headaches, and what they would consider to be the minimum meaningful decrease in headache intensity from medication. The survey was designed to take \approx 10 minutes to complete.

Recruitment

Adolescent and parent dyads who were current patients of the UCSF Child & Adolescent Headache Program who met inclusion criteria were invited to participate. When possible, participants were recruited during in-person or telemedicine appointments. For those recruited between visits, charts were reviewed for eligibility by a pediatric headache neurologist (C.M.), and patients were contacted by email. An attempt was made to enroll dyads; however, both members of the dyad were not required to complete the survey for either the adolescent or parent to participate.

All patients identified during clinic visits as meeting inclusion criteria were approached for participation. Participants recruited in clinic were provided with iPads and a link to the survey. Those who were not able or preferred not to complete the survey in the clinic (including those recruited by telehealth appointment or identified through chart review) had the option of completing it from home through the same link.

In October 2020, a list was generated of all patients seen within the prior 1.5 years who met eligibility criteria. Initial screening pulled all patients with an ICD-10 diagnosis code for chronic migraine; the list was further reviewed for eligibility by a pediatric headache neurologist (C.M.). This list estimated that 59 patients met criteria, so recruitment was closed once we obtained >50 surveys from both parents and adolescents.

Data Analysis

Descriptive statistics were used for demographic variables and headache characteristics. Means and SDs were reported for

continuous variables, and proportions were reported for categorical variables. To avoid false precision, results were rounded to the degree of precision with which they were measured; for example, mean age was rounded to the nearest year because participants provided their age in years (i.e., 16 not 16.3 years). Participants were asked to rank their top 3 choices for the following variables: (1) most important category of outcome measure, (2) most important functional impact outcome measure, and (3) most important associated symptom outcome measures. For the variable of most important overall outcome measure, participants were asked to rank their top 5 choices. For questions involving ranking, a weighted average rank was calculated for each possibility by assigning numbers to each choice and computing the average. For example, if the possible choices for a situation were first, second, third, or not picked, the corresponding scores were 3, 2, 1, and 0. Analyses were performed with Excel 2016 (Microsoft, Redmond, WA) and SAS 9.4 (SAS Institute Inc, Cary, NC).

Data Availability

The datasets generated or analyzed during the current study are available from the corresponding author on reasonable request and may require interinstitutional data-sharing agreements to be put in place.

Results

The survey was completed by 56 adolescents and 61 parents of adolescents with continuous headache due to chronic migraine. One adolescent and 1 parent were subsequently excluded due to reporting 0 months of continuous daily headache. Data were therefore analyzed from 55 adolescents and 60 parents.

Demographics and Clinical Characteristics

Demographics of the surveyed population are shown in Table 1. Mean age reported by adolescents and parents (who were reporting their child's age) was 16 years (SD 1 year for adolescents, 1 year for parents; range 12–17 years) with 82% (45 of 55) female per adolescents and 75% (45 of 60) female per parents.

Among parents, 33 of 58 (57%) reported having a history of headaches themselves, 19 of whom reported a history of migraine. Additional self-reported headache diagnoses included tension-type headache (1 of 33), headache due to allergies (1 of 33), and unknown or unreported (13 of 33). All subsequent data reported as coming from parents refer to the parents' assessment of their child's headache disorder, not their own.

Characteristic features of participants' headaches and medication use are shown in Table 2. Adolescents reported a median of 24 months of continuous headache (interquartile range [IQR] 12–39 months), and parents reported a median duration of 30 months (IQR 12–42 months). The mean

Table 1 Demographics of Adolescents With Continuous Headache Due to Chronic Migraine

	Adolescents (n = 55)	Parent ^b (n = 60)
Age, mean (SD), y	16 (1)	16 (1)
Sex assigned at birth, n (%)		
Female	47 (86)	47 (78)
Male	8 (15)	13 (22)
Gender identity, n (%)		
Female	45 (82)	45 (75)
Male	8 (15)	12 (20)
Other	2 (4)	3 (5)
Race, ^a n (%)		
American Indian/Alaska Native	2 (4)	3 (5)
Asian	9 (16)	2 (3)
Black or African American	5 (9)	1 (2)
White	44 (80)	51 (85)
>1 Race	6 (11)	2 (3)
Unknown/declined to state	2 (4)	3 (5)

^a Participants could select >1 option; hence, totals add up to >100%.

^b Parental report of their child's demographics.

intensity of the background headache was rated as 6 of 10 (SD 2) by adolescents and 5 of 10 (SD 2) by parents. One hundred percent of adolescents and 98% (58 of 59) of parents reported experiencing periods of more severe headaches in addition to baseline or background headache.

Median frequency of acute medication use was 2 d/wk per both adolescents and parents. Adolescents reported a median of 2 prior preventive medication trials (IQR 0–5), while parents reported a median of 3 prior preventives (IQR 1–6). Fewer than a quarter of preventive medications were perceived as helpful by either adolescents (median 13%) or their parents (median 10%).

In terms of functional impact of headaches, adolescents and parents reported missing a median of 10 days of activities per month. Adolescents reported missing a median of 3 full days and 0 partial days of school per month, while parents reported a median of 4 full days and 2 partial days of school missed per month.

Treatment Outcome Preferences

The minimum meaningful decrease in intensity of background headache was reported as (mean) 3 (SD 2) by adolescents and 3 (SD 1) by parents (Table 3). The minimum meaningful decrease in intensity of severe headache was

reported as (mean) 3 (SD 2) by adolescents and 4 (SD 2) by parents. Adolescents were willing to participate in a trial for (median) 3 months (IQR 2–6 months), and parents were willing to have their child participate for (median) 4 months (IQR 3–6 months). The majority of adolescents and parents were willing to tolerate minimal or some side effects.

Patient-Valued Outcome Measures

Parent and adolescent preferences for overall category of outcome measures are shown in Figure 1. For adolescents, the most important category of outcome measure was headache severity. For parents, the most important category of outcome measure was functional impact of headaches, followed closely by headache frequency and severity.

Parent and adolescent preferences for specific outcomes are shown in Figure 2. Within the categories of headache frequency and severity, adolescents reported that it was more important to measure both the frequency of severe headaches (61%) and the intensity of severe headaches (70%) than the frequency or intensity of background headaches, while parents were more divided. Among outcomes reflecting need for acute intervention, both parents and adolescents felt that improved efficacy of acute medications was more important than a decrease in frequency of acute medication use. When considering impact on interactions with medical team, parents felt that a decrease in frequency of contacting providers (75%, n = 41 of 55) was more meaningful than a decrease in frequency of emergency room visits (26%, n = 14 of 55), while adolescents valued these measures equally.

When evaluating specific outcomes related to functional impact of headache (Figure 3), both adolescents and parents ranked the mental or cognitive impact of headaches as most important; this was followed by physical impact of headache for adolescents and emotional impact of headache for parents. Similarly, among outcomes related to associated symptoms, both adolescents and parents indicated that brain fog was the most important outcome measure.

Last, when asked to select the outcome measure most important to them in assessing response to headache treatment, both adolescents and parents selected frequency of severe headaches followed by intensity of background headache (Figure 4). Overall, outcome measures related to characteristics of the headaches themselves (e.g., frequency and intensity of headaches) were more highly ranked than those related to functional impact, associated symptoms, or acute medication use.

Discussion

Adolescents with chronic migraine who experience continuous headache represent an important patient population that is often excluded from clinical trials.^{3–5} It is unknown whether commonly used outcome measures in migraine preventive

Table 2 Headache Characteristics of Adolescents With Continuous Headache Due to Chronic Migraine, as Reported by the Adolescents and Their Parents/Caregivers

	Adolescents	Parents ^a
Months of continuous headache, median (IQR)	24 (12–39) (n = 53)	30 (12–42) (n = 60)
Intensity of background headache (0–10), mean (SD)	6 (2) (n = 52)	5 (2) (n = 59)
More severe headaches or spikes experienced, % yes (n)	100 (53/53)	98 (58/59)
Frequency of severe headache, d/mo, median (IQR)	10 (4–19) (n = 52)	8 (4–20) (n = 59)
<1/mo–1/wk, % of participants	17	34
2–6/wk, % of participants	60	46
≥1/d, % of participants	23	20
Intensity of severe headache (0–10), mean (SD)	8 (2) (n = 26)	8 (2) (n = 28)
Duration of severe headache, median (IQR), h	5 (3–24) (n = 49)	8 (3–24) (n = 56)
Severe headaches lasting at least 1 h, % yes (n)	96 (51/53)	98 (57/58)
Medication use		
Frequency of acute medication use, median (IQR), d/wk	2 (1–5) (n = 48)	2 (1–4) (n = 54)
Prior preventive trials, median (IQR), n	2 (0–5) (n = 50)	3 (1–6) (n = 57)
Preventives stopped due to side effects, median (IQR), n	0 (0–1) (n = 50)	1 (0–3) (n = 56)
Prior preventives perceived as helpful, median (IQR), %	13 (2–40) (n = 47)	10 (1–30) (n = 56)
Functional impact of headaches (past 30 d)		
Full days of school missed, median (IQR)	3 (0–9) (n = 49)	4 (0–14) (n = 55)
Partial days of school missed, median (IQR)	0 (0–4) (n = 49)	2 (0–7) (n = 55)
Days of activities missed, median (IQR)	10 (3–15) (n = 50)	10 (3–20) (n = 58)

Abbreviation: IQR = interquartile range.

^a Parental report of their child's headache characteristics.

trials such as headache days or migraine days per month are meaningful to use in this patient population. The goal of this study was to better understand which preventive treatment outcome measures are valued by adolescents with continuous headache due to chronic migraine and their parents. In surveying this understudied patient population, we also learned valuable information about their baseline headache characteristics and experiences with headache treatment.

Among adolescents with chronic headache disorders, mean frequency of headaches has been reported as 25 d/mo.¹³ Up to 7% of all patients with headache and 20% of patients with chronic headache disorders presenting to a quaternary pediatric headache clinic reported continuous headache without breaks.¹ In a population of adolescents prescribed a calcitonin gene-related peptide pathway monoclonal antibody for preventive treatment of headache, more than two-thirds reported having continuous headache,¹⁴ suggesting that patients with continuous headache likely represent an even higher percentage of patients with medically refractory migraine necessitating off-label treatments compared to the overall population with chronic migraine.

Participants in this study reported long-standing, treatment-refractory headache from chronic migraine, with median duration of nearly 2 years. Participants had tried multiple preventive medications (median 2–3) and found fewer than a quarter of these to be helpful. Problematically for this patient population, arguably most in need of novel, effective preventive treatment strategies, failure of ≥3 prior preventive medication trials has been an exclusion criterion in many clinical trials.^{15–17}

In addition to continuous headache, >98% of parent participants and 100% of adolescent participants in this study reported periods of increased severity of headaches or severe headaches. The frequency of these more severe headaches was high, with 60% of adolescent participants reporting 2 to 6 severe headaches per week and 23% reporting at least 1 severe headache per day. Notably, prior studies have reported that up to 60% of teens with chronic daily headache had medication overuse.¹⁸ In contrast, the participants in this study used only a median of 2 acute medications per week, with some taking no acute medications per week. While severe headaches have primarily been the target of acute medications, the frequency

Table 3 Treatment-Trial Related Preferences of Adolescents With Continuous Headache Due to Chronic Migraine and Their Parents/Caregivers

	Adolescents (n = 51)	Parents (n = 57)
Best time frame to assess number of severe headache days, n (%)		
1 wk	15 (29)	19 (33)
2 wk	10 (19)	5 (9)
1 mo	19 (37)	26 (46)
2 mo	3 (6)	0
3 mo	1 (2)	4 (7)
6 mo	3 (6)	3 (5)
Months willing to participate in a study before seeing improvement, median (IQR)		
	3 (2–6)	4 (3–6)
Side-effect level that would be tolerable in a study, n (%)		
No side effects	2 (4)	5 (9)
Minimal side effects	29 (57)	31 (54)
Some side effects	18 (35)	20 (35)
Significant side effects	2 (4)	1 (2)
Minimum meaningful decrease in headache intensity (0–10), mean (SD)		
Background headache	3 (2)	3 (1)
Severe headache	3 (2)	4 (2)

Abbreviation: IQR = interquartile range.

of severe headaches endorsed by this population significantly exceeds the recommendations for frequency of acute medication use. Therefore, it seems within reason that among teens with continuous headache, severe headaches are a reasonable target for preventive treatment.

Adolescents largely favored outcome measures reflecting change in frequency and intensity of severe headaches over frequency and intensity of background headache. Thus, the traditional

primary outcome measure used in many migraine preventive clinical trials, i.e., monthly migraine days or headache days,^{4,8} may not adequately reflect clinically meaningful changes in headache in this population. Assessment of other headache features such as frequency of severe headaches and intensity of both severe and background headache may provide a better picture of overall improvement in adolescents with continuous headache.

Measures of functional impact were also valued by both adolescents and parents. This was the most valued category of outcome measure among parents and the second most valued among adolescents after headache severity. In addition, adolescents and parents felt that assessment of brain fog was the best way to measure the impact of a treatment on associated symptoms. This measure likely reflects the significant cognitive burden that continuous headache due to chronic migraine causes in this population, as reflected by evidence that higher frequency of headaches is associated with poorer school performance.¹⁹

In our clinical experience, adolescents with continuous headache frequently use the health care system, through either calls or messages to clinic or emergency room visits. While use of medical resources may be directly observable to health care providers, both parents and adolescents ranked this outcome as relatively unimportant in measuring treatment response.

Figure 1 Most Important Outcome Category for Assessing Response to Headache Treatment per Adolescents With Continuous Headache Due to Chronic Migraine and Their Parents/Caregivers

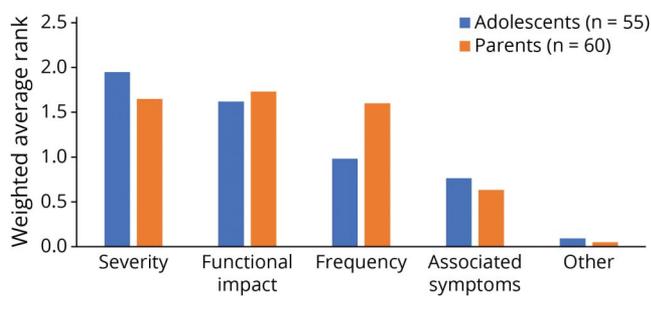
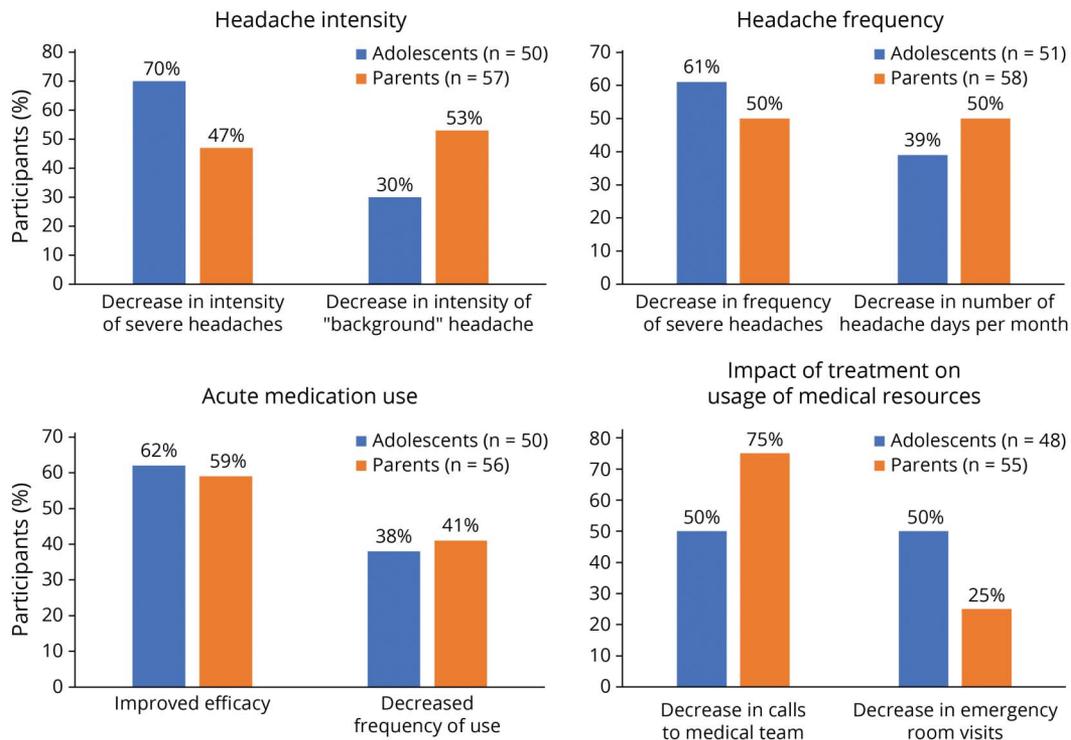


Figure 2 Adolescent and Parent Preferences for Specific Outcome Measures

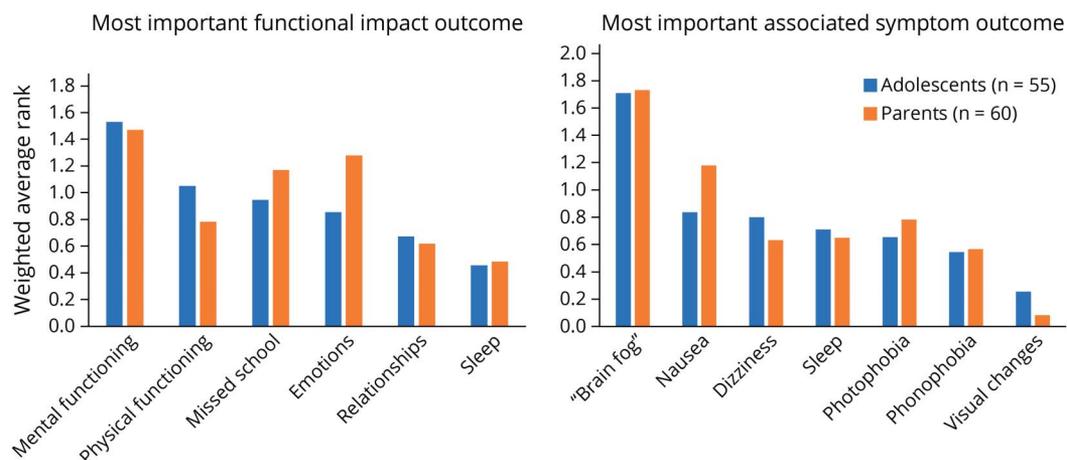


Participants were asked to choose between 2 options regarding which was the best way to measure treatment outcome within each category.

It is notable that most adolescents and parents in this study preferred using a 1-month or 1-week period when assessing the number of severe headache days over a certain time period; <5% felt that a 3-month period provided the best assessment. This suggests that the 3-month time period reflected in the pediatric measure of headache-associated disability (i.e., Pediatric Migraine Disability Assessment [PedMIDAS])²⁰ may not be the most valued

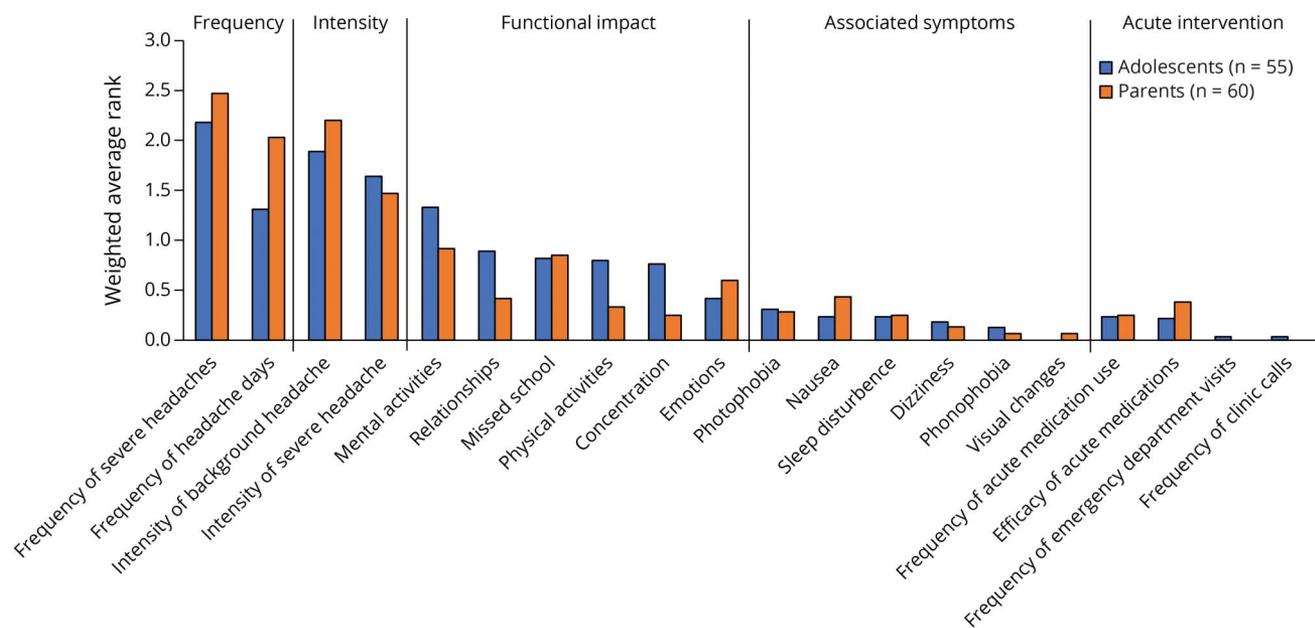
time frame over which to evaluate headache burden in this population. Likewise, when describing periods of more severe headache intensity, both parents and adolescents reported that they prefer to be asked more detailed questions about the severe headaches rather than only about the number of days per month with a more severe headache. While it may be beyond the scope of clinical trials to delve into details of the patient history, it is important to consider

Figure 3 Adolescent and Parent Rankings for Most Important Trial Outcomes



Left) Outcome that would best measure how treatment affects functioning. (Right) Outcome that would best measure how treatment affects other symptoms experienced during headaches.

Figure 4 Adolescent and Parent Rankings for Most Important Treatment Outcomes Across Categories



that adolescents have a wide range of migraine symptoms, and more detailed assessment of these symptoms could provide a more comprehensive picture of response to treatment.

In terms of differences in preferences between adolescents and their parents, outcome measures valued by both groups were similar overall but with a few notable exceptions. When assessing headache frequency and intensity, adolescents show a marked preference for assessing decrease in frequency and intensity of severe headaches, while parents were more evenly divided on whether to focus on background or severe headaches in both categories. Clinically, these differences may be important when prioritizing the lived experience of the patient in helping families assess treatment outcomes while simultaneously recognizing the parent's drive to eliminate their child's pain.²¹

Strengths of this study include the use of ICHD-3 criteria and diagnosis by pediatric headache specialists, as well as a focus on a new question in an understudied population. Limitations include the relatively small numbers of participants, the use of nonvalidated questionnaires, and the inability to assess direct comparison of the opinions of patients and their own caretakers because adolescents/parents were not enrolled as dyads. In addition, due to recruitment methodology, we do not have data on adolescents and parents who were offered participation but chose not to participate, so we are unable to calculate a response rate. However, our review of charts estimated 59 children with continuous headache due to chronic migraine in our program, so we estimate that we received responses from nearly all patients who met eligibility with 56 participants. Participants were recruited from a single subspecialty pediatric headache clinic and had tried multiple preventives previously without benefit, both of which may limit generalizability of results. Last,

use of nonmedication preventive treatments (such as cognitive behavioral therapy or neuromodulation devices) was not included in this survey, possibly underestimating how refractory to treatment these adolescents' headaches were.

While this study has provided groundwork for evaluating treatment outcomes in adolescents with continuous headache due to chronic migraine, future research is encouraged to build on this work in a broader population with validated surveys that incorporate NIH common data elements and validated instruments such as PedMIDAS for assessing disability, as well as evaluation of specific headache features (e.g., length of continuous headache to date) as potential moderators of patient preferences.

The results of this study provide valuable insight that can help shape how clinicians discuss treatment success with adolescents who experience continuous daily headache due to chronic migraine and their parents. In the longer term, we hope these results will help guide design of future treatment trials, laying the foundation for evidence-based treatment options for this population.

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Kaitlin Greene, MD	Doernbecher Children's Hospital Child and Adolescent Headache Program, Division of Pediatric Neurology, Department of Pediatrics, Oregon Health and Science University, Portland	Drafting/revision of the manuscript for content, including medical writing for content; major role in the acquisition of data; study concept or design
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Appendix (continued)

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