Published in final edited form as:

Headache. 2018 May ; 58(5): 661–675. doi:10.1111/head.13285.

CBT for pediatric migraine: A qualitative study of patient and parent experience

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Abstract

Objective—The goal of this study was to determine which cognitive behavioral therapy (CBT-HA) treatment components pediatric headache patient stakeholders would report to be most helpful and essential to reducing headache frequency and related disability in order to develop a streamlined, less burdensome treatment package that would be more accessible to patients and families.

Background—Pediatric migraine is a prevalent and disabling condition. CBT-HA has been shown to reduce headache frequency and related disability, but may not be readily available or accepted by many migraine sufferers due to treatment burden entailed. Research is needed to determine systematic ways of reducing barriers to CBT-HA.

Methods—Qualitative interviews were conducted with 10 patients and 9 of their parents who had undergone CBT-HA. Interviews were analyzed using an inductive thematic analysis approach based upon modified grounded theory. Patients were 13 to 17.5 years of age ($M = 15.4$, $SD = 1.63$) and had undergone CBT-HA approximately one to two years prior to participating in the study.

Results—Overall, patients and their parents reported that CBT-HA was helpful in reducing headache frequency and related disability. Although patients provided mixed reports on the effectiveness of different CBT-HA skills, the majority of patients indicated that the mind and body relaxation skills of CBT-HA (deep breathing, progressive muscle relaxation, and activity pacing in particular) were the most helpful and most frequently used skills. Patients and parents also generally reported that treatment was easy to learn, and noted at least some aspect of treatment was enjoyable.

Conclusions—Results from these qualitative interviews indicate that mind and body CBT-HA relaxation skills emerged as popular and effective based on patient and parent report. Future

research examining the effectiveness of streamlined pediatric migraine non-pharmacological interventions should include these patient-preferred skills.

Keywords

pediatric migraine; cognitive behavioral therapy; mind and body intervention; qualitative methods

Introduction

Pediatric migraine is a prevalent childhood condition,¹ occurring in 9.1% of children and adolescents² and often persisting into adulthood.³ Pediatric chronic migraine is defined as 15 or more headache days per month, with at least 8 episodes of migraine including features such as moderate to severe intensity, pulsating quality, and associated symptoms of nausea, vomiting, phonophobia and photophobia.⁴ Approximately 1.75% of youth are affected by chronic migraine,⁵ and the majority experience severe burden due to their condition including reduction in school activity and quality of life.⁶ Effective treatments aimed at decreasing pain and disability are essential for minimizing the impact of pain throughout childhood and beyond. Cognitive behavioral therapy for headache (CBT-HA) has been shown to be effective for improving pediatric migraine outcomes.⁷ A recent study demonstrated that CBT-HA that included 8 sessions across 2 months, plus 5 booster sessions across the subsequent 7 months reduced number of days with headache.⁸ Session content included eight techniques commonly found in CBT-HA and adapted from studies previously demonstrated as efficacious in other pain conditions (e.g., psychoeducation, physiologic relaxation, cognitive restructuring, activity pacing, problem-solving). Despite it being a relatively brief treatment, there was a notable rate of refusal to participate, with some families citing extensive treatment burden as the reason for opting out. Being “too busy” has been cited in other pediatric psychology literature as a reason of declining therapy.⁹ Thus, minimizing burden by creating a streamlined treatment for pediatric migraine will likely increase accessibility for pediatric migraine sufferers.

To effectively streamline treatment, it is important to determine key components related to treatment success. One approach to discovering features of treatment that are most helpful is to directly ask the key people involved in the process (i.e., patients/families) about their experiences in therapy, either while therapy is on-going or after it has concluded. Elliot¹⁰ refers to this as “helpful factors” research and highlights the alignment of this approach with the movement toward viewing the patient as a “consumer” of mental health. Within the pediatric realm, directly assessing the perspective of the patient and family involved in treatment dovetails well with the current “family-centered care” paradigm in which the perspective of the family is highly valued in considering health care provision, and recognizes the child and family as active participants in the therapeutic process.¹¹ It also addresses the noted dearth of studies valuing children and adolescents’ “voices” as related to mental health research.¹² Of note, adolescents’ perspectives on CBT for depression have been analyzed successfully by means of qualitative methodology.¹³ Using systematic qualitative research methodology, rich data driven by the perspective of therapy stakeholders can be organized and integrated to provide insights that inform treatment development and implementation.^{14, 15} This approach of incorporating stakeholders has been used in previous

research designed to improve evidence-based health interventions,¹⁵ including reports of the experience of adult headache patients in using medications;^{16, 17} qualitative analysis of the experience of children and non-pharmacologic headache treatment has not yet been reported.

Understanding the experiences of the patients and parents invested in CBT for pediatric migraine will enrich our understanding of key features of treatment and guide development of treatments that focus on the most essential components, thereby reducing treatment burden. Thus, the objectives of this study were to use a modified grounded theory qualitative methodology to obtain and explore rich stakeholder data about patient and parent's perspectives on their experiences with CBT-HA.¹⁸ Because patient and parent experiences are not yet fully understood, the design was exploratory in nature and was not intended to develop a theoretical model. Obtaining this information allows us to explore aspects of CBT-HA that key stakeholders perceive to be the most effective skills/components of treatment to inform future development of refined, less burdensome CBT-HA treatments. The CBT-HA that these patients participated in was based on a psychological pain treatment shown in a randomized clinical trial to improve migraine outcomes when added to traditional medical management,⁸ and used to effectively treat juvenile fibromyalgia pain.¹⁹ We were particularly interested in understanding the long-term impact of CBT-HA treatment, as well as patient and parent reports of their experiences learning and utilizing specific treatment components. Additionally, using a clinical sample for the current investigation allows for greater generalizability of the study results.

Method

Participants

The sample consisted of 10 participants ("patients") and 9 of their parents (one parent of a patient declined to participate) who had completed CBT-HA treatment at a large Midwestern medical center outpatient clinic within the past 10–24 months. All participants completed CBT-HA treatment with one of two psychologists. Eligibility inclusion criteria were: (a) patients aged 11–17 years at time of treatment; (b) primary diagnosis of headache and/or migraine (includes migraine with and without aura; chronic migraine; and new daily persistent headache for the current sample); (c) minimum attendance of 3 CBT-HA sessions including at least 3 main components of treatment (see below); (d) indication of willingness to be approached for research studies as part of outpatient treatment (e) no additional CBT treatment for other medical or psychosocial conditions and (f) patients and parents fluent in English.

Sampling

Only those patients treated by two psychologists who report that a substantial proportion of their clinical work is related to pediatric migraine pain, and who report strong fidelity to CBT-HA were initially selected. To identify this pool of possible participants we obtained the list of patients who ended treatment 1–2 years earlier. We then narrowed this list to patients who were ages 11–17 years old at the end of CBT-HA treatment and had not received services for other psychological issues since the end of migraine treatment. Screening was then conducted by the psychologists who delivered the CBT-HA to eliminate

any participants who may be adversely impacted by being contacted for participation based on their clinical judgment and experience with the patients (e.g., may deter willingness of the participant to return to treatment), or any patients that had an atypical course of treatment (typically due to comorbid psychiatric issues). After receiving the “psychologist-approved” list of patients, we corroborated treatment focus on migraine fidelity to treatment, use of CBT-HA for treatment and confirmation of treatment focus on migraine by chart review of treatment notes from patient’s medical records. Treatment notes were also reviewed to ensure that the patient was given at least 3 components of evidence-based treatment for pain management beyond the initial intake session, including diaphragmatic breathing, progressive muscle relaxation, imagery, activity pacing, cognitive modification, distraction/pleasant activities, problem-solving, gate control psychoeducation, and cued relaxation. This criterion was chosen based on the psychologists’ reports that in actual clinical practice treatment duration was typically shorter than the 8 sessions that comprised the clinical trial protocol on which the clinical treatment was based.⁸ Sixty potential participants met the inclusion criteria and were invited to participate. Interviews were conducted on a first-come first-served basis for those patients that responded to our letters inviting them to participate, with the data coded and reviewed as each interview was completed. We repeated this process until theme saturation was achieved, which occurred with a sample of 10 patients,²⁰ after which no further participants were invited. Parents of the above patients were also invited to participate in the study. If two parents were active in the patients’ care, the parent who was most knowledgeable about/most involved in their child’s pediatric migraine treatment was invited to participate. Regardless of the age of the patient, if neither of his/her parents agreed to participate in the study, the patient was not able to participate, but parents could only participate if their child was part of the study (given that adolescents were primarily involved in treatment with parent involvement limited to a few sessions).

Procedure

Following IRB approval, eligible participants and their parents each received letters (sent in the same envelope) explaining the study and inviting them to participate. Letters explained the purpose of the study as ‘designed to identify aspects of CBT children and parents find most helpful in reducing migraine frequency and intensity and improving quality of life’. They were instructed to return a “do not contact” postcard (included in mailing with postage provided) if they did not wish to participate. Families who did not decline to participate via postcard were contacted and provided with more information about the study. Interviews were scheduled with the first families who were reached via phone and indicated interest in the study. A few families declined to participate in the study once reached via phone due to time constraints and/or distance from the study location. Only 2 to 3 interviews were conducted at a time to allow for ongoing qualitative analysis of interviews in order to determine when interviews were no longer needed due to theme saturation being reached. For the qualitative analysis, an inductive approach with thematic coding was used, followed by an iterative process for further clarification of themes.^{21, 22}

All interviews were conducted in outpatient clinic rooms and lasted, on average, 60 minutes. During the interview appointment, both patients and parents met together for study explanation and obtaining informed consent/assent, then were interviewed separately. All

patients and parents were interviewed by the same person, a second-year pediatric psychology post-doctoral fellow (AKVD) with limited CBT-HA treatment experience and no known biases regarding CBT-HA or pediatric migraine treatment prior to beginning this study. Participants had no prior relationship with the interviewer, and were informed that the purpose of the study was to obtain patient and parent perspectives regarding CBT-HA. After interview completion, both patients and parents completed questions regarding demographic and headache characteristics via REDCap portal using a designated study laptop. Patient participants received \$20 for their participation (parents were not compensated).

Sample Characteristics

Parents completed a demographic questionnaire providing information about their own and their child's age, gender and school/employment status. A headache frequency questionnaire was completed by both patients and parents to document patient's current headache frequency, intensity and associated disability. Additional data on participant's course of treatment was conducted via chart review to obtain information on number of treatment sessions and treatment components implemented according to session notes. Session-by-session treatment outcome data used as part of routine clinical care were noted, which were a 0–10 visual analogue scale (VAS) of average pain intensity and the Functional Disability Index (FDI).²³ The FDI is clinically validated self-report assessment of pain-related disability that is commonly used in pediatric chronic pain research and clinical settings and has established cut-points for classification of disability level (No/Minimal Disability, FDI 12; Moderate Disability, FDI = 13 – 29; Severe Disability, FDI = 30).²⁴

Interview

A semi-structured interview was developed to assess a variety of factors related to CBT-HA, including headache/functioning status at the beginning of treatment, what was remembered about the treatment, what was expected of the treatment, and what was helpful/unhelpful about the treatment (broadly and related to specific CBT-HA components). Both patients and parents were prompted regarding components of treatment and were given a hand-out about the components to review. The interview included inquiries about each of the CBT-HA treatment components (described in detail in Powers et al., 2013) including: diaphragmatic breathing, progressive muscle relaxation, imagery, activity pacing, cognitive modification, distraction/pleasant activities, problem-solving, gate control psychoeducation, and cued relaxation. The parent interview was the same as the patient interview but focused on what parents learned through participation in CBT-HA sessions (including parent guidelines for managing their child's migraines at home), discussion with their child after sessions, and/or observing skills their child was using at home for migraine management. The parent interview also included parent-focused questions related to parental expectation for treatment.

Data Analysis

Interviews were audiotaped, transcribed by a professional transcription company, and de-identified by research staff. Qualitative analyses were conducted using an inductive approach with thematic coding and a subsequent iterative process for further clarification of themes.^{21, 22} With a thematic analysis approach, the intention is not to produce generalizable results

but instead to systematically identify meaningful themes/patterns around a specific area of interest.^{22, 25} During familiarization, or phase 1, two members of the research team knowledgeable about CBT-HA (AKVD & MME) independently reviewed a subset of patient and parent interviews to derive the initial codebook. In phase 2 (generating initial codes), three research team members (AKVD, MME, & LMV) systematically coded interesting features, direct quotations, and patterns across the entire data set, adding additional codes as appropriate until theme saturation occurred. Theme saturation was expected with anywhere from 5 to 20 interviews from each group (patients and parents separately) based on previous qualitative studies interviewing patients post-intervention which accomplished theme saturation with a range of patients between 5 and 26.^{14, 26, 27} Discrepancies (which were rare) in coding were discussed until coders arrived at consensus. During phase 3, searching for themes, the data were collated into potential themes by gathering all data relevant to each potential theme. During phase 4 (reviewing themes), the team used the constant comparison method to examine and refine the themes by comparing and contrasting information within each interview and across all the interviews.^{18, 28} In phase 5, defining and naming themes, the team conducted ongoing analysis to refine each theme and further condense the themes into an overall story.

Results

Participants

Of the 10 patients, 8 were female, 1 was bi-racial (Asian/White) and 1 was Hispanic. Patients' ages ranged from 13 –17.5 years at time of interview, with an average of 15 months since last CBT-HA session. At time of treatment initiation, 4 patients were reporting moderate disability on the FDI, the average pain severity rating was 4 out of 10, and headache frequency ranged from about 1×/month up to nearly daily (average ~ 3 headaches/week). Table 1 provides additional patient characteristics (names changed to protect participant identity).

On average, patients completed 5.7 CBT-HA sessions, and all were taught 6 components. According to chart review, all patients received psychoeducation, relaxation strategies of diaphragmatic breathing, progressive muscle relaxation, and imagery, biofeedback, and cognitive modification; 9/10 patients were taught activity pacing skills, 1/10 patients were taught problem-solving, and no patients received instruction on increasing pleasant activities. Of note, while it is unlikely that therapists charted about a strategy that was not actually taught during a session, it is possible that strategies were discussed but not charted. By treatment end, 90% of patients were in the mild range of disability (3 of the 4 patients originally in the moderate range moved into the mild range), and 3 of the patients had demonstrated a reduction of at least 3 points on the pain VAS. Data collected from the headache characteristics questions at the time of the interview indicate that 50% of the patients report having only mild headaches, on average. Six patients reported having fewer than 4 headache days per month (average of 7.1 headache days per month for all patients).

Themes

Prior to beginning CBT-HA

Functional disability: All patients reported some level of headache related disability prior to participating in CBT-HA. Such disability included missing out on social activities and/or sports, or being present for these activities but not being able to engage and participate as much as they typically would. Sample quote: *“I would like miss some soccer practices and I normally didn't function well, like at the best of my ability with a lot of things”* (Helen, 17yo). The majority of patients also reported missing full or partial days of school and/or having difficulty focusing during school as a result of pain.

Similar to patients, many parents reported HA interference with participation in social activities or sports or decreased performance in such events. Four parents also reported patients missed partial or full days of school as a result of HA.

Expectations and motivation: Many patients reported that they were hopeful that participating in CBT-HA would improve their ability to manage migraine pain, while a few patients weren't sure what to think about participating in CBT-HA prior to their first appointment. Half of patients reported being willing to attend CBT-HA on their own, and three patients reported needing encouragement from parents to attend treatment.

Parents reported being hopeful that CBT-HA would help their child manage migraines, with some stating they believed CBT-HA would provide their child with tools for migraine management, and two believing CBT-HA would give their child confidence and control over migraines.

CBT-HA treatment

Overall treatment: Most patients described the CBT-HA as being helpful overall, and all patients noted that a variety of techniques were useful for headache improvement. Example quotes include: *“It gave me more options of what to do with my headache while I was dealing with them or to prevent them”* (Dana, 14yo); *“It also helps me not be like ‘it hurts, it hurts, it hurts’, whatever, because I like not freak out... so like not think about it or do something else”* (Ingrid, 15yo). One patient noted that the treatment did not necessarily help headache per se, but did help with sleep, and one patient did not feel that the CBT-HA was beneficial at all.

The majority of the parents also described CBT-HA as helpful overall, noting the improvement related to different techniques as well as the issue of improved self-efficacy or benefit for other treatment targets. For example, *“I think it gave her good tools...she understands the idea of tension in her body and the ability to have your mind take control and then physically begin to release it. I think that's very powerful”* (mom of 14yo Amy). Some parents noted that the patient-treatment fit was important when discussing if/which aspects of treatment were helpful (*“I think they gave her several techniques to use and I think some of the techniques aren't helpful for her...I think some worked for her to a degree and others just don't work at all for her. That doesn't mean they don't work for other people”* Mom of 17yo Helen). Finally, two parents noted that it was difficult to determine if

treatment was helpful, either because they were not seeing the patient use skills, or because other treatment changes were occurring at the same time such as medication changes or initiation of physical therapy.

Both patients and parents also noted aspects of treatment that were not helpful. Responses were varied, and typically related to specific techniques. For example, *“The imagery one was hard to do when I had a headache...it required a lot of thinking and focusing that I didn’t really have at that point.”* (Amy 14yo); *“Some of the stuff just didn’t make sense and didn’t help at all. Um – like the one thing that you had to like stretch out all your muscles and then it would help, but it doesn’t help”* (Frank 13yo). A few patients also noted that material were presented in a way that did not fit their developmental level or processing abilities. Sample quote: *“The visual cues didn’t work for me but that’s more because I’m more auditory learning and stuff like that”* (Ed 17yo).

Beyond the idiosyncratic nature of treatment fitting children in specific ways, there was little consensus among parents as to what was not helpful about treatment.

In terms of other treatment characteristics, both patients and parents reported that, overall, treatment was generally easy to participate in, and most reported that there were at least some aspects of treatment that they enjoyed or found fun. Biofeedback was frequently noted as being fun by patients and parents: *“I think it was fun for [patient] when they hooked her up to the monitors and she was able to see how her heart rate would change based on the stress level in her at that point and how it changed whenever she did one of the techniques that the psychologist suggested.”* (Mom of 14yo Dana).

Barriers to treatment were not frequently noted by patients or parents. The barriers to treatment that were reported included one patient and parent from the same family noting that missing school and having a busy schedule after school were barriers.

Specific treatment characteristics: Table 2 describes the different treatment components, with interview content coded according to whether patients or parents 1) described the component as essential and/or helpful, 2) reported the patient was still using the technique, and 3) made any negative comments about the component. As indicated in Table 2, the relaxations strategies were most consistently described as both essential and helpful components, particularly diaphragmatic breathing. Of note, imagery was the component that also received the most negative feedback by both patients and parents. Activity pacing was the component most consistently still used according to patients. Both cognitive restructuring and pleasant activities were noted as essential and helpful by some patients (suggesting that pleasant activities were discussed by patients and therapists even if not documented in the medical record).

Some parents found the parent guidelines helpful, particularly not focusing on their child’s pain. Example quote: *“I think the main thing was...they [grandparents] kept asking her...“How do you feel? Does your head hurt?” So getting them all to stop that, I think, made a huge difference because they would bring it to her attention every time they saw her”* (Mom of 15yo Ingrid). However, one parent found the recommendations to be difficult to

implement: “*The not focusing on the pain one is such a mixed signal...It’s such a catch 22 of ‘Okay, I’m supposed to treat them early but not focus on the pain.’ It’s pretty clear as mud to me.*” (Mom of 14yo Amy).

Other treatment targets: In addition to treatment helping patients with HA management, patients identified CBT-HA as helping them with other symptoms. Half of the patients (50%) reported improvement in sleep, one-third reported reductions in anxiety, and one patient (10%) reported that deep breathing helped with nausea (“*The deep breathing helped me... When I get really bad headaches, I get nauseous and that would help with it*” Barb, 15.5yo). Parents also reported improvements in sleep and reductions in anxiety from CBT-HA.

CBT homework: The majority of patients reported doing the home practice routinely, but half noted that it was also difficult to remember and needed reminders from parents or other things: “*That was hard...I think it was like probably the hardest part was trying to remember to do everything at home...and finding the time to do it in my schedule*” (Helen, 17yo).

Many parents commented that their children routinely did the practice, although sometimes it was unclear because the children were practicing in their room. Two parents also noted that it took some evidence that the practice would pay off to help their children be motivated to complete it: “*Once she got onboard and realized, ‘okay, this is really gonna help me’, then, yeah, she was more inclined to practicing*” (Mom of 14yo Dana).

Design a “future” treatment: Both patients and parents were asked for recommendations they would make if they were designing a CBT-HA program. This was an open ended question, allowing patients and parents to suggest anything as part of a desired treatment (e.g., skills already discussed and/or any other ideas not already part of CBT-HA). Patients noted specific skills that they thought should be included such as relaxation, activity pacing, pleasant activities, cognitive strategies, and self-monitoring of skills practice. One patient noted the importance of offering multiple techniques for patients to try: “*I do think it’s helpful to put all the different things they tried for each kid because you’re able to single out their needs and specify treatment for them*” (Ed, 17yo). Finally, including a means to encourage people to give the program a try was noted by two participants, and one suggested making the program interesting or fun and easy.

Parents also noted specific techniques such as relaxation strategies and biofeedback. One parent commented on improving the method of self-monitoring headaches, such as using eHealth applications via personal electronic devices to record migraine occurrences. Similar to the patient suggestions, one parent also noted the importance of offering a variety of techniques within a program to better fit the needs of participants: “*I think the program as it stands is very useful so I really would hate to see strategies that work for some and not for others being cut out of it.*” (Mom of 17yo Helen).

Parent Involvement: Both patients and parents noted the importance of parent involvement. One patient suggested having parents involved for younger children, while two others suggested parents check to make sure their kids practice skills. Parents noted the importance

of making sure patients use skills and also encouraging their child to give the treatment a chance to work. Example quote: *“I think it definitely is a process that the parents have to be involved with and have to be willing to put the time and effort in to make sure their kids are practicing. Easy for me to say because mine did it on her own but, you know, make sure they're at least practicing and giving it a chance to work.”* (Mom of 17yo Helen). One parent commented that they would have preferred to know more about the treatment in order to better support their child.

Discussion

Using a qualitative methodology, the current study sought to obtain feedback from patients and parents who had completed CBT-HA about which components of treatment they found most helpful in reducing headache frequency and related disability in order to inform development of a streamlined version of CBT-HA that was less time and cost intensive (including cost of time and travel to sessions), thereby increasing accessibility of treatment. Themes indicate that most patients (9/10) and parents (7/9) who completed outpatient CBT-HA treatment approximately one to two years prior to being interviewed believed that CBT-HA was effective in reducing pain and disability related to migraines. This is particularly notable given that all patients and parents indicated that patient's experienced some degree of disability related to migraine (e.g., missing school, unable to participate in extracurricular activities, decreased participation due to pain) prior to CBT-HA. Most patients and parents also reported that these decreases in disability and improvements in patients' abilities to manage migraine pain were sustained through the time of this interview, which occurred on average 15 months after completing CBT-HA treatment.

Patients' perspectives on helpfulness of each of the CBT-HA skills were mixed, but patients indicated that the mind and body skills, particularly diaphragmatic breathing and progressive muscle relaxation (6/10 listed both as helpful), were the most helpful skills they learned and used. Diaphragmatic breathing was also reported as 'most essential' by 3 patients for including in a future streamlined version of CBT-HA. Seven patients also reported continuing to use activity pacing as a means of managing migraine and stress. Cognitive modification, which was introduced to all patients, was less frequently noted as being helpful (4/10), essential (1/10) or still utilized (1/10). Problem-solving (which was less frequently introduced to patients) was also not as highly recommended by patients (2/10) or parents (1/10). Parents weren't able to provide as much specific feedback on each CBT-HA component, primarily due to parents being less involved in CBT-HA sessions focusing on skill development. However, parents who did mention skills were more likely to mention that their child was observed or reported practicing mind and body relaxation skills more than other CBT-HA skills. Based on this preliminary information, a streamlined version of CBT-HA should focus on the mind and body relaxation.

Two notable themes were discovered from the interviews that were not related to specific CBT-HA skills. First, parents' reported noticing increased confidence and self-efficacy in patients throughout the CBT-HA treatment (7/9). While this was not a direct target of treatment, increased knowledge of coping skills to manage headache pain that results in decreased migraine and related disability would likely result in patients gaining a sense of

confidence and control over their headache pain. Thus, in accordance with current literature, increases in confidence and self-efficacy gained through use of CBT skills combined with biofeedback may be a major contributing factor to overall improvement in migraines and increases in quality of life.²⁹ Second, some patients and parents indicated that patients saw improvements in symptoms other than migraine pain. Reductions in anxiety (3/10 patients and 3/9 parents) and sleep problems (5/10 patients and 4/9 parents) were the most commonly reported improvements after completing CBT-HA treatment. Given that comorbid symptoms of anxiety and sleep problems could exacerbate migraines,³⁰ reductions in these symptoms could potentially lead to improvements in migraine above and beyond reductions in migraine frequency alone.

Importantly, while the CBT-HA research protocol that guided treatment for participants from the current study included 8 weekly sessions, followed by booster sessions, patients from this study attended only an average of 5.7 total sessions. Despite attending fewer sessions, all patients were still able to receive training on at least 6 CBT-HA coping skills, and all received training on the mind and body relaxation components. These relaxation components were also taught first in the CBT-HA protocol. Altogether, these findings indicate that a shorter version of CBT-HA would not only be more convenient and less burdensome for families, but is also likely to still be effective in reducing migraine frequency and disability among children.

Although themes indicate that many patients and parents agree that mind and body relaxation skills are the most helpful for migraine pain management and essential to keep in a streamlined version of CBT-HA, not all patients agreed that all three main relaxation skills (deep breathing, progressive muscle relaxation, guided imagery) were equally helpful. Of these three relaxation skills, patients' responses regarding guided imagery were the most inconsistent: 4 out of 10 patients indicated that the skill was more difficult to learn and/or less helpful than the other relaxation skills. Importantly, while patients had varied responses to effectiveness of certain skills, it is possible that more home practice of imagery may be required for patients to achieve true "mastery" of this skill to make it effective. Because of varying lengths of treatment, some patients may have found imagery to be effective because they spent more time practicing both in treatment sessions and at home. Further, some patients and parents discussed how some skills may work better for some children depending on their style of learning and developmental level. It is plausible that imagery in particular may be a skill that is more sensitive to patient styles of learning or age. Therefore, while mindfulness relaxation skills stand out as the most essential aspects of CBT-HA treatment, it is still important to consider assessing for individual differences to tailor CBT-HA treatment as needed for each patient.

Despite parents not being involved in the majority of CBT-HA sessions, they were all included in the first CBT-HA session that included parent guidelines for ways to help their child manage migraines. These guidelines included suggestions such as encouraging children to go to school even when they have a headache and eliminating status checks (i.e. frequently asking "does your head hurt?" or "do you have a migraine?"). Four out of 9 parents reported finding these strategies helpful, particularly citing the eliminating status checks recommendation. Interestingly, of the four parents who reported the guidelines to be

helpful, three indicated they were hesitant about this at first, not wanting to miss out on valuable information about their child's migraines and/or not wanting their child to think they no longer cared about their migraines. However, they reported being more comfortable with this recommendation after learning that part of CBT-HA focuses on teaching children to report their migraines to others in an effort to independently manage their migraines (with assistance as needed), and eliminating status checks reduces chances of bringing a focus to migraine pain for a child using distraction or other skills to cope. One parent did indicate that this particular guideline was confusing, indicating that professionals using these guidelines need to clearly emphasize the reasons why eliminating status checks are helpful and ensure both patients and parents understand the rationale for this guideline.

In addition to comments on the parent guidelines, two parents indicated they would have liked to have been more involved in their child's CBT-HA treatment. As noted by one parent, including parents more frequently in patient sessions could increase parents' understanding of what their child is learning to allow them to provide support to their children when using CBT-HA skills at home. Further, parents knowing that their children are assigned CBT-HA homework and what that homework is could allow parents to monitor home practice of skills if needed. This inclusion of parents in sessions could include brief check-ins at the end of sessions (e.g., 5–10 minutes) to review skills learned in that particular sessions and the home practice of skills assigned for the upcoming week. Although parents expressed a desire to be more involved in treatment, it is important to consider that the treating psychologist(s) may have a desire for parents to be less involved in treatment. For example, parent's own lack of motivation for treatment and/or psychopathology could be perceived as having the potential to interfere with their child's CBT-HA treatment. Psychologists may also want to reduce parental involvement in treatment to prevent (or reduce existing) enmeshment between parents and children, and allow patients to develop independence and confidence in managing their migraines without assistance. Thus, psychologist's assessment of patient's developmental level and overall family dynamics is warranted in determining level of parent/family involvement in treatment. In either case, additional educational handouts about the skills learned and homework assigned could be provided directly to parents at the end of each session.

Interestingly, and perhaps not in accordance with prior literature, barriers to participation in CBT-HA treatment were not commonly cited by patients or parents from the current study. Previous research has suggested that patients are often unable to participate in CBT-HA treatment due to barriers such as time, travel, and costs.⁸ However, only one patient-parent dyad reported difficulty attending CBT-HA due to missing school and scheduling. These results could possibly be a sample selection bias given that patients who would identify barriers to participation in CBT-HA may be less likely to agree to participate in this study due to the same barriers. As such, results from this study may be less generalizable to patients and parents who identify more treatment barriers for CBT-HA.

While the current study provides valuable qualitative data to inform development of a streamlined CBT-HA treatment for pediatric migraine patients, limitations of the study should be discussed. First, the sample was homogeneous and included primarily White females from one clinic seen by 1 of 2 psychologists. However, the sample characteristics

are consistent with the typical headache and migraine population seen at the neurology clinic from the large Midwestern institute where the study occurred.⁸ Additionally, the majority of our sample had some form of migraine diagnosis, and only one had a diagnosis of new persistent daily headache, which further limits our knowledge on the generalizability of study results to populations of pediatric patients with other headache diagnoses (e.g., tension-type headache). However, it is important to note that other research has demonstrated effectiveness of CBT-HA for other such headache diagnoses within pediatric populations.^{31, 32} Thus, it is plausible that patient and parent reports of CBT-HA treatment effectiveness and preferred skills/components of treatment may be similar across different headache and migraine diagnoses.

Second, as a qualitative study the sample size was necessarily small so caution should be used in generalizing the findings to a broader, more diverse pediatric migraine population. While a higher participation rate could potentially increase generalizability, the range of experiences reported provides beneficial information and theme saturation was achieved increasing confidence in our findings within this sample. Third, although we were particularly interested in the longer-term utility of aspects of CBT for pediatric headache, the developmental level of the patients and the time elapsed since treatment may have limited both recollection of treatment components and ability to comment cogently on salient aspects of treatment, thereby decreasing richness of the data. Finally, although using a true clinical sample for this qualitative investigation allows for discovery of themes that are more generalizable in a “real world” setting, greater flexibility in terms of treatment components covered during CBT-HA treatment was required. This flexibility results in patients having somewhat differing experiences in CBT-HA, which may have influenced their overall perception of and responsiveness to CBT-HA and in turn impacting their responses to the current interview questions. However, given that flexibility is required in a true clinical setting based on each individual patient/family, results are likely to still reflect a typical CBT-HA experience from the patient and parent perspective.

Findings from the current study provide preliminary data instructive for the development of a streamlined version of CBT-HA treatment that is less burdensome for families to be tested in future research. Steps towards this study could include creating a streamlined CBT-HA protocol, and obtaining key stakeholder feedback (including professionals implementing treatment and patients and families receiving treatment) on the revised protocol prior to engaging in pilot testing of the streamlined intervention. Additional refinement of the streamlined CBT-HA could occur following future studies determining the amount of time and intensity of treatment needed for patients to learn and develop CBT-HA skills. Future research could further explore other ways of implementing treatment (i.e., delivered in outpatient neurology clinics by allied health professionals/nurses) to make treatment more accessible to patients.

Importantly, this study identified patient and parent preferences for skills that were most enjoyed and most helpful from CBT-HA treatment. While this information is highly useful in developing a streamlined CBT-HA treatment, the true mechanisms of change within CBT-HA are still unknown. Future research is needed to identify the key components of CBT-HA

that are supported by research evidence as drivers of change in order to have both a patient preferred and an evidence-based version of streamlined CBT-HA.

Results from this qualitative study indicate that patients and parents find CBT-HA to be effective in reducing headache and migraine frequency and related disability, while increasing overall quality of life. These positive results were sustained through the time of these interviews, which occurred an average of 15 months following completion of CBT-HA treatment. Mind and body relaxation skills from CBT-HA, such as deep breathing and progressive muscle relaxation, were noted as most helpful, fun, and easy to learn by most patients and some of their parents. Thus, based on patient and parent preferences, streamlined CBT-HA should include mind and body relaxation skills to remain effective for management of migraine pain.

Acknowledgments

Financial Support: U.S. Department of Health and Human Services, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases

Abbreviations

CBT-HA	Cognitive behavioral therapy for pediatric migraine
CBT	Cognitive behavioral therapy

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Participant characteristics and clinical outcomes

Table 1

Patient	Gender	Current age (years)	ICHD-III Diagnosis	Months since last treatment session	# of treatment sessions	PedMIDAS initial neurology appointment	FDI initial session	FDI last treatment session	Average pain rating initial session	Average pain rating last treatment session	Headache frequency initial session	Headache frequency follow-up neurology appointment
Amy	F	14	Migraine without aura	14	7	15	16	7	3	2	3–5×/week	1–3/month
Barb	F	15.5	Chronic migraine; Migraine without aura	15	4	14	5	4	4	3	4×/week	>3/week
Carol	F	17.5	Chronic migraine; Migraine without aura	15	4	14	8	8	4	7	4×/week	Daily
Dana	F	14	Migraine with aura	17	6	5	0	0	1	0	1–3×/month	1–3×/month
Ed	M	17	Migraine without aura	17	5	17	20	9	6	3	5×/week	1–3/month
Frank	M	13	Migraine without aura.	15	6	50	23	0	4	0	1–2×/week	1×/week
Gail	F	14	Migraine without aura	10	8	86	17	19	6	5	3×/week	Daily
Helen	F	17	Chronic migraine; Migraine without aura; New daily-persistent headache	11	7	N/A	10	10	5	4	Almost daily	3/week
Ingrid	F	15	Chronic migraine; Migraine without aura	24	5	55	0	0	2	3	3–5×/week	3/week
Joan	F	17	Migraine without aura	15	5	6	3	0	5	0	3×/month	1–3×/month

Note: # of treatment sessions include new visit and follow-up sessions. PedMIDAS unavailable for “Helen”. FDI = Functional Disability Inventory (FDI; Walker & Greene, 1991). Pain ratings were intensity 0–10 (high) on a visual analogue scale. Headache frequency at neurology follow-up closest to final CBT appointment.

Table 2

Patient-centered treatment components with patient and parent themes, and descriptive quotes

Treatment components		Descriptive quotes		Descriptive quotes	
		Patients (n=10)		Parents (n=9)	
Diaphragmatic Breathing	Essential 3	<i>You breathe in through your nose and then you breathe out through your mouth but like you do something with your belly. (Dana, 14 yo)</i>		Essential 0	<i>Sometimes reminding herself to breathe helps. (Mom of 15.5yo Barb)</i>
	Helpful 6			Helpful 2	
	Still doing 3			Still doing 2	
	Negative 0			Negative 0	
Progressive muscle relaxation	Essential 0	<i>You tighten like starting with maybe your fingers and then you gradually like tighten more and more of your body. Then you release and so it kind of destresses you and you relax more. (Helen, 17 yo)</i>		Essential 0	<i>Being able to chill and lie down and think about relaxing muscles, tensing and relaxing. (Mom of 14yo Amy)</i>
	Helpful 6			Helpful 1	
	Still doing 1			Still doing 0	
	Negative 1			Negative 0	
Imagery	Essential 1	<i>If I had a migraine I'd be freaking out, I'd be tensed up. But I'd have to think of a happy place and calm myself down. (Dana, 14 yo)</i>		Essential 0	<i>She is a teenager so when you start talking about – thinking about placing yourself on a beach, I don't know, to them it's kind of like, "Okay, why are we doing this crap?" (Mom of 15.5yo Barb)</i>
	Helpful 5			Helpful 0	
	Still doing 1			Still doing 0	
	Negative 4			Negative 3	
Activity pacing	Essential 1	<i>Thinking about times to relax during the day... like taking breaks in between practices and whenever other activities after school and kind of relax. (Ed, 17 yo)</i>		Essential 0	<i>Whether it was just with activities or homework or something like that, making sure she paced herself gave herself that rest period in between. (Mom of 17yo Helen)</i>
	Helpful 6			Helpful 4	
	Still doing 7			Still doing 1	
	Negative 0			Negative 0	
Cognitive modification	Essential 1	<i>I learned just to change the way I'm thinking and even if I have a headache I can still do some things even if it's not what I normally can do. (Helen, 17 yo)</i>		Essential 0	<i>No specific comments by parents.</i>
	Helpful 4			Helpful 0	
	Still doing 1			Still doing 0	
	Negative 0			Negative 0	
Distraction/Pleasant activities	Essential 1	<i>Read or do other things that help you, like maybe go outside and exercise or whatever to like get your mind off the pain. (Ingrid, 15 yo)</i>		Essential 0	<i>I was talking to her about the whole, in the beginning, obsessing about my head hurting, the "think about something else or do something else." (Mom of 15yo Ingrid)</i>
	Helpful 3			Helpful 1	
	Still doing 2			Still doing 0	
	Negative 0			Negative 0	
Problem-solving	Essential 0	<i>If you're having a problem like thinking of ways to solve them. (Helen, 17 yo)</i>		Essential 0	<i>Identifying the problem area, revealing the problem stuff, and picking a solution to help. (Mom of 17yo Helen)</i>
	Helpful 2			Helpful 1	
	Still doing 2			Still doing 1	
	Negative 0			Negative 0	
Gate control psycho-education	Essential 0	<i>If you are stressed, like the gate is open and then like if you're like all calm and stuff and you think calm thoughts then the gate's closed. (Gail, 14 yo)</i>		Essential 0	<i>You block out the pain with the gate control. (Mom of 17yo Helen)</i>
	Helpful 0			Helpful 2	
	Still doing 0			Still doing 1	
	Negative 1			Negative 1	

Treatment components		Descriptive quotes			Descriptive quotes
		Patients (n=10)		Parents (n=9)	
Biofeedback	Essential 1	<i>They like strap like things on your fingers to see your heartbeat and you had to like make it go down....It was fun because it was difficult.Because like you've got to think in different ways to get it to go down. (Frank, 13 yo)</i>		Essential 0	<i>He could watch his own heartrate go up and down...I think those visual help. (Mom of 13yo Frank)</i>
	Helpful 3			Helpful 2	
	Still doing 0			Still doing 0	
	Negative 2			Negative 0	
Cued-relaxation	Essential 0	<i>The stickers as cues to remind to relax. (Ed, 17 yo)</i>		Essential 0	<i>You put the little star on a post-it note around that was trying to help you when you're in a situation where you can't necessarily pull yourself out. (Mom of 14yo Amy)</i>
	Helpful 1			Helpful 1	
	Still doing 0			Still doing 0	
	Negative 1			Negative 2	

Note: 4 patients indicated relaxation as “essential” but not specific to type of relaxation. 1 parent indicated relaxation as “essential” but not specific to type of relaxation. 6 parents indicated relaxation as “helpful” but not specific to type of relaxation. 4 patients indicated they were still doing “relaxation” but not specific to type of relaxation. 1 parent indicated patient was still doing “relaxation” but not specific to type of relaxation.