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Cognitive-behavioral therapy: How medical providers can increase patient and family openness and access to evidence-based multimodal therapy for pediatric migraine

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Abstract

While evidence supports the recommendation for cognitive behavioral therapy (CBT) for pediatric migraine, few children actually receive this evidence-based intervention. In this article we briefly review the most recent empirical evidence supporting CBT. We then identify both provider/system-related barriers as well as patient-related barriers. Finally, we provide practical solutions to addressing these barriers in the service of facilitating children receiving optimal comprehensive management of their headaches.

Keywords

pediatric migraine; cognitive-behavioral therapy; care integration

INTRODUCTION

Pediatric migraine is associated with significant pain and disability.^{1,2} In addition, pediatric migraine often persists into adulthood,³ with adult migraine ranked as the 8th leading cause of years lived with disability.⁴ ICHD-3 beta definition of chronic migraine is having at least 15 days per month of headache (8 of which have migraine features) for more than 3 months in the absence of medication overuse. Migraine symptoms must include at least 2 of the characteristics of unilateral location, pulsating quality, moderate or severe pain intensity,

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and aggravation by or causing avoidance of routine physical, and must be accompanied by either nausea and/or emesis, or photophobia or phonophobia.⁵ Chronic migraine is reported in a majority of youth seeking services in headache specialty clinics.⁶ Clearly, identification and implementation of effective treatments for migraine are critical for serving this pediatric population and, hopefully, preventing further negative sequelae into adulthood.

Cognitive-behavioral therapy (CBT), a psychological treatment, has demonstrated efficacy in the treatment of chronic pain in youth.^{7,8} CBT typically includes biobehavioral treatment components of cognitive training (e.g., cognitive modification and distraction) and behavioral change strategies (e.g., relaxation training with or without biofeedback, activity pacing, adherence plans), and is often presented as a package of these different components.⁷ A recent Cochrane review reported effects favoring these types of treatment of headache compared with control groups, with a risk ratio of 2.47 (95% confidence interval 1.97–3.09) for headache pain and an effect size (standardized mean difference) of –0.49 for disability reduction.⁹ Another meta-analytic review of psychological treatment utilizing CBT components for pediatric chronic headache also supported this approach, and found that 70% of children receiving these interventions experienced clinical significant improvement, defined as at least a 50% reduction in headache.⁸ Recently, our research team sought to extend the evidence-base for pediatric migraine by evaluating the benefit of adding cognitive-behavioral treatment to standard medication practice (e.g., amitriptyline) in 10–17 year old children with chronic migraine.¹⁰ The CBT included a variety of the cognitive-behavioral strategies described above, as described in Table 1. We strove to maximize methodological rigor by including adequate sample size to power our analyses, utilizing a credible and attention-matched behavioral “control” condition (i.e., headache education), and to have sufficient follow-up (1 year). In addition, we insured that all participants met ICHD-II criteria of chronic migraine (the current criteria at the time of the study).¹¹ The children we studied, at baseline, reported a high level of headache days (21 days with headache out of 28) and severe disability (average PedMIDAS score of 68). Results at the 1 year follow-up demonstrated that patients that received CBT had significant reduction in headache days (86% of patients had reduced headache days by at least 50%) and improvement in quality of life (88% fell into no or minimal disability criteria). These outcomes were superior to the education “placebo” condition (in which 69% of patients had a 50% reduction in headache days and 76% met the no/minimal disability criteria). Thus, CBT in combination with amitriptyline resulted in nearly 9 out of 10 patients demonstrating clinically meaningful improvement in headache days and quality of life. Notably, this treatment was relatively brief (8 weekly 1 hour individual sessions followed by 2 booster sessions at weeks 12 and 16); however, patients were able to document improvement of pain, function and overall quality of life. Therefore, medical practitioners can be confident in knowing that there is evidence to support the rationale of recommending cognitive-behavioral pain management as part of the treatment plan in chronic migraine patients in the service of achieving the best pain and quality of life outcomes for their patients.

Despite positive outcomes, few children¹ and adults¹³ participate in cognitive-behavioral pain management interventions, even when recommended by their pain specialist.¹⁴ Both providers and patients may feel challenged by obstacles in incorporating CBT as part of the headache treatment plan.¹³ In this article we provide detailed information and practical

suggestions for addressing these barriers in the service of facilitating providers' ability to recommend CBT pain management as part of multimodal treatment of pediatric migraine. Table 2 provides an outline of these barriers and potential solutions.

PROVIDER/SYSTEM-RELATED BARRIERS

Providers who are knowledgeable about CBT are most likely to be the most effective in persuading and in referring patients for the treatment. CBT should be presented to families as an option in a similar manner as one would discuss the rationale for and risks and benefits of medication therapies. We have provided a detailed explanation of the cognitive-behavioral model as applied to headache management elsewhere,¹⁵ but in brief: CBT has as a basic assumption that our thoughts (cognitions), feelings (both emotions and physical sensation) and behaviors (or "actions") are interactive and typically interdependent. For example, a person who experiences a headache (physical sensation) may feel frustrated (emotion) and think to herself "this will never get any better" (thought) and choose to stay home from school (behavior). With CBT, patients acquire skills to make healthy changes in thoughts, feelings, physical sensations and behaviors with the goal of improving their pain and overall daily experience. CBT emphasizes the mind-body connection, and highlights how natural and adaptive body processes (e.g., the stress response) may have gone awry but can be restored through purposeful practice of evidence-based techniques that are directly related to the target areas. The "Gate-Control theory of pain"¹⁶ is commonly used as a conceptual framework for pain-focused CBT, and is often reviewed with the child and parent in the initial stages of CBT. This model highlights that the experience of pain is an integration of peripheral stimuli and cortical processes, with a neurochemical "gate" in the spinal cord involved in pain perception. CBT aims to close the "pain gate" by teaching skills such as physiologic regulation (e.g., diaphragmatic breathing, guided imagery or progressive muscle relaxation), activity pacing, problem-solving, cognitive modification (identification of unhelpful thoughts and replacing them with more adaptive –albeit realistic thoughts), distraction and planned engagement in pleasant activities.

Biofeedback is sometimes used to assist with physiologic regulation skill training.¹⁷ This involves patients being connected to biofeedback equipment which measures key physical parameters (e.g., facial muscle tension or peripheral temperature) and transmits these signals to a visual display, typically a computer screen. Patients practice relaxation skills while observing physiologic changes which are graphically displayed, thereby learning from this feedback that they can control these body processes and identify specific strategies that optimize these changes.

Parents are often involved in treatment and are provided guidelines that facilitate their ability to productively support their child's use of coping strategies while minimizing attention to nonproductive pain complaints or avoidance behaviors. Treatment will also address issues related to non-adherence to headache medication; while child adherence data have not been published, adult studies suggest poor adherence to both acute and preventative headache medication.¹⁸ CBT for headache management is frequently completed in 6 – 8 sessions,⁸ with home practice considered essential for treatment success.¹⁸ Table 1 outlines the session content of the CBT program shown to be effective in reducing headache days

and improving disability.¹⁰ This information can be shared with patients and families when introducing CBT as part of their evidence-based migraine management.

CBT should be highly recommended to any patient who is dissatisfied with their current headache status, but certainly for those patients who have chronic migraine or are experiencing moderate or greater disability (e.g., PedMIDAS¹² scores above 30). Additional indications for referral include the presence of symptoms of anxiety or depression, evidence of significant psychosocial stressors, or perception of family over-involvement or over-protection as related to headache. Those patients already receiving counseling for mental health concerns can benefit from a referral for pain-focused CBT. In cases of significant mental health issues (e.g., trauma history), CBT for pain may be deferred until these issues improve although CBT for headache management has been shown to be effective even in the presence of comorbid psychopathology.¹⁹ Patients or parents who have already received CBT for psychological issues may be more familiar and therefore more accepting of the referral.²⁰ Patients with cognitive deficits or learning challenges can be referred for CBT, which has been shown to have efficacy when these issues are present.²¹ Experienced mental health clinicians may be able to take advantage of the literature supporting matching specific components of CBT to specific patient subgroups,²² such as specifically targeting pain-related fear in those pediatric patients for whom fear contributes to disability.²³

Another obstacle to CBT is that providers may feel a lack of confidence in communicating rationale for CBT and encouraging follow-through. Physicians making evidence-based treatment recommendations can learn to use persuasive communication while at the same time acknowledging patient and family autonomy and perspective. Research suggests a number of dimensions important to medical advising including communication related to the seriousness of the problem and effectiveness of the recommended treatment, fostering patients' confidence in their ability to follow-through with the treatment plan and acknowledging potential limitations to the plan as well as a plan for addressing.²⁴ Studies have shown increased adherence to care recommendations when patients are given a good understanding of the causes related to their medical condition and rationale for treatment, signs indicating whether or not treatment is working, strategies for fitting treatment into routines and educating on expectations for treatments.²⁵ Research investigating communication specific to migraine highlights the value of open-ended questions and checking to insure that providers properly understand what families are communicating.²⁶ Finally, motivational communication strategies highlight the importance of validating and empathizing with the patient perspective, aligning treatment recommendations with patient values and working with patients to increase confidence in their ability to follow-through with recommendations. It is important to also recognize that patients may be at different stages in terms of interest and ability to take action, and that providers' thoughtful dialogue may set the stage for later willingness to engage in health behaviors.²⁷ Notably, preliminary research investigating stages of change in pediatric pain populations have found that adoption of a biopsychosocial approach is related to greater willingness to self-manage pain, particularly for parents.²⁸ Thus, health care providers that emphasize the mind-body connection may be enhancing self-management in families dealing with chronic migraine.

Studies suggest that both children and their parents value physicians speaking directly to the child, at a level that the child is most comfortable. In addition, a child's adherence to treatment recommendations is enhanced when they experience their medical provider being supportive and genuinely interested in them beyond their illness or symptoms. Furthermore, children respond when providers do not "order" them in terms of how to act, when they encourage patient self-care and when the patient perspective is valued.^{29,30} It is important to engage using body language (e.g., looking patients in the eye, getting down to their level in terms of posture/height) and verbal content (e.g., follow-up questions) as it conveys a genuine interest in patient's activities and hobbies. As a result, the provider builds a good rapport while at the same time sets the stage for discussion to learn how their headache is impacting their quality of life. The patient will gain increasing motivation to do what is recommended to participate in valued activities and hobbies. Table 3 provides an example of language that can be used to facilitate adherence to treatment recommendations based on the research above and our clinical experience. For a list of "frequently asked questions" from patients and families and potential responses, see Appendix B.

We appreciate the time constraints that providers have in today's health care setting. A well thought-out approach can be utilized to effectively convey information in a short period of time. First, a communication "strategy" such as we have proposed and outlined in Table 3 takes just a few minutes, especially when practiced or rehearsed. Second, the use of written materials, including hand-outs (see Appendix A), journal articles¹⁰ or information from the internet (see Appendix C) can provide parents valuable information about CBT. Clinic personnel can assist the primary care provider by reinforcing information and address follow-up.

Finally, medical providers may feel limited by the lack of adequate referral options. For those providers who are already collaborating with psychologists trained in pain management CBT, developing relationships that permit expedient access to services will increase the likelihood that families will attend appointments. For providers who do not have established relationships with psychological pain management experts, there are a number of ways referral streams can be developed (see Table 2). While this "leg-work" takes time up front and may be outside of typical activities, the long-term payoff can be immense for patients. In our own experience, both within our Headache Center as well as in working with numerous other medical providers, fruitful collaborations have been built in which both medical providers and psychologists are able to provide an integrated care plan and share "ownership" of patient outcomes. Frequent communication between providers enhances the collaborative relationship and allows for prompt adjustments to treatment plans as indicated. In addition, patients and families understand their care to be comprehensive and coordinated rather than have the perception of being "passed along" from provider to provider. This communication is particularly important when working with psychologists who may have experience with CBT, but have not yet worked with pain populations. It may be especially vital for medical providers to clarify the level of functioning that should be expected even with pain symptoms, so that psychologists can encourage and problem-solve a return to typical activities. Creating a multidisciplinary "team" approach can be very rewarding and beneficial for patients and providers alike.

Alternatively, another option for providers to consider is to bring CBT “in-house”, by adding a pain management psychologist as part of the clinic. At Cincinnati Children’s Hospital Headache Center, each patient is seen by a headache specialty neurologist followed by a pain psychologist for consultation and brief CBT intervention. Referral for the complete CBT program is made as indicated. While this may not be feasible for a general neurology practice, creative scheduling strategies such as having a “high-risk” or a “complex care” clinic once per month for those patients with more disability, symptom severity, or complex psychosocial situations may allow for including psychology routinely in targeted populations.¹⁵ Another option that can be effectively utilized is to invest in training clinic staff in the use of focused cognitive-behavioral treatments such as biofeedback, which has demonstrated efficacy in improving headache even in a single session protocol.³¹ This may be especially appropriate for patients without significant disability or symptom severity. If a local CBT provider cannot be identified, consider locating a CBT pain provider in major cities that may be willing to consider tele-health services.³² Additionally, motivated patients and families can be provided access to basic relaxation strategies and stress management via the internet or smart phone apps (Appendix C).

PATIENT-RELATED BARRIERS

Children and parents may identify a variety of barriers when presented with a recommendation for CBT. This may, in fact, be a positive sign, in that it may mean that families are seriously considering this option and are wondering how to incorporate it successfully into their life. Patients may fear the stigma associated with “psychology” or mental health treatment resulting in negative reactions from families. In our experience, these negative associations are seen in a minority of the families that we have treated. In fact, many prefer non-pharmacologic options for managing headache pain³³ and parents have reported the belief that learning to cope with the pain is extremely important.³⁴ One component of the “stigma” may be simply that parents lack knowledge about CBT. Thus, the communication strategies outlined above as well as specific recommendations in Table 2 will likely put family concerns at ease (see also Appendix B).

Relatedly, patients may not have experience with therapy referrals as they do with medication prescriptions. When given a prescription, families have “learned” that they need to take this prescription to the pharmacy, fill it and then take the medicine as prescribed (although, admittedly, this is actually done quite imperfectly). Families do not have a similar learning history with referrals for CBT. Thus, borrowing from their other learning history may facilitate follow-through, such that writing an actual prescription out for the therapy, and having specific written steps as to who to contact for treatment, should be helpful. In addition, it is critical that medical providers affirm that they will remain on-going participants in patient care – that care is being shared among providers, not transitioned from the medical provider to a psychological provider.

Perception of treatment burden may be another patient-related barrier to participation in CBT. In fact, the recruitment process for our own clinical trial highlighted some barriers to people attending regular therapy sessions. For example, of the 361 patients who were

eligible for inclusion in the study, 28% refused to participate for reasons related to distance to the treatment center, not enough time to participate, or participation would cause additional stress. This compares to 2.8% of people refusing to participate because they did not want to take the medication. Notably, once in the study, attrition was remarkably low (92% of participants completed the trial and follow-up assessments), suggesting that once people actually come to a therapy good retention is possible.¹⁰ Working with families to understand the time-limited nature of brief CBT, and comparing it to other types of programs or therapies that families might use as reference can help with appropriate perspective on treatment burden. For example, the 2–3 month time commitment is likely similar to a course of physical therapy or a study skills program, and less time-intensive than participation in a school play. In addition, working with families to identify what might be “cut-out” temporarily to make room for treatment can facilitate willingness, such as temporarily suspending another activity (preferably an activity that is less preferred by the child!). If there is loss time at school or parents’ ability to be at work has been compromised by migraine, this can be used to demonstrate that poorly managed migraine actually likely takes up more time than CBT will take. It can be helpful to underscore for parents that an ability to participate in meaningful activities is a major treatment target for CBT, so that after CBT children may be able to engage in even more activities, even more efficiently and effectively. Ultimately, highlighting for families that children will be learning actual coping skills that can be applied to their headache as well as to more general stress can off-set for families the time burden – the likelihood that this short-term investment in time and resources will have long-term pay off can be motivating for parents. Kids get to “keep” these skills forever. Indeed, children often demonstrate continued improvement in headache and disability in the months following the end of treatment.¹⁰ Importantly, while noting that the short-term nature of CBT is warranted, it is critical that appropriate expectations for home practice are outlined (15–20 minutes most days of the week), such that children and their parents are given an accurate expectation of the level of treatment participation that is likely necessary for successful outcomes.

Another patient-related barrier that families might discuss is the issue of CBT financial cost and payment. Parents may perceive payment for frequent CBT clinic visits as more expensive than the less frequent medical visits, although a cost-comparison study examining the relative costs of various formats of CBT versus a variety of medication across time demonstrated that the cost of CBT becomes comparable to medication within 6 months of treatment and become more cost effective than most medications after approximately 1 year.³⁵ Parents may be unclear as to how insurance coverage (if had) applies to covering the costs of adding an additional provider to the care team (as opposed to adding a medication). Families should be encouraged to call their insurance company to discuss options for coverage of psychological services. For families with high deductible insurance plans, having a chronic condition such as migraine may actually be somewhat fortuitous, in that families may have met their deductible through the medical care costs, and may have little to no costs associated with CBT. Whether CBT is covered by insurance may be impacted by the diagnosis under which CBT is billed. CBT for headache is a behavioral health treatment for the medical issue of migraine. Thus, the most correct diagnosis under which CBT should be billed is the migraine diagnosis itself, in which case medical insurance funds would be

accessed. “Health and Behavior” (or H&B) billing codes have been successfully utilized in our own headache clinic, as in others,³⁶ to obtain reimbursement for behavioral treatment addressing medical conditions or symptoms. Some mental-health-focused practitioners may not be familiar with these codes, and physicians developing collaborations with community psychologists to enhance CBT treatment options for their patients may be in a position to encourage psychologists to explore this billing option by providing resources (Appendix C). Unfortunately, H&B codes are not recognized by all insurances (in particular, are often rejected by Medicaid), and if they are recognized may be reimbursed at lower rates than mental health CPT codes. However, advocacy strategies such as providing literature to insurance companies on the evidence for CBT for improving medical outcomes and reporting on outcomes within the clinic, particularly when this advocacy comes from a medical provider or clinic business personnel, can be useful for increasing insurance companies’ willingness to reimburse H&B codes. The other option for insurance coverage is to provide services billing through mental health funds, which necessitates a mental health diagnosis (typically, “adjustment disorders” or “psychological factors impacting medical condition”). Specific reimbursement codes also exist for biofeedback-only treatment.³⁷ Families, medical providers, and CBT providers can work in concert to petition insurance companies to reimburse needed services, with success enhanced by providing companies empirical literature supporting the treatment.¹⁰ We realize that these advocacy activities may not be ones that medical providers have been trained to do or are part of routine practice; nonetheless, they can be extremely important for optimizing care for patients, and once a “petition process” is in place, can become stream-lined.

Ultimately, children or parents may decide against pursuing CBT. In some instances, parents may be interested in the recommendation whereas the child is not. If there is a long-standing pattern of child-parent conflict, it may not be prudent to have the parent set firm limits around participation, as CBT may then become another “battlefield” for the family. On the other hand, CBT can (and should be) thought of as a treatment recommendation to be taken as seriously as other recommendations (e.g., medications), and it is sometimes successful for parents to set a firm expectation that their child at least “check out” CBT before making a decision as to whether the treatment will be helpful. Other times, children may be more open to CBT than their parents. In this instance, it may be helpful to speak alone with parents to fully appreciate their concerns while also highlighting the primacy of addressing their child’s medical condition. When both parents and children are opposed to pursuing CBT, it is important to remain open to and respect families’ autonomy, while at the same time framing for families that treatment-decisions can be revisited and revised as the course of the migraine continues. In this instance, close medical follow-up is indicated, with clear criteria for when other treatment options (including CBT) should be discussed again (e.g., no improvement or worsening symptoms or disability within a specified time frame). Families should be encouraged to keep a headache diary (either electronically; see Appendix C) or on paper¹⁵ in order to track the course of their migraine. This may also help families more clearly identify the role of stress in migraine experience and increase willingness to participate in CBT. While family “push-back” may be off-putting to providers, remembering that families may be “more ready” to consider CBT at future appointments can help

providers remain committed to reviewing this treatment option repeatedly (albeit judiciously).

SUMMARY

Providers treating pediatric migraine should be routinely recommending CBT as an evidence-based treatment strategy for decreasing pain experience and improving quality of life. Having a “referral plan” as outlined here will likely increase provider comfort and effectiveness in making the referral for CBT pain management, thereby enhancing the treatment options and, ultimately, clinical outcomes for their patients and families. Admittedly, incorporating CBT into comprehensive migraine treatment requires more effort on the part of both medical providers and families than does a strictly medical approach, given that there is not a ready-made “referral system” in place for CBT (i.e., can’t go to a pharmacy and pick CBT up). In addition, neither providers nor families may have much experience with CBT, and participating in the “unknown” can invoke hesitancy. However, the same skills that providers use in reviewing medical options and addressing related barriers can be applied when recommending participation in CBT. Given the evidence in support of this treatment option, it is imperative that medical providers and psychologists work together to meet this challenge. Strong advocacy in terms of developing referral streams and negotiating with insurance companies may be necessary to secure optimal treatment options for families, but the evidence suggests that positive outcomes following CBT can have long-lasting effects and will be worth the initial investment.

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Abbreviations

CBT	cognitive-behavioral therapy
ICHD-3 beta	International Classification of Headache Disorders, 3 rd edition (beta version)
ICHD-II	International Classification of Headache Disorders, 2 nd edition
H&B	Health and Behavior Codes

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Appendix A

Comprehensive management of headache

Research tells us that a comprehensive approach to managing headache is most effective. This can include multiple components:

Medication. A number of medicines have been shown to be effective to prevent and treat headache pain. It is important to limit pain medication to no more than 2–3 days per week because frequent medication use can actually worsen headache.

Healthy lifestyle. The same healthy behaviors that are recommended for overall health are good for headache management, but there are some specific behaviors that have been shown to be really important:

- Diet: Green leafy vegetables, dairy products, and protein, and eat at regularly scheduled times. Don't skip meals.

- Hydration: Drink at least 64 ounces daily. Avoid caffeine. Take a water bottle to school. Drink 32 ounces of sports drink at onset of headache.
- Exercise: Regular exercise (3–4× week for 30 minutes)
- Sleep: Keep a set bedtime schedule (~ 8–9 hours per night), even on the weekends.

Stress management

- Body calming/reducing muscle tension: Learning to reduce the stress response in your body
- Strategies to help manage the challenges in your life
 - Learning more helpful ways of thinking about your pain or stress
 - Developing better problem-solving skills
 - Pacing activities (not overdoing it!)
 - Making sure to do pleasant activities
 - Effective use of distraction

COGNITIVE-BEHAVIORAL PAIN MANAGEMENT is a highly recommended treatment approach that has been shown to help kids have fewer days with headache and decrease the negative impact of headache on their life. It directly targets stress management and body regulation. It is focused, skills-based and is usually conducted by psychologists who act as “health coaches” while teaching kids and parents new ways to prevent or respond to pain. Psychologists specialize in understanding thoughts and feelings, and the way we think about our pain/stress can make a difference in how much pain we have or how it influences our life. This treatment is usually short- term, typically lasting 2–3 months.

BIOFEEDBACK is a recommended technique for decreasing body stress. Using a computer to monitor easily recorded changes in the body (e.g., temperature, breathing and muscle tension), kids can practice strategies designed to decrease body tension and use the feedback provided by the computer display to guide their practice of these strategies and get the best results. Biofeedback can help kids learn more effectively the strategies taught during cognitive-behavioral pain management treatment.

Appendix B

Families’ “Frequently Asked Questions” and potential responses

1. *Do you think my child is crazy?* No. Migraine is a very common in children and adults, and is best served by a comprehensive approach. While there is more anxiety and depression in people with migraine, most children with migraine do not have psychological disorders. However, just like with any other chronic condition, most people do need to learn to do new things to manage the condition, and psychologists can help people learn these new things.
2. *Don’t only crazy people go to a psychologist?* While psychologists do work with people with emotional or behavioral problems, there are psychologists who focus

on health issues and who work with people without major psychological problems to improve their physical health. For example, many people with heart problems see psychologists for general stress management. Or, athletes will go to psychologists to improve their performance (which often includes work on stress management or body system regulation).

3. *Will my insurance cover it?* This depends on your insurance, and what diagnosis is used to bill. Many psychologists can bill for their services using the medical diagnosis of “migraine”, so medical fund dollars will cover it. Other psychologists may bill under a mental health diagnosis. If your child is actually experiencing a mental health issue that needs to be addressed, this may be the diagnosis that is used. Otherwise, there are “health-related” mental health diagnoses that can be used, such as “psychic factors impacting health conditions” which are appropriate to use when we are working on addressing pain-related behaviors. When you call your insurance, ask them about coverage for cognitive-behavioral therapy.
4. *How do I explain it to my child?* You can tell them that there is a terrific set of skills they can learn to help them have more control over their headache and that can help the headache have less control of their life, and that a psychologist is a “health coach” that can help them do it.
5. *It will take too much time.* Pain management treatment can be relatively short-term – it often is completed within 2–3 months. There are other things that you can try first that may be able to help your child manage things without going to therapy. For many families, the time invested in treatment is actually shorter than the time it can take for staying home with their child from school, spending time in the ED, etc. In addition, once treatment is over, your child will have learned a set of skills that can help them cope with future stress or headaches, and may help them be more efficient with their own time in the future.
6. *Will I learn anything?* Yes. It will be important for you to know the skills the child is working on so that you can support their home practice. Plus, the psychologist will probably have some recommendations for how to respond when your child is in pain – many parents report feeling helpless or frustrated when this happens, and appreciate having some guidelines. Plus, many children with migraine have parents who have migraine, so you might actually learn something to help with your own pain.
7. *My child doesn't like to talk about his feelings – will it work?* This type of treatment does not depend on spending a lot of time talking about feelings. A lot of the focus is on specific strategies to decrease stress in the body, and learning to pace activities. There is some focus on thoughts and feelings, but these are often specific to pain. Often, once kids have seen some of the benefit of the body strategies, they will be more willing to talk about some of the thoughts and feelings that cause them stress.
8. *How will I know if my therapist is good?* Ideally, you will find a psychologist who has experience in pain management. At the very least, you should find a

psychologist who has experience in cognitive-behavioral interventions. Therapists who work with anxious kids also likely know body relaxation strategies, so that can also be a lead. Your therapist should be assigning weekly homework, keeping track of pain ratings, and should be able to clearly explain how the weekly practice is designed to help change the impact of pain on the child's life.

9. *Will the therapist get too personal? I don't want anyone in our business.* Cognitive-behavioral therapy is very problem-focused. Your therapist will likely focus specifically on those areas important to improving the headache.
10. *We don't believe in therapy.* Many people feel nervous about therapy – usually because they have a specific idea of what therapy is which may or may not be accurate. Sometimes they have ideas about things from TV or movies, or they may even have had or heard about past negative experiences. Few people have had specific pain-focused therapy which is very skill-based. I'd really encourage you to go at least once to see if you feel that the psychologist has something to offer you or your child. I'm recommending this because excellent research studies show that this treatment works and I want the very best results for your child.
11. *Shouldn't we just be able to handle this on our own?* Migraine is known to be a very difficult and sometimes debilitating chronic condition for children. There are certainly things that can be done "on your own". I want to make sure you have all the resources you can to minimize the amount of pain your child has or the impact that the pain is having on your child. Why make it tougher on them than it needs to be?
12. *Isn't my child too young for therapy?* Research has shown that kids as young as 6 can benefit from learning pain management skills.
13. *Are the headaches really bad enough to warrant seeing a psychologist? How bad do they need to be?* There are some self-help tools I can provide to you. I would encourage you to not wait too long because we know that the longer kids have headaches the worse the headache can become and the greater the negative impact on their life. The skills you would learn in behavioral pain-management programs will be helpful in reducing these negative consequences of the migraine. In addition, the skills can be applied to other challenging situations (for example, nervousness about tests).
14. *Why shouldn't we just stick with the medicine?* Medication is often an important aspect of migraine management, and I do want you to follow the medicine as prescribed. For many people, medicine alone does not provide them with the relief or improvement in functioning that they desire, and adding this component of treatment gets them closer to their goals. Plus, these skills can be used across many aspects of their life.
15. *Don't you believe I have pain? Are you saying that the pain is all in my head?* I do believe you have pain. Just because psychological treatment (for example, changing behaviors, working on stress management or looking at pain-related thoughts) can improve migraine for your child does not mean that the pain is

“psychological” or “all in your head”. Just because changing health behaviors improves obesity or diabetes management doesn’t mean that obesity or diabetes is “all in a person’s head”, does it? Cognitive-behavioral treatments work for all sorts of physical symptoms because there is a mind-body connection.

16. *Why will I need to go to?* You are an expert on your child – it will be important for you to share your perspective on what makes the migraine better or worse for your child. You can also support the skills your child is learning.
17. *My child does not have stress.* That’s great. Some kids will have a lot of stress and tell us that it makes their headache worse; some kids say they have stress but it doesn’t impact their migraine, and some kids say they don’t have any stress. We do know the migraine is related to changes in the body, and when we work on decreasing physical tension in the body kids’ migraines can improve.
18. *Will the pain go away?* Many kids will see great improvements after treatment – this may mean that they are having fewer headaches, that when they do have headaches they are less intense or last less time, or it might mean that they are able to get back to doing the things they like or need to do, even if they still have headaches.
19. *My child says she refuses to go see a shrink.* This is a common first reaction. Reassure them that you believe they have a headache, and it is that very reason why you want to make sure they are given every recommended treatment. Set the expectation that, just as you would insist that they go to a doctor’s office if you felt that treatment was needed, you expect them to go meet with the psychologist for at least 3 sessions, and to give the treatment a good try. Usually, once a child actually meets with a psychologist they feel more comfortable, and feel good to know that there are things they can do to help themselves feel better.

Appendix C

Electronic resources

Appendix C

Electronic resources

Websites		
Explains migraines to children	http://kidshealth.org/kid/ill_injure/aches/migraines.html#	The Nemours Foundation/KidsHealth.
Explains comprehensive headache care (including video)	http://www.cincinnatichildrens.org/service/h/headache-center/about/	Cincinnati Children's Hospital Medical Center
Video of adolescent patient with migraine discussing CBT	http://jama.jamanetwork.com/multimediaPlayer.aspx?mediaid=7384053	The Journal of the American Medical Association
Child-friendly website about headache & stomachache, includes relaxation exercises and parent recommendations	http://www.painretreat.net/	Camp Pain Retreat
Video of child teaching diaphragmatic breathing	http://copingclub.com/amber-shows-some-belly-breathing-techniques/	Kosair Children's Hospital
Explains CBT to adult patients	http://www.achenet.org/resources/behavioral_treatment_of_headache_and_migraine_patients_making_referrals/	American Headache Society Committee on Headache Education (ACHE)
Explains use of Health & Behavior Codes	http://www.apapracticecentral.org/reimbursement/billing/	American Psychological Association
Headache webpage (e.g., headache calendar)	http://www.commondataelements.ninds.nih.gov/Headache.aspx#tab=Data_Standards	NINDS Common Data Elements (CDE) [Internet]. Bethesda (MD): National Institute of Neurological Disorders and Stroke (US); 2015
Smart Phone Apps		
Diaphragmatic breathing	Breathing Zone (Breathing Zone Limited)**	
Diaphragmatic breathing	Breathe2Relax (The National Center for Telehealth & Technology, Department of Defense, 2011)**	
General stress management	Take a Chill-Stressed Teens (Channel Capital, LLC)*	
Guided imagery	General Pain Management Guided Imagery (Shelley Spencer-Hellmich)**	
Relaxation for younger kids	Healing Buddies Comfort Kit (Designwise Medical)*	
Headache diary	ecoHeadache (ecoTouchMedia)*	

** Apple and Android;

* Apple only

Informed by:

Smith K, Iversen C, Coakley R. Apple apps to help manage pain and pain-related stress. Society of Pediatric Psychology Annual Conference, Philadelphia, PA2014.
Hundert AS, Huguet A, McGrath PJ, Stinson JN, Wheaton M. Commercially Available Mobile Phone Headache Diary Apps: A Systematic Review. JMIR mHealth and uHealth 2014;2.

Table 1

Cognitive-behavioral treatment: Example of session content.

Session	Content	Home practice
1 C & P	Gate Control Theory Rationale for CBT Parent guidelines	Headache monitor
2 C	Diaphragmatic breathing Progressive muscle relaxation (PMR) Biofeedback practice Mini-relaxation	Above plus: PMR 1×/day Mini-relaxation practice 5×/day
3 C	Pleasant imagery Pleasant activity scheduling	Above plus: Pleasant imagery 1×/day Pleasant activities 2×/week
4 C	Activity pacing Problem-solving	Headache monitor PMR or imagery 1×/day Mini-relaxation 5×/day Pleasant activities 2×/week Pacing Problem-solving
5 C & P	Skill review Biofeedback practice	See above
6 C	Impact of thoughts and feelings on headache Calming statements	Above plus: Calming statements
7 C	Skill review Biofeedback practice Self-monitoring progress	See above
8 C & P	Skill review Maintenance plan	

C = child session; C & P = child and parent together session

Based on Powers et al., 2013¹⁰, Supplementary materials (<http://jama.jamanetwork.com/>).

Table 2

Barriers and potential solutions.

Barriers	Potential Solutions
Provider/System-related	
Provider lacks specific knowledge about CBT	See information in text.
	Review Table 1.
	Review Ernst & Powers (2008) ¹⁵ .
Provider lacks confidence in explaining CBT	Review Table 3.
	Provide articles to families (including Powers et al 2013 ¹⁰).
	Provide handouts to families (see Appendix A).
Provider lacks time to discuss	Use handouts.
	Use other clinic personnel.
Provider lacks referral options	<p><i>Identify local child mental health providers:</i> Contact local child mental health agency. Use web-based search engines for "child behavioral pain management" or "health psychologists". Post inquiries on professional society list-serves. Contact local or state board of psychology or psychology associations. Contact nearest major children's hospital psychology department. Use APA's Psychologist Locator (http://locator.apa.org/). Encourage the family to call their insurance company for a list of CBT providers.</p> <p><i>Collaborate with community providers in developing expertise:</i> Identify local providers familiar with CBT, particularly those who do child anxiety treatment. Provide them with references.^{10,15} Note: Our treatment manual is available upon request.</p> <p>Train staff in clinic to do biofeedback or basic stress/lifestyle management (web search on "biofeedback training" for links to reputable agencies and training programs).</p> <p>Identify local biofeedback practitioners via the Association for Applied Psychophysiology and Biofeedback (www.aapb.org).</p> <p>For long-distance providers, explore options related to Skype, telephone contact, or minimal contact therapies.</p>
Patient-related	
Stigma	Present CBT in a matter-of-fact manner.
	Discuss role of health psychologists - using mind-body-behavior principals to improve health.
	Write out a "prescription" for CBT - this is a "headache" treatment as valid as the medical prescription.
	Highlight that the majority of children using CBT for pain <u>do not</u> have psychological disorders, but are interested in improving their headache and quality of life.
	Highlight focused, skills-based nature of CBT versus TV or movie portrayals of longer-term, "drama-filled" therapy. CBT for pain management is closer to a "study skills" class or PT than to what the media portrays, or what some adults have experienced.
Family has no time/treatment burden	Identify short-term adjustments in priorities/activities to account for treatment time and home practice.
Treatment cost & payment	Give family research articles to submit to their insurance company.
	Call insurance company on family's behalf.
Family not interested	Promote use of most appropriate billing codes (e.g., H & B, versus mental health versus biofeedback codes).
	Explore barriers.
	<p>For child resistance: Encourage family to set expectation for child to participate (or at least keep an open mind during the first 2 sessions) - just as the parent would expect the child to take medicine that has been prescribed</p> <p>For parent resistance: Set criterion with family for when treatment options (including CBT) can be reconsidered (e.g., no improvement or worsening symptoms during next 2 months).</p>

Table 3

Language to facilitate introduction to and follow-through with CBT.

Content area	Example content
Assessment of problem, including <u>impact on daily life</u>	<i>Inquire as to frequency, intensity, duration of headaches, as well as associated symptoms and triggers.</i> I am also really interested in the impact the headaches are having on the things that are important to you. How do you like to spend your time? How does having a headache, or worrying about your headaches, affect the things you like to do?
Seriousness of problem	We know headaches can be very upsetting for kids and have a big impact on their ability to fully participate in and enjoy activities that they need to do. You are telling me that you (your child) are experiencing _____ headaches per week, which are painful and get in the way of the things you like to do – this certainly fits with our understanding of how serious migraines can be. Without effective treatment, headache can get worse over time and persist into adulthood.
Importance to family	How important is it to you to work on improving these headaches at this time? <i>If of low importance, ask</i> What would it take to make it more important? When will you know that it has become more important to you and you want to take the next step? Let me go over different treatment options, and you can decide which you would like to do, knowing that there are different options available. <i>If of high importance:</i> Great. We have effective comprehensive treatment for headaches.
Causes of headache related to treatment	We know that migraine is related to a lack of balance in the normal stress response in the body, related to changes in the blood system in the body as well as changes in how the brain handles pain and other signals. The body becomes worse and worse at shutting down the stress response. Because of that, anything that stresses the body, such as worry, feeling overwhelmed or overdoing activities, can worsen headaches. One of the most important things that a person with a migraine should do is learn to help their body become more “balanced” – re-teach the body to respond helpfully to stress.
Why CBT – Effectiveness of treatment	I am recommending that you (your child) participate in <u>cognitive-behavioral pain management for headache</u> . Data from numerous research studies show that most patients experience at least a 50% <u>reduction in headache with this treatment</u> . This treatment can also decrease the negative interference of headache on their life. In my own experience, my patients have _____.
What is CBT	CBT gives kids the skills to teach their body to respond more helpfully to stress by learning stress reducing strategies such as diaphragmatic (belly) breathing and progressive muscle relaxation. It also helps kids learn to decrease the amount of stress they are experiencing by teaching them ways to plan their activities, become better problem-solvers and think more positively about difficult things. Even for kids who say they do not have stress, we know that migraines themselves are stressful! BIOFEEDBACK is often included to help with learning ways to decrease stress in the body. Using a computer to monitor easily recorded changes in the body (e.g., temperature, breathing and muscle tension), kids can practice strategies designed to decrease body tension and use the feedback provided by the computer display to guide their practice of these strategies and get the best results. CBT is usually, but not always, conducted by psychologists because it focuses on teaching new behaviors related to better managing pain. In this case, the psychologist takes the role of a health “coach” – teaching skills and making recommendations for home practice.
What to expect/how to know it is working	CBT will be very skills-based – you (your child) will be taught techniques to practice at home. Because it is pretty brief, you (your child) should begin to see some improvement in headache frequency or intensity, the ability to participate more fully in activities, or increased confidence in managing headaches within the first few weeks. You will also continue to see me as your medical provider and you and I can talk about progress when we meet.
Questions	See FAQ (Appendix B).
Confidence in following-through	So, as you can tell, I strongly believe that CBT is something that would be helpful for you (your child) to do. What is your confidence in being able to follow-through with this recommendation? <i>If low confidence: ask</i> What is getting in the way of your feeling more confident (see Barriers table). <i>If high confidence:</i> Great. I look forward to hearing how it has gone.
Barriers & addressing	See Barriers Table 2.