

# Improved and Sustained Functional Outcomes of a Multidisciplinary Care Program for Patients with Chronic Primary Headache Disorders

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## Abstract

**Context:** In children and adolescents, primary headache is the most prevalent type of reported pain. When treating pediatric chronic headache conditions, the multidisciplinary approach has been found to be quite successful in both short-term and long-term improvement. However, outcome data from multidisciplinary clinics have largely been focused on headache frequency, with little data on functional outcomes, such as disability and school attendance.

**Objective:** To evaluate a multidisciplinary clinic for pediatric headache and to determine if multidisciplinary treatment is more effective for certain headache diagnoses.

**Method:** 376 patients, age 6-18 years, who underwent a multidisciplinary evaluation at a tertiary headache clinic in a large, urban northeast pediatric hospital, were included in this study. Patients completed a measure of functional disability (FDI), rated the general intensity of their pain, and reported on school attendance and hospital visits at their initial visit, the first follow-up (Median=3 months) and the second follow up (Median=7 months).

**Results:** Patients reported a significant decrease in functional disability, pain intensity, emergency room visits, and school absences ( $p < 0.001$ ) at the initial follow-up visit. These decreases remained significant at the second follow-up visit ( $p < 0.05$ ). Outcomes did not significantly differ based on headache diagnosis.

**Conclusion:** A multidisciplinary plan presented at first visit and reviewed for compliance at follow-up visits, results in sustained functional improvement and increased school attendance, despite primary headache classification.

**Keywords:** Headache; Pain; Migraine; Multidisciplinary care; Children; Pediatrics; Disability; School attendance

**Abbreviations:** TTH: Tension-Type Headache; NDPH: New Daily Persistent Headache; FDI: Functional Disability Inventory; ER: Emergency Room

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## Introduction

Primary headache is the most prevalent type of pain reported in pediatric populations [1, 2]. A review and analysis of recent literature approximates 60% of children and adolescents to be prone to headache worldwide [3]. A recent, significant sample study in Turkey found that nearly 50% of the children and

adolescents between the ages of 5 and 13 participating in the study have severe, debilitating headaches [4], and similar studies worldwide have repeatedly found a similarly high prevalence [5-8].

Chronic headaches are also often difficult to manage and treat [9]. These may result from a diverse range of etiologies [10] and often present with comorbid psychopathology, both of which can complicate the diagnostic and treatment processes [11].

Individuals with chronic headaches have been found to be at significantly higher risk for psychiatric disorders in comparison to those without headaches, and these comorbidities can alter the evolution and outcomes of symptomology and treatment [12]. Related, and of critical concern, a large sample study found that suicidal ideation can be elevated by up to 4.6 times in pediatric patients with chronic migraine [13].

Similar to other chronic pain conditions, headaches are often best managed through an integrated approach of pharmacological and non-pharmacological treatments. Chronic pain treatment specialists typically endorse coordinated, multidisciplinary treatment as the most effective approach to treating intractable headache, integrating neurologists, anesthesiologists, and pain medicine specialists with behavioral medicine, psychology, physical therapists, or other relevant clinicians needed to better address the unique needs of these cases [9]. These integrated methods are particularly important for pediatric headache patients as most medications have little to no research supporting their efficacy in this population [14], and complex pathophysiology requires tailored care plans intended to address psychological and physiological factors through pharmacological and non-pharmacological means [15].

In order to address challenges in the care of patients with chronic headaches, some facilities have opened headache specific clinics staffed with headache experts and equipped to address the specific diagnostic and treatment challenges these cases often present. Studies have found that optimal patient care offered at non-specialized clinics may have been impeded by excessive, unnecessary diagnostic testing, conflicting diagnoses due to repeated specialist referrals, and frequent utilization of emergency medical services as well as hospital admissions [9]. The most successful headache clinics address these problems through coordinated, multidisciplinary care that integrates various specialties and resources [9], however, few pediatric specialized headache clinics currently exist [16].

In a review of current literature, there have been many studies on the effectiveness of specific multidisciplinary treatments for adults' headaches. There have been fewer investigating the efficacy of multidisciplinary treatments for any disorder in pediatric populations and even fewer regarding outcomes of multidisciplinary headache clinics [16]. Various studies evaluating these clinics have found that the multidisciplinary approach is quite successful in both short-term and long-term improvement of pediatric chronic headache conditions [17-19].

Soe and colleagues [16] evaluated one such clinic, the Children's Headache Clinic in Denmark. The clinic is staffed by specialized physicians, nurses, a physiotherapist, and a psychologist who together evaluates and treats pediatric headache disorders through Multidisciplinary strategy that integrates pharmacologic and non-pharmacologic methods. They found that for patients treated in the clinic headache frequency decreased and quality of life increased. Unfortunately, due to a problem with data collection, school absence was not included as an outcome measure [16].

As more information is collected on the efficacy of specialized

multidisciplinary care clinics for pediatric headache, it is important to identify various outcome measures that may indicate the efficacy of the program. Headache frequency and changes in quality of life have been the most popular outcome variables utilized in studies of treatment efficacy in this population [20], but we suggest that school attendance and functional disability are the most significant problems in the pediatric population.

For children and adolescents, school attendance and performance tend to be negatively affected by headache symptomology [21]. Children who suffer from headaches are more likely to have frequent school absences compared to those without headaches [22]. A study comparing children with migraines to their healthy siblings found that missed school days attributed to migraines could result in lower overall educational attainment [23]. Even when present in school, children and adolescents' chronic headaches have severe negative effects on ability to learn due to impaired attention and memory [23-25].

Additionally, as chronic pain may have such a significant impact on functioning and ability to sufficiently participate in day-to-day activities; experts have suggested that in addition to pain intensity, changes in physical functioning and ability are important clinical outcome measures when evaluating treatments [26]. Primary headache disorders can be severe and disabling for children with significant effects on a child's functioning and quality of life [27]. In fact, in comparison to children with various chronic illnesses including asthma, cancer, and diabetes, pediatric patients with headaches had the lowest measured quality of life [28].

This present study is an evaluation of the efficacy of a multidisciplinary clinic for pediatric headache, the Pediatric Chronic Headache Program at Boston Children's Hospital. Given the literature reviewed, we have elected to report functional disability, pain severity, school attendance, and utilization of emergency medical services as clinical outcome measures in order to add novel and valuable information to the current literature on the efficacy of these programs. This study also aims to determine if multidisciplinary treatment is more effective in improving outcomes for specific primary headache diagnoses.

## Method

### Sample

Three hundred seventy-six patients ages 6-18 years (mean 13.7 years,  $SD=2.61$ ) who underwent multidisciplinary evaluation between January 2011 and December 2014 and returned for at least one follow-up were included in this study. Of those 376 patients, 256 also returned for a second follow-up visit. International Headache Classification (ICHD-9) diagnosis, as determined by a neurologist during the initial evaluation, included: migraine (29.2%), tension-type headache (TTH; 16.1%), new daily persistent headache (NDPH; 11.8%), migraine and tension-type headache (M & TTH; 14.7%), and other headache diagnoses (e.g., occipital neuralgia, post-concussive headache; 28.2%). The sample was predominantly Caucasian (93.3%) and female (70.0%), representative of patients seen in the clinic. At the time of the initial evaluation, patients' mean duration of pain was about 2 years, ( $M=23.4$  months  $SD=31.1$ ). The majority of

parents were married (81.3%) and well educated (i.e., college graduate or above: 76.3% of mothers and 69.0% of fathers).

Due to the large sample size and the method of data collection, complete outcome data was unavailable for every patient (**Figure 1**) details the pattern of missing data at each visit.

## Pediatric Chronic Headache Program

The Pediatric Chronic Headache Program represents the only tertiary care center in the Northeast, United States to provide comprehensive, multidisciplinary treatment of intractable pediatric headache. The multidisciplinary evaluation consists of a medical history and physical exam performed by a pediatric neurologist and a structured clinical interview conducted by a clinical psychologist. Team conferences involving both providers and a headache nurse occur following each session. Nursing education and feedback based on clinician recommendations concludes the visit. Comprehensive follow-up care is provided by the physicians and nurse practitioners. Treatment options include both pharmacologic options, such as medication, injections, and infusions, and non-pharmacologic approaches, including cognitive behavioral therapy, biofeedback, acupuncture, Reiki, and physical therapy.

## Procedure

Parents and children each completed questionnaires individually prior to the child's multidisciplinary headache clinic evaluation. Children then underwent evaluation by a neurologist and clinical psychologist. All of the questionnaires were reviewed by the neurologist and psychologist prior to the evaluation. Patients then returned for a follow-up visit and similarly completed questionnaires prior to their follow-up visit. This procedure was repeated for the second follow-up visit if the patient elected to return.

## Measures

**Demographics:** Basic demographic (e.g., age, gender) and medical information (e.g., diagnosis) were collected from a review of patients' medical records.

**Pain intensity:** Patient-reported rating of typical headache-related pain intensity was obtained during the evaluation with the psychologist. Headache intensity was coded from "no pain" (0) to "worst pain experienced" (10).

**School attendance:** Parents reported the number of days within the past three months that their child (1) missed school; or (2) was dismissed early from school due to pain.

**Hospital visits:** Parents reported the number of instances within the past three months that their child visited the emergency room or stayed overnight in the hospital due to pain.

**Functional disability inventory (FDI):** The FDI [29, 30] assesses children's self-reported difficulty in physical and psychosocial functioning due to their physical health. The measure consists of 15 items concerning perceptions of children's activity limitations during the past two weeks. Children rate these activities on a 5-point scale ranging from 0 ("No trouble") to 4 ("Impossible"), and total scores are computed by summing the items. Scores on the FDI range from 0 to 60, with higher scores indicating greater disability. The FDI has demonstrated reliability and validity in children and adolescents ages 8-17 [29, 30].

## Ethics

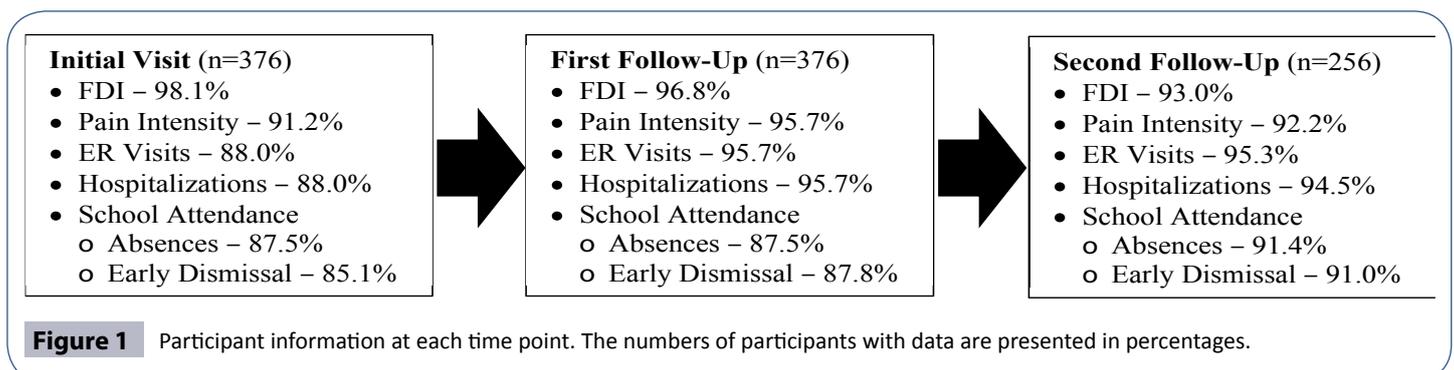
Approval from the hospital's Institutional Review Board was obtained prior to conducting the retrospective chart review.

## Statistics

All statistical analyses were conducted using SPSS version 21. Descriptive statistics were first calculated for each of the time points. Paired sample t-tests were then conducted to test the differences in outcome measures between the initial visit and the two follow-up visits. Finally, mixed factor, repeated-measures ANOVA with Greenhouse-Geisser degrees of freedom corrections for sphericity were conducted to test for differences in primary outcomes (functional disability, pain intensity, and school absences) over time based on diagnosis. For all analysis, two-tailed p-values at a level of  $p < 0.05$  were considered statistically significant.

## Results

A reduction in functional disability, pain intensity, emergency room visits, and school absences and early dismissals were all reported at both the first follow-up visit (Median=3 months) and the second follow-up visit (Median=7 months). Overnight hospital stays did not significantly decrease until the second follow-up visit. Specific means and statistics for the paired differences between the initial visit and the first and second follow-up visits can be found in (**Tables 1 and 2**), respectively.



**Table 1** Differences in outcome measures from initial visit to first follow-up visit.

Measure	n	Initial Visit Mean	Follow-Up Visit Mean	t	sig
Functional Disability	357	20.83	11.55	13.92	<0.001
Pain Intensity	330	5.93	4.32	10.39	<0.001
School Attendance (days/3 months)					
Absences	289	6.38	3.85	4.55	<0.001
Early Dismissals	284	2.66	1.70	2.33	0.021
ER Visits	315	0.44	0.23	3.75	<0.001
Overnight Hospital Stays	315	0.09	0.08	0.28	.782

**Table 2** Differences in outcome measures from initial visit to second follow-up visit.

Measure	n	Initial Visit Mean	Follow-Up Visit Mean	t	sig
Functional Disability	233	20.91	10.56	11.61	<0.001
Pain Intensity	218	6.02	3.84	10.49	<0.001
School Attendance (days/3 months)					
Absences	214	7.43	3.44	4.79	<0.001
Early Dismissals	208	2.99	1.63	2.34	0.020
ER Visits	212	0.47	0.15	4.57	<0.001
Overnight Hospital Stays	211	0.09	0.03	2.22	0.028

## Functional Disability

At the initial visit, children reported a mean FDI score of 20.69 (SD=13.06). Following multidisciplinary treatment, patients exhibited a downward trend in FDI scores, as shown by the “Entire Sample” line in (Figure 2). This resulted in mean FDI scores of 11.53 (SD=10.71) at the first follow-up visit and 10.39 (SD=10.95) at the second follow-up visit.

Subsequent analysis to determine if treatment was more effective in reducing functional disability for specific diagnoses did not yield significant results. While results of a mixed design, repeated-measure ANOVA confirmed the significant difference across the three time points [F (1.86, 400.05) =90.08, p<0.001], there were no significant differences between diagnoses [F (4,215) =1.703, p=0.151]. A significant interaction between time and diagnosis was also found [F (7.44, 400.05) =2.649, p=0.009]. Diagnosis specific trends in FDI scores can also be found in (Figure 2).

## Pain Intensity

At the initial visit, participants report a mean pain intensity of 5.94 (SD=1.88). Following multidisciplinary treatment, patients exhibited a downward trend in pain intensity, as shown by the “Entire Sample” line in (Figure 3). This resulted in mean pain intensity of 4.37 (SD=2.57) at the first follow-up visit and 3.80 (SD=2.72) at the second follow-up visit.

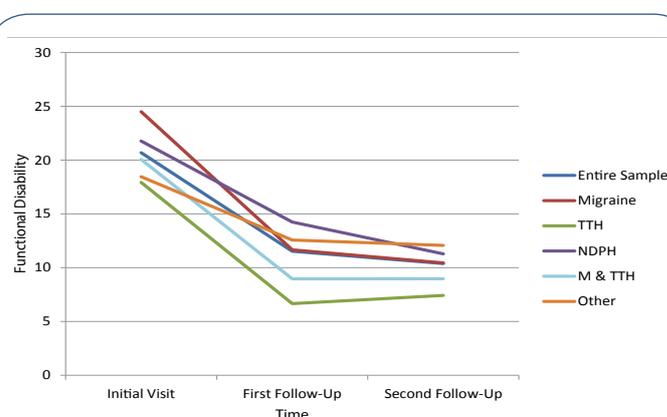
Subsequent analysis to determine if treatment was more effective in reducing pain intensity for specific diagnoses did not yield significant results. While results of a mixed design, repeated-measure ANOVA confirmed the significant difference across the three time points [F (1.80, 369.23) =65.93, p<0.001], there were no significant differences between diagnoses [F (4,205) =1.00, p=0.408] or a significant interaction between time and diagnosis [F (7.20, 369.23) =1.63, p=0.124]. Diagnosis specific trends in pain

intensity can also be found in (Figure 3).

## School Absences

At the initial visit, parents reported a mean of 7.56 (SD=10.57) school absences within the past three months. Following multidisciplinary treatment, patients exhibited a downward trend in school absences, as shown by the “Entire Sample” line in (Figure 4). This resulted in mean school absences of 3.75 (SD=7.82) at the first follow-up visit and 3.42 (SD=9.14) at the second follow-up visit.

Subsequent analysis to determine if treatment was more effective in reducing school absences for specific diagnoses did not yield



**Figure 2** Functional Disability. Mean FDI scores for the entire sample and for each headache diagnosis are displayed at each time point.

TTH: Tension-Type Headache; NDPH: New Daily Persistent Headache; M & TTH: Migraine and Tension-type Headache.

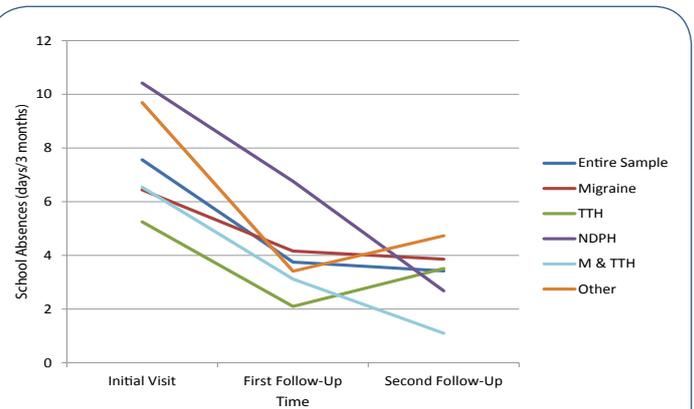
significant results. While results of a mixed design, repeated-measure ANOVA confirmed the significant difference across the three time points [ $F(1.69, 306.58) = 8.62, p < 0.001$ ], there were no significant differences between diagnoses [ $F(4, 181) = 1.66, p = 0.161$ ] or a significant interaction between time and diagnosis [ $F(6.78, 306.58) = 1.42, p = 0.124$ ]. Diagnosis specific trends in school absences can also be found in (Figure 4).

## Discussion

The present study investigated the efficacy of a multidisciplinary pediatric headache program by tracking various clinical outcome measures including pain intensity, functional disability, school attendance, and utilization of emergency medical services from an initial visit through up to two follow-up visits. This study also assessed if multidisciplinary treatment is more effective in improving outcomes for specific headache diagnoses.

The results presented demonstrate the significant effects of the multidisciplinary treatment model of the Pediatric Chronic Headache Program of Boston Children's Hospital for children with various primary headache conditions. We found significant decreases in pain severity, functional disability, and number of school absences and early dismissals, ER visits, and overnight hospitalizations. These results reflect the traditional measures regarding pain measurements used in previous studies while also presenting new supportive data regarding outcomes of school attendance, headache induced disability, and utilization of medical services.

These results, showing statistically significant and substantial sustained improvement in a large sample, contribute to the external validity of this study and support the broad applicability of the multidisciplinary treatment model in even larger populations. Similar functional improvements were seen in each of the primary chronic headache populations reviewed indicates the model is appropriate for treating all types of primary headaches.



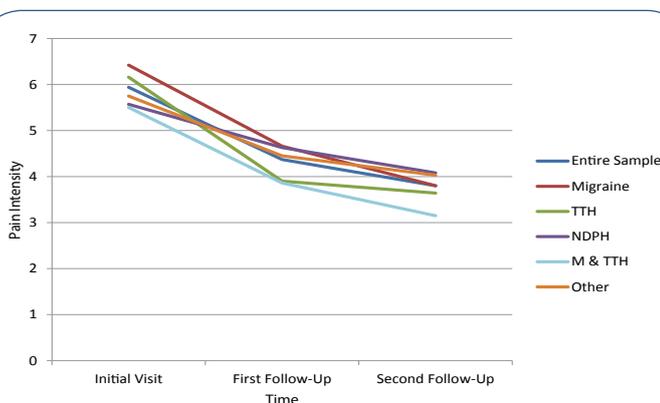
**Figure 4** School Absences. Mean school absences for the entire sample and for each headache diagnosis are displayed at each time point.

TTH: Tension-Type Headache; NDPH: New Daily Persistent Headache; M & TTH: Migraine and Tension-Type Headache.

Between the initial visit and the second follow up, the patient's self-reported average pain intensity was reduced by more than 2 points. As pain intensity is a measure of the amount of pain the patient is typically experiencing at any given moment, this reduction implies an improvement in the quality of a patient's daily routine. Although this measure doesn't report frequency, and reduction in headache frequency has been the most typical outcome measure in headache treatment studies of late [20], pain intensity adds an additional perspective to the assessment of the patient experience. For example, for some chronic headache conditions, such as New Daily Persistent Headache, where the pain is constant such that every day is a headache day, a reduction in the average pain experienced should be an important goal of treatment.

On average, functional disability decreased by just over 10 points between the initial visit and the second follow-up. As FDI is a 60 point scale, this indicates a decrease by 1/6 of the total measure thereby reflecting a significant improvement in functioning and ability. The questions in this tool address the child's ability to perform many activities that are important for daily functioning, quality of life, and healthy development, including activities such as using the bathroom, sleeping, being able to socialize with friends, being at school all day or going shopping. Therefore, a significant decrease in this measure could be associated with enhanced routine function.

School attendance demonstrated a major improvement between the initial visit and second follow-up through a decrease in both absences as well as early dismissals. Patients' absences decreased by approximately 4 days per three month period. To better illustrate the magnitude of this change, this measure would equate to the student being able to attend approximately 3 more weeks of school per year than they would have otherwise. Additionally, as early dismissals decreased by approximately 1.3 per three month period between initial visit and second follow up, this measure indicates that students are staying in school



**Figure 3** Pain Intensity. Mean pain intensity scores for the entire sample and for each headache diagnosis are displayed at each time point.

TTH: Tension-Type Headache; NDPH: New Daily Persistent Headache; M & TTH: Migraine and Tension-Type Headache.

for the full day about 5 more times than they had been before initiating treatment. Of particular note is the large improvement in school attendance for participants diagnosed with New Daily Persistent Headache, a particularly persistent and challenging diagnosis. The decrease in school absences by about 8 days per three month period equates to the student attending 6 more weeks of school a year. As school engagement and attendance are important to the positive social, emotional, and intellectual development of children and adolescents, frequent absences related to headache can have a profoundly negative impact on a child's development [31, 32].

There were also statistically significant decreases in the number of ER visits per three month period and, by the second follow up, a significant decrease in the number of overnight hospitalizations. Headache is the third most common cause for pediatric patients to seek treatment in the ER, resulting in huge societal expenses and high health care costs for those affected [33]. In many chronic condition treatment models, the main goals are generally to improve the quality of care provided while also reducing costs for these complicated cases. ER visits and extended hospital stays are two of the most expensive utilizations of health care services [34], so the reduction found in this study highlights an added benefit of multidisciplinary treatment. Not only does multidisciplinary care reduce a patient's pain and improve their functioning, but it also reduces the burden of additional healthcare costs on a family.

The findings of this study must be interpreted in the context of the following limitations. First, the sample was largely Caucasian and female, and, while this sample's demographics are consistent with samples drawn from other pediatric chronic pain programs (e.g., Eccleston, Crombez, Scotford, Clinch, & Connell, 2004; Bursch, Tsao, Meldrum, & Zeltzer, 2006) [35, 36], the results of this study may not generalize to more diverse populations. Second, while the multidisciplinary approach offered at this clinic was associated with improvement in patients' functioning and school attendance, due to the lack of a control group, we cannot say with certainty that this was not affected by a placebo effect. It is possible that simply seeking treatment may have helped improve these patients' functioning and not the specific care model offered at this clinic. Finally, as this study focused on

functional outcomes, we did not collect data on general headache frequency or the reduction in headache days, which historically are very popular outcome measures. Due to this decision, we were unable to compare the two outcome approaches.

The findings of this study highlight the clinical and research importance of these outcome measures. Clinically speaking, tracking school attendance, emergency room visits, and functional disability in addition to the traditional measures of headache frequency and pain intensity is useful in enhancing the description of these patients' progress. Future studies should also include a mix of both types of outcome measures in evaluations of multidisciplinary care centers.

Often the intensity of a patient's pain cannot be reduced immediately. In these more time intensive cases, it is important to work to improve the patient's quality of life despite their pain intensity. Clinicians are best advised to approach care in a holistic manner, focusing both on a reduction in headache frequency and pain and on an improvement in quality of life. Ultimately, the efficacy of multidisciplinary care evident in this and other studies highlights the need for additional clinics and practitioners to adopt the multidisciplinary model.

This study found that a multidisciplinary approach to treating pediatric headache is effective in improving functioning and school attendance, adding to the increasing literature. However, there is no single clinical outcome measure of headache treatment that can best characterize a mixed sample of patients. As patients with chronic headache present with complex profiles of variable disability, the measures used to assess the efficacy of their treatments must also be comprehensive and, hopefully, reflect important challenges of living with chronic pain.

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## Conflict of Interest Statement

There were no conflicts of interest for any of the authors listed above.

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