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Law EF, Beals-Erickson SE, Fisher E, Lang EA, Palermo TM. Components of Effective Cognitive-Behavioral Therapy for Pediatric Headache: A Mixed Methods Approach. Clin Pract Pediatr Psychol. 2017;5(4):376-391. doi:10.1037/cpp0000216

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Published in final edited form as: Clin Pract Pediatr Psychol. 2017; 5(4): 376–391. doi:10.1037/cpp0000216.

# Components of Effective Cognitive-Behavioral Therapy for Pediatric Headache: A Mixed Methods Approach

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#### **Abstract**

Internet-delivered treatment has the potential to expand access to evidence-based cognitive-behavioral therapy (CBT) for pediatric headache, and has demonstrated efficacy in small trials for some youth with headache. We used a mixed methods approach to identify effective components of CBT for this population. In Study 1, component profile analysis identified common interventions delivered in published RCTs of effective CBT protocols for pediatric headache delivered face-to-face or via the Internet. We identified a core set of three treatment components that were common across face-to-face and Internet protocols: 1) headache education, 2) relaxation training, and 3) cognitive interventions. Biofeedback was identified as an additional core treatment component delivered in face-to-face protocols only. In Study 2, we conducted qualitative interviews to describe the perspectives of youth with headache and their parents on successful components of an Internet CBT intervention. Eleven themes emerged from the qualitative data analysis, which broadly focused on patient experiences using the treatment components and suggestions for new treatment components. In the Discussion, these mixed methods findings are integrated to inform the adaptation of an Internet CBT protocol for youth with headache.

#### **Keywords**

Headache; Cognitive-Behavioral Therapy; Internet; Technology; Child; Adolescent; Parent

#### Introduction

Headache is common in young people, impacting as many as 1 in 3 children and adolescents (King et al., 2011). As headache becomes more frequent, children and adolescents report greater activity limitations, anxiety and depressive symptoms, and poor quality of life (Lipton et al., 2011; Powers, Patton, Hommel, & Hershey, 2003). Childhood headache can persist into adulthood and result in significant disability (Brna, Dooley, Gordon, & Dewan, 2005). Indeed, headache disorders are the third leading cause of disability worldwide (Global Burden of Disease Study, 2015). Effective management of headache in childhood could prevent trajectories of pain and disability from continuing into adulthood.

There is growing evidence to support cognitive-behavioral therapy (CBT) as a first-line intervention for pediatric headache (Fisher, Heathcote, et al., 2014). However, the predominant trend in the clinical care of youth with headache is medication management and many do not receive CBT (Ernst, O'Brien, & Powers, 2015). From a provider perspective, there is often limited access to mental health professionals trained in CBT for pediatric headache management, and as a result providers may struggle with determining how to best allocate this scarce treatment resource (Ernst et al., 2015). There are also multiple barriers to care from the patient's perspective, including distance from care providers, cost, perceived burden, and stigma against mental health treatment (Ernst et al., 2015). Internet-delivered CBT is emerging as a treatment option with the potential to reduce such barriers to care. However, there is limited understanding of which CBT treatment components can be effectively delivered using the Internet.

Over the past 30 years, there have been 24 published randomized controlled trials (RCTs) investigating the efficacy of CBT for youth with headache (Fisher et al., 2014). Most trials have evaluated interventions delivered face-to-face. The primary treatment outcome is typically headache frequency, with clinically significant change defined as 50% reduction in headache days. In a recent meta-analysis of these trials, a greater proportion of youth achieved a clinically significant reduction in headache days in response to CBT compared to control (Fisher et al., 2014). The number needed to treat to benefit (NNTB) was 3 at post-treatment and 2 at follow-up. In other words, one out of every 2–3 children may experience a clinically significant improvement in headache in response to CBT, making it a very promising intervention.

Two additional systematic reviews have pooled the evidence for CBT for youth with mixed chronic pain conditions delivered face-to-face (Eccleston et al., 2014) and remotely (Fisher, Law, Palermo, & Eccleston, 2015). Among the remotely delivered CBT trials identified by Fisher et al. (2015), only one Internet CBT protocol was specifically designed for youth with headache, which was developed and tested in Germany (Trautmann & Kroner-Herewig, 2010). Although limited by a small sample size, results for Internet CBT were promising with a greater number of youth achieving a clinically significant reduction in headache days compared to education control (NNTB = 2.0; Trautmann & Kroner-Herwig, 2010).

Over the past decade our research team has developed and evaluated a multi-component Internet-delivered CBT pain management program for youth with mixed chronic pain conditions, called Web-based Management for Adolescent Pain (Web-MAP; Palermo, Wilson, Peters, Lewandowski, & Somhegyi, 2009; Palermo et al., 2016). In a recent multi-site trial, youth with mixed chronic pain conditions randomized to the Internet CBT arm had greater improvements in the primary outcome of activity limitations compared to youth randomized to the control Internet pain education arm (Palermo et al., 2016). We also conducted a small pilot randomized controlled trial that compared the effectiveness of adjunctive Web-MAP + standard care in a specialty pediatric headache clinic (n = 44) to standard care in the headache clinic alone (n = 39) (Law, Beals-Erickson, Noel, Claar, & Palermo, 2015). Contrary to our expectation, Web-MAP + standard care in the specialty headache clinic and standard care alone resulted in equivalent improvements in headache

and related disability. Notably, Web-MAP has not been adapted in any way to address the unique treatment needs and preferences of youth with headache.

While there are likely shared psychological mechanisms and pathways that are relevant to youth with different types of chronic pain, adapting Web-MAP to meet the specific needs of youth with headache may enhance its effectiveness and thereby improve its utility for this population. For example, there may be treatment components that should be removed from the protocol or others that should be added. Indeed, there is variability in the treatment components delivered across existing face-to-face and Internet CBT protocols for pediatric chronic pain (Fisher et al., 2014). For example, some protocols include only relaxation training while others include multiple treatment components (Fisher et al., 2014). Among those protocols that include multiple treatment components, some deliver treatment only to children while others include treatment components for parents (Fisher et al., 2014). In addition, research has not been conducted to describe the preferences and experiences of youth with headache and their families who have received Internet CBT.

To inform adaptation of Web-MAP for youth with headache, we conducted two studies that aimed to: 1) identify the successful treatment components of CBT for pediatric headache, and 2) describe patient and family preferences and experiences implementing Web-MAP treatment strategies in their daily lives. In Study 1, a component profile analysis was conducted to identify common treatment components in effective face-to-face and Internet CBT protocols for pediatric headache. In Study 2, qualitative interviews with families of youth with headache who received Internet CBT were conducted to describe their experience using the treatment components and integrating these skills into their daily lives. We expected to identify a range of treatment components targeting children's pain self-management that were deemed successful across the quantitative and qualitative studies. In the Discussion, we integrate these findings and describe how they will inform our planned adaptation of Web-MAP for youth with headache.

## Study 1: Component Profile Analysis of CBT Protocols for Pediatric Headache

#### Methods

**Study Identification**—Procedures for the component profile analysis were based on McCarty & Weisz (2007). Consistent with these procedures, only effective treatment protocols were included in the analysis. Effective face-to-face and Internet CBT protocols for pediatric headache were identified using the following inclusion criteria: 1) evaluated in a RCT included in the Eccleston et al. (2014) or the Fisher et al. (2015) systematic review and meta-analysis, and 2) achieved a NNTB of 4.0 or lower for the primary outcome of clinically significant improvement in headache frequency (i.e., 50% reduction in number of headache days).

**Data Extraction**—Data were extracted by two authors (one post-doctoral psychology fellow and one licensed pediatric psychologist) and disagreements were arbitrated by a third author (a licensed pediatric psychologist). All authors had expertise in cognitive-behavioral

therapy for youth with chronic pain. Extracted data included: 1) study characteristics, and 2) descriptions of all of the treatment components for each protocol. Operational definitions for the treatment components emerged from the data analysis and were also informed by a recent published text for clinicians on CBT for youth with chronic pain (Palermo, 2012). To ease interpretation of the data and enhance clinical utility of the findings, we classed treatment components into two categories: 1) core treatment components (i.e., included in 50% of the protocols) and 2) secondary treatment components (i.e., all others).

#### Results

**Study Characteristics**—Thirteen studies met the inclusion criteria; 10 studies evaluated face-to-face CBT protocols and three studies evaluated Internet CBT protocols (see Table 1). Protocols evaluated by the same research team in more than one study were considered as a single protocol in the component profile analysis. Thus, the component profile analysis included 13 studies of 11 protocols (eight face-to-face protocols, and three Internet protocols; see Table 2).

As shown in Table 1, most protocols were delivered to youth with episodic headache conditions (i.e., < 14 headache days/month for at least three months) including tension-type, migraine, and mixed tension-type and migraine. Only two protocols were delivered to youth with chronic headache (i.e., > 15 headache days/month for at least three months). Treatment was delivered in an average of 8 sessions ( $M_{\text{face-to-face}} = 9$  sessions, range  $_{\text{face-to-face}} = 4-13$  sessions;  $M_{\text{Internet}} = 7$  sessions, range  $_{\text{face-to-face}} = 6-8$  sessions) over an average of 8 hours ( $M_{\text{face-to-face}} = 8$  hrs, range = 3 hrs 20 m - 13 hrs; Internet = 1 protocol reported on treatment duration and it was 5 hrs). The Internet CBT protocols delivered nearly twice as many treatment components and achieved this in an average of 7 sessions, as opposed to the average number of 9 sessions across face-to-face protocols.

**Component Profile Analysis Summary of Findings**—Table 2 shows a matrix of the treatment components from the protocols included in the component profile analysis, and Table 3 provides operational definitions of each treatment component.

Across both face-to-face and Internet CBT protocols, we identified a core set of three treatment components: 1) headache education (10/11 protocols), 2) relaxation training (11/11 protocols), and 3) cognitive skills training (8/11 protocols). For face-to-face protocols only, biofeedback training was identified as an additional core treatment component (4/8 protocols). We identified a set of secondary treatment components common among three of the four protocols evaluated in the past decade, which were delivered face-to-face and via the Internet: 1) parent interventions, 2) lifestyle interventions, and 3) school interventions.

We propose that the mode of treatment delivery (face-to-face vs. Internet) may facilitate some of these treatment components and impede others. For example, biofeedback training via the Internet may require adaptation or innovation in traditional office-based biofeedback technology. On the other hand, increased scheduling flexibility of Internet CBT may enhance the feasibility of delivering additional treatment components as well as treatment components targeting additional family members that would otherwise be limited by barriers related to time or distance. In the Discussion, we will describe how results from this

component profile analysis will inform our planned adaptation of Web-MAP for youth with headache.

## Study 2: Qualitative Interviews with Patients about Internet CBT for Pediatric Headache

#### Methods

Here, we present original data from qualitative interviews of youth with headache and their parents who were randomized to the Internet CBT arm of our recent RCT (Palermo et al., 2016). The Institutional Review Board approved this study. We have previously published manuscripts reporting outcome analyses from this RCT (Palermo et al., 2016), trajectories of children's pain and function during the treatment period (Palermo et al., 2015), concordance between parent and child treatment goals (Fisher et al., 2017), and longitudinal associations between parent and child functioning after treatment (Law et al., 2017). These papers did not present qualitative data regarding patient perspectives about the Internet CBT treatment.

Participants—Participants were recruited from the pool of families who enrolled in the Palermo et al. (2016) RCT, which included children ages 11–17 years old referred from 15 multidisciplinary pediatric pain management clinics across the United States and Canada. Inclusion/exclusion criteria for enrollment in the RCT can be found in Palermo et al. (2016). Participants were eligible to complete qualitative interviews if they met the following inclusion criteria: 1) randomized to the Internet CBT arm of the RCT, 2) completed the final outcome assessment for the RCT, and 3) child endorsed headache as their primary pain condition at pre-treatment.

Based on the above criteria, our potential participant pool included 37 parent-child dyads. Parent-child dyads were purposively selected for this study to represent treatment responders and non-responders, and children of both genders. Our attempt to enroll children of both genders was not successful; our potential pool included only four boys and all were unable to be reached. However, treatment responders and non-responders were equally represented. Potential participants were told that the purpose of the interview was for them to share their experience with the Internet program to help improve the program. All contacted dyads enrolled in the study and recruitment cased when saturation was achieved. Twelve parent-child dyads were enrolled.

**Qualitative Interview Procedures**—Parents provided informed consent and children provided assent prior to initiating the qualitative interviews. Parents and children were interviewed separately by telephone and the interviews were audio recorded. Parents and children were provided with gift cards (\$20 each) after completing the interviews.

Interviews were conducted by a post-doctoral fellow in pediatric psychology with prior experience in conducting qualitative interviews with families of children with chronic pain. Interviews were transcribed by an undergraduate research assistant and were reviewed as they were conducted in weekly supervision meetings led by a licensed pediatric psychologist with expertise in qualitative methodology. Interviews included a semi-structured set of

questions and probes focused on participants' perspectives about successful treatment components in the Internet CBT protocol (see supplemental online materials for the interview guide). The interview guide remained consistent throughout the course of the project.

Web-MAP CBT Protocol—Children and parents accessed separate versions of the Internet program to complete eight 30-minute modules over 8–10 weeks. Participants accessed the Internet program via a web browser on a desktop computer or a mobile device. Children completed the following modules: 1) pain education, goal setting, 2) education about associations between stress and pain, 3) relaxation training (deep breathing, progressive muscle relaxation, guided imagery), 4) school interventions (communicating with school staff and peers, how to make a plan to reach school goals), 5) cognitive skills training (cognitive restructuring, thought stopping), 6) lifestyle interventions I (healthy nutrition habits, sleep hygiene education), 7) lifestyle interventions II (increasing physical activity, activity pacing, pleasant activity scheduling), and 8) maintenance and relapse prevention (review of skills, planning for the future).

Parents completed the following modules: 1) pain education, goal setting, 2) education about associations between stress and pain, 3) operant training I (using attention to change child behaviors), 4) operant training II (reward systems), 5) parent intervention: modeling and cognitive strategies (modeling positive coping, cognitive restructuring, thought stopping), 6) supporting child lifestyle interventions (sleep hygiene education, healthy nutrition habits, increasing physical activity), 7) communication skills training (communicating with teens and school staff), and 8) maintenance and relapse prevention (review of skills, planning for the future). Parents were also provided with information on the treatment components their child was learning in each module. See Palermo et al. (2016) for more details on the Internet program.

Qualitative Data Analysis Procedures—The qualitative coding team included an undergraduate research assistant (primary coder), a post-doctoral fellow in pediatric psychology (secondary coder), and a licensed pediatric psychologist (secondary coder). All members of the coding team had prior experience in qualitative coding methods. Transcripts of parent and teen interviews were analyzed as interviews were completed using inductive thematic analysis (Braun & Clarke, 2006). Using this approach, all codes were derived directly from the data. Our goal was to describe patient and family preferences and experiences implementing the treatment components delivered in our Internet CBT protocol. As such, we chose to conduct thematic analysis at the semantic or explicit/topical level in order to retain a description of the patient and family experience with our Internet CBT program (Braun & Clarke, 2006); we did not have a goal to develop or apply a conceptual model to the data. NVivo software was used to facilitate coding (QSR, 2012).

To promote rigor and transparency in our qualitative data analysis procedures, we followed the methodology guidelines proposed by Wu, Thompson, Aroian, McQuaid & Deatrick (2016). Prior to initiating coding, the team reviewed the audio recordings and corresponding transcripts. A primary coder identified recurring concepts in the transcripts and assigned initial codes, all of which were reviewed and refined by a secondary coder. The research

team met weekly with the primary and secondary coders to review the codes, organize the codes into themes, and obtain consensus. The coding process was iterative, such that all of the codes and themes were compared across the interviews to identify similarities and differences. The research team kept a notebook to track ideas emerging from the data and to document decisions and operational definitions of the codes. The same coding dictionary was used for parent and child transcripts. The research team judged that saturation was achieved when there were no additional concepts identified from the data. To ensure dependability of our interpretation of the data, the transcripts and final coding scheme were reviewed by a member of the research team who had not participated in the conduct, transcription, or coding of the interviews.

#### Results

**Demographic Characteristics of Participants**—Enrolled participants were 11 mothers, one father, and 12 female children ages 11-17 years-old (M=14.5, SD=1.9). Parent-child dyads were primarily Anglo-American and middle to high socio-economic status. At pre-treatment, children experienced an average of six headache days per week. At follow-up, six of the children achieved a 50% reduction in headache frequency (i.e., treatment responders), and six did not reach this criterion for headache improvement (i.e., non-responders). Parents and children were highly engaged with the intervention, completing an average of 7 out of 8 treatment modules. Module completion did not differ between participants who enrolled in the qualitative interview study and those who did not. On average, parent-child dyads were interviewed 22.6 months after completing Web-MAP (range 12-36 months). The average duration of the interviews was 36 minutes per parent-child dyad (range 20-53 minutes).

**Qualitative Data Analysis**—The qualitative data analysis resulted in eleven themes that describe patient and parent preferences and experiences using the treatment components, as well as their suggestions for new treatment components. We organized these into four topic areas: 1) Core treatment components, 2) Secondary treatment components, 3) General program structure and components, and 4) Suggestions for new treatment components. See Table 4 for example quotes.

Core treatment components: Parents and children described their experience with the core treatment components of pain education, relaxation training, and cognitive skills training. Three themes were identified: 1) content of the pain education component is too broad, 2) the relaxation training component includes beneficial strategies, and 3) the cognitive skills component teaches skills that are used and are helpful.

Pain education in Web-MAP was designed for youth with mixed chronic pain conditions and their parents, and both responders and non-responders to treatment found this content to be too broad and requested more specific headache education. Regarding relaxation training, children who were responders and non-responders to treatment described progressive muscle relaxation and abdominal breathing as beneficial strategies and discussed their use of these skills in their daily lives. Parents noticed their children using relaxation methods and treatment responders and non-responders similarly viewed these strategies as beneficial.

Children also described using cognitive skills and found these to be beneficial. For example, one child (ID4) described how thought stopping was beneficial because it helped her to feel more in control.

Secondary treatment components: Parents and children described their experience with secondary treatment components, including parent interventions, lifestyle interventions, and school interventions. Three themes were identified: 1) the parent intervention component results in parents setting consistent expectations and using attention to increase desired behavior, 2) lifestyle interventions are used and considered to be beneficial, and 3) the school intervention component is considered to be helpful.

Regarding parent interventions, parents of children who were responders and non-responders to treatment described following instructions to set consistent expectations that their child participate in daily activities despite pain and to use attention to increase desired behaviors (e.g., school attendance) and decrease undesired behaviors (e.g., avoidance of activities). Although parents were also taught reward systems, modeling, cognitive strategies, and communication skills, they did not spontaneously discuss their experience using these skills.

Parents described supporting their child's use of lifestyle interventions, including treatment components targeting nutrition, physical activity, and sleep. Similar experiences using lifestyle interventions were shared by treatment responders and non-responders. For example, one parent (ID1) described learning to make fluids more accessible for her child to increase her hydration. Parents and children also discussed the benefit they received from education about exercise as a pain management strategy, and described adjusting their exercise plans to find the most helpful amount and type of exercise. Regarding sleep hygiene training, some children described using relaxation strategies for difficulties with sleep onset, although they did not discuss any other sleep hygiene strategies.

School interventions included instruction for parents and children to support school goals, including making a plan for coping with pain at school and how to communicate with school staff. One child (ID8) described this training as generally helpful, but otherwise participants did not comment on their experience using school interventions.

General program structure and components: Three themes related to the general structure of the program and components were identified: 1) a desire for a family-based treatment approach, 2) appreciation for multiple treatment components, and 3) dissatisfaction with the focus of the treatment program.

Parents of treatment responders and non-responders were pleased with the overall family-based treatment approach and felt it met their needs. For example, one father (ID4) shared that he had searched for a similar family-based treatment approach and had not been able to find this in his community. Parents and children also valued that the program included multiple treatment components. This view was shared by several parents and children, including treatment responders and non-responders. For example, one parent (ID9) shared

that it was helpful to learn numerous strategies because some worked better than others at certain times.

Several non-responders to treatment described that the overall focus of the program was unhelpful because it did not meet their specific treatment needs. For example, one mother (ID4) described that her child had many symptoms beyond headache that were not addressed by the program. Another mother (ID10) felt that the program was not relevant for her family because of the broad focus on mixed chronic pain conditions. One child (ID2) felt that the program was focused on youth who were facing a long-term problem with chronic pain and did not view her own pain problem in those terms. Similar views were not shared by treatment responders.

Suggestions for new treatment components: Within this topic area, two themes were identified: 1) social support interventions, and 2) booster sessions. Several parents and children classed as treatment responders were interested in receiving social support from other families of children with headache and spontaneously provided this suggestion during the interviews. Although Web-MAP includes videos of peer models discussing their experience using the treatment components, parents and children suggested that real-time interaction with their peers would also be helpful. One child (ID9) suggested video conferencing as a way to connect with other children with headache. Booster sessions were also raised as a possible new treatment component, which was suggested by both treatment responders and non-responders. Parents shared observations of their child's use of treatment skills during the program, and some requested ongoing support to help their child continue using treatment skills after the program ended. For example, one parent (ID8) suggested a brief, once a month contact to provide a tip or reminder related to maintenance of treatment skills.

#### **Discussion**

To inform our approach for refining our Internet CBT program to meet the needs and preferences of youth with headache, we sought to integrate findings from a component profile analysis of effective CBT protocols for youth with headache (Study 1) with qualitative interviews from children with headache and their parents who completed our Internet CBT program (Study 2). Our component profile analysis revealed three core treatment components that are common among effective face-to-face and Internet CBT protocols for pediatric headache: 1) headache education, 2) relaxation training, and 3) cognitive skills training. Among face-to-face protocols only, biofeedback training was identified as an additional core treatment component. We also identified three secondary treatment components that were common among effective face-to-face and Internet protocols evaluated in the past decade: 1) parent interventions, 2) lifestyle interventions, and 3) school interventions. With the exception of biofeedback, our Internet CBT program includes all of the core and secondary treatment components identified in the component profile analysis. We are considering approaches to pilot test the addition of biofeedback to our Internet CBT protocol via at-home portable biofeedback monitors or thermal biofeedback cards (e.g., Scharff et al., 2002).

In qualitative interviews, families of treatment responders and non-responders described several successful treatment components, including relaxation methods, cognitive skills, parent interventions (specifically, using attention to change child behavior), and lifestyle interventions. This is consistent with data from the component profile analysis and suggests that it may be reasonable to retain these components in our adaptation of the Web-MAP protocol for youth with headache.

Some parents and children (treatment responders and non-responders) reported being unsatisfied with the pain education component of the program. Indeed, this program was developed for a broad audience of youth with chronic pain and not specifically focused on headache. Headache education was identified as a core treatment component in the component profile analysis. Thus, we will plan to adapt the content of the pain education component in our existing Internet CBT program to focus on headache. This would include the addition of general education about headache medications, developed in partnership with pediatric headache medicine physicians and nurse practitioners, and training in strategies to support effective communication with medical teams.

It is unclear how to interpret children and parents' lack of spontaneous recall of other treatment components (e.g., reward systems, communication skills training). This may reflect that these treatment components were perceived as less beneficial or may simply reflect the language that families use to discuss CBT skills which may not as readily include the terms reward systems, modeling, and communication skills. Future qualitative studies could more comprehensively assess all of the treatment components by providing participants with a list of the treatment components or asking children and parents to show the parts of the Internet program that they found to be more or less helpful.

Parents and children described the benefit of learning multiple treatment components, and parents appreciated that the protocol was family-based. This is consistent with findings from the component profile analysis, which also identified multiple treatment components as a common feature of effective CBT protocols, and suggests that our adaptation of Web-MAP could retain this approach. Indeed, an intervention that offers multiple treatment components targeting children and parents is consistent with conceptual models of children's adaptation to chronic pain (Palermo & Chambers, 2005; Palermo, Valrie, & Karlson, 2014). However, it is unknown whether varying the number and type of treatment components offered in our Internet CBT protocol would impact efficacy, patient engagement or treatment satisfaction.

Non-responders to treatment described that the program was not matched to their specific treatment needs. For some families, this issue could be resolved by adapting the program to specifically target youth with headache. However, other families described that their child had multiple treatment needs in addition to headache management. Among Internet CBT protocols for other pediatric medical conditions, one strategy to address this concern is to deliver a standard set of core treatment components to all participants, and then assign secondary treatment components targeting other treatment needs based on an interim assessment of treatment response (e.g., Ritterband et al., 2003; Wade, Wolfe, Brown, & Pestian, 2005). An alternate approach is to use a tailoring algorithm to match treatment components based on the child's pre-treatment psychosocial needs (e.g., Fortier et al., 2015).

Research is needed to determine whether matching Internet CBT treatment components to the needs and preferences of youth with headache and their families would improve treatment response, treatment engagement and cost-effectiveness.

Families also suggested new treatment components, some of which could be easily delivered via the Internet (e.g., booster sessions). We are considering pilot testing approaches to delivering booster sessions in our revised Internet CBT program. Other suggestions from families require further consideration, such as social support interventions. For example, there is some early research supporting the feasibility and acceptability of online peer mentoring among youth with mixed chronic pain conditions (Ahola Kohut et al., 2016) However, limited efficacy data are available and this approach has not been examined among youth with headache. Research is needed to determine whether social support interventions are feasible, acceptable, and effective for youth with headache.

#### Limitations and future directions for research

Findings from our component profile analysis should be interpreted with the understanding that our analysis was limited to effective CBT protocols from trials with a NNTB less than 4. In addition, we identified treatment components using the treatment descriptions in published clinical trial manuscripts. Thus, our results reflect a broad understanding of the treatment content in these protocols but may fail to capture nuances in specific treatment strategies. In addition, this study does not address the relative efficacy of individual treatment components, which would be a direction for future research. Finally, our results should be interpreted with the understanding that our knowledge about effective CBT protocols will evolve as new clinical trials are conducted.

Our qualitative interview also had limitations. Although semi-structured in nature, we did not ask specific probes about all relevant areas that may impact treatment effectiveness, program engagement, and cost/burden, such as the ideal number of treatment components or optimal treatment duration. We also did not specifically query families about each treatment component in the program, but rather allowed children and parents to spontaneously discuss these. Thus, we are unable to interpret child and parent experiences with the full range of treatment components that are presented in the Internet CBT program. We interviewed participants up to three years after completing the Internet CBT protocol, which may have impacted recall. Like other published studies of youth with headache (e.g., Eccleston et al., 2014), our sample was primarily female, Anglo-American, and middle-to-upper middle class. Demographic characteristics and treatment engagement of participants were reflective of the average participant from the RCT (Palermo et al., 2016). Treatment perceptions may differ among patients from more diverse demographic backgrounds, those with very low treatment engagement, and those who dropped out of the RCT. As we develop and evaluate new Internet CBT protocols for youth with headache, we encourage the incorporation of patient, family and provider feedback in all phases of study.

#### Clinical Implications

Children with headache and their parents may have questions for clinicians regarding existing Internet CBT programs as well as mobile applications (apps) for headache pain.

Indeed, there are hundreds of publicly available mobile apps purported to target pain self-management (Lalloo, Jibb, Rivera, Agarwal, & Stinson, 2015). Most have been developed without input from health care providers and have not undergone efficacy testing (Lallo et al., 2015). In the future, there are likely to be many publicly available eHealth and mHealth products (i.e., technology-delivered health interventions, such as via the Internet or a mobile device) for youth with headache. Research will be critical for establishing efficacy data on these products so that clinicians can advise families on how to incorporate these tools into the child's treatment plan.

#### **Conclusions**

The development and evaluation of Internet CBT for pediatric headache is in its infancy. To date only one Internet CBT protocol has been developed and tested specifically for youth with headache (Trautmann & Kroner-Herwig, 2010), which demonstrated promising effects on reducing headache frequency. The remaining few Internet CBT protocols have been developed for broader populations of children with mixed chronic pain conditions. Little is known about strategies to enhance the treatment benefits and engagement of youth and their parents using Internet CBT for headache. Continued development and evaluation of Internet CBT is needed in youth with headache to expand the evidence base. Synthesizing component profile analysis and qualitative data from patients has the potential to guide the development and refinement of Internet CBT protocols for pediatric headache.

#### **Supplementary Material**

Refer to Web version on PubMed Central for supplementary material.

#### **Acknowledgments**

Financial Support: This work was supported by the following grants: Seattle Children's Research Institute Center for Child Health Behavior and Development Mentored Scholars Program, to EFL; the National Institutes of Health/National Institute of Neurological Disorders and Stroke (grant number K23NS089966), to EFL; and the National Institutes of Health/Eunice Kennedy Shriver National Institute of Child Health and Human Development (grant number R01HD062538), to TMP.

We would like to acknowledge Lindsay Durkin, B.A. for her assistance with study coordination and data management, and Dr. Carolyn A. McCarty for her consultation on the design and conduct of the component profile analysis. We also thank the children and parents who participated in this study.

#### References

- Ahola Kohut S, Stinson JN, Ruskin D, Forgeron P, Harris L, van Wyk M, ... Campbell F. iPeer2Peer program: A pilot feasibility study in adolescents with chronic pain. Pain. 2016; 157(5):1146–1155. [PubMed: 26808145]
- Brna P, Dooley J, Gordon K, Dewan T. The prognosis of childhood headache: A 20-year follow-up. Arch PediatrAdoles Med. 2005; 159(12):1157–1160.
- Eccleston C, Palermo TM, Williams AC, Lewandowski Holley A, Morley S, Fisher E, Law E. Psychological therapies for the management of chronic and recurrent pain in children and adolescents. Cochrane Database Syst Rev. 2014; 5:CD003968.
- Ernst MM, O'Brien HL, Powers SW. Cognitive-behavioral therapy: How medical providers can increase patient and family openness and access to evidence-based multimodal therapy for pediatric migraine. Headache. 2015; 55(10):1382–1396. [PubMed: 26198185]

Fichtel A, Larsson B. Does relaxation treatment have differential effects on migraine and tension-type headache in adolescents? Headache. 2001; 41(3):290–296. [PubMed: 11264690]

- Fisher E, Bromberg MH, Palermo TM. Adoelscent and parent treatment goals in an Internet-delivered chronic pain self-management program. Does agreement of treatment goals matter? Journal of Pediatric Psychology. 2017; 42(6):657–666. [PubMed: 28008004]
- Fisher E, Heathcote L, Palermo TM, de CWAC, Lau J, Eccleston C. Systematic review and metaanalysis of psychological therapies for children with chronic pain. J Pediatr Psychol. 2014; 39(8): 763–782. [PubMed: 24602890]
- Fisher E, Law E, Palermo TM, Eccleston C. Psychological therapies (remotely delivered) for the management of chronic and recurrent pain in children and adolescents. Cochrane Database Syst Rev. 2015:2014.
- Fortier MA, Bunzli E, Walthall J, Olshansky E, Saadat H, Santistevan R, ... Kain ZN. Web-based tailored intervention for preparation of parents and children for outpatient surgery (WebTIPS): Formative evaluation and randomized controlled trial. Anesth & Analg. 2015; 120(4):915–922.
- Global Burden of Disease Study C. Global, regional, and national incidence, prevalence, and years lived with disability for 301 acute and chronic diseases and injuries in 188 countries, 1990–2013: A systematic analysis for the Global Burden of Disease Study 2013. Lancet. 2015; 386(9995): 743–800. [PubMed: 26063472]
- Griffiths JD, Martin PR. Clinical-versus home-based treatment formats for children with chronic headache. Brit J Health Psych. 1996; 1:155–166.
- Hicks CL, von Baeyer CL, McGrath PJ. Online psychological treatment for pediatric recurrent pain: A randomized evaluation. J Pediatr Psychol. 2006; 31(7):724–736. [PubMed: 16093516]
- King S, Chambers CT, Huguet A, MacNevin RC, McGrath PJ, Parker L, MacDonald AJ. The epidemiology of chronic pain in children and adolescents revisited: a systematic review. Pain. 2011; 152(12):2729–2738. [PubMed: 22078064]
- Labbe EL. Treatment of childhood migraine with autogenic training and skin temperature biofeedback: A component analysis. Headache. 1995; 35:10–13. [PubMed: 7868327]
- Labbe EL, Williamson DA. Treatment of childhood migraine using autogenic feedback training. J Consult Clin Psychol. 1984; 52(6):968–976. [PubMed: 6520289]
- Lalloo C, Jibb LA, Rivera J, Agarwal A, Stinson JN. "There's a pain app for that": Review of patient-targeted smartphone applications for pain management. Clin J Pain. 2015; 31(6):557–563. [PubMed: 25370138]
- Larsson B, Carlsson J. A school-based, nurse-administered relaxation training for children with chronic tension-type headache. J Pediatr Psychol. 1995; 21(5):603–614.
- Larsson B, Daleflod B, Hakansson L, Melin L. Therapist-assisted versus self-help relaxation treatment of chronic headaches in adolescents: A school-based intervention. J Child Psychol Psychiat. 1987; 28(1):127–136. [PubMed: 3104371]
- Law EF, Beals-Erickson SE, Noel M, Claar R, Palermo TM. Pilot randomized controlled trial of Internet-delivered cognitive-behavioral treatment for pediatric headache. Headache. 2015; 55(10): 1410–1425. [PubMed: 26316194]
- Law EF, Fisher E, Howard WJ, Levy R, Ritterband L, Palermo TM. Longitudinal change in parent and child functioning after Internet-delivered cogntive-behavioral therapy for chronic pain. Pain. 2017; Advance online publication. doi: 10.1097/j.pain.00000000000099
- Lipton RB, Manack A, Ricci JA, Chee E, Turkel CC, Winner P. Prevalence and Burden of Chronic Migraine in Adolescents: Results of the Chronic Daily Headache in Adolescents Study (C-dAS). Headache. 2011; 51(5):693–706. [PubMed: 21521206]
- McCarty CA, Weisz JR. Effects of psychotherapy for depression in children and adolescents: what we can (and can't) learn from meta-analysis and component profiling. J Amer Acad Child & Adolesc Psych. 2007; 46(7):879–886.
- Osterhaus SO, Lange A, Linssen WH, Passchier J. A behavioral treatment of young migrainous and nonmigrainous headache patients: prediction of treatment success. Int J Behav Med. 1997; 4(4): 378–396. [PubMed: 16250725]
- Palermo, TM. Cognitive-behavioral therapy for children and adoelscents with chronic pain. New York: Oxford University Press; 2012.

Palermo TM, Chambers C. Parent and family factors in pediatric chronic pain and disability: An integrative approach. Pain. 2005; 119(1–3):1–4. [PubMed: 16298492]

- Palermo TM, Law EF, Fales J, Bromberg MH, Jessen-Fiddick T, Tai G. Internet-delivered cognitive-behavioral treatment for adolescents with chronic pain and their parents: A randomized controlled multicenter trial. Pain. 2016; 157(1):174–185. [PubMed: 26335910]
- Palermo TM, Law EF, Zhou C, Lewandowski Holley A, Logan D, Tai G. Trajectories of change during a randomized controlled trial of Internet-delivered psychological treatment for adolescent chronic pain: How does change in pain and function relate? Pain. 2015b; 156(4):626–634. [PubMed: 25775441]
- Palermo TM, Valrie C, Karlson C. Family and parent influences on pediatric chronic pain: A developmental perspective. Am Psychol. 2014; 69(2):142–152. [PubMed: 24547800]
- Palermo TM, Wilson AC, Peters M, Lewandowski A, Somhegyi H. Randomized controlled trial of an Internet-delivered family cognitive-behavioral therapy intervention for children and adolescents with chronic pain. Pain. 2009; 146(1–2):205–213. [PubMed: 19695776]
- Powers SW, Kashikar-Zuck SM, Allen JR, LeCates SL, Slater SK, Zafar M, ... Hershey AD. Cognitive behavioral therapy plus amitriptyline for chronic migraine in children and adolescents: a randomized clinical trial. JAMA. 2013; 310(24):2622–2630. [PubMed: 24368463]
- Powers SW, Patton SR, Hommel KA, Hershey AD. Quality of life in childhood migraines: clinical impact and comparison to other chronic illnesses. Pediatrics. 2003; 112(1 Pt 1):e1–5. [PubMed: 12837897]
- QSR. NVivo Qualitative Data Analysis Software for Windows, v.10. Victoria, Australia: QSR International Pty Ltd; 2012.
- Ritterband LM, Cox DJ, Walker LS, Kovatchev B, McKnight L, Patel K, ... Sutphen J. An Internet intervention as adjunctive therapy for pediatric encopresis. J Cons Clin Psych. 2003; 71(5):910– 917.
- Sartory G, Miller B, Metsch J, Pothmann R. A comparison of psychological and pharmacological treatment of pediatric migraine. Behav Res Ther. 1998; 36:1155–1170. [PubMed: 9745800]
- Scharff L, Marcus DA, Masek BJ. A controlled study of minimal-contact thermal biofeedback treatment in children with migraine. J Pediatr Psychol. 2002; 27(2):109–119. [PubMed: 11821495]
- Trautmann E, Kroner-Herwig B. A RCT of Internet-based self-help training for recurrent headache in childhood and adolescence. Beh Res Ther. 2010; 48(1):28–37.
- Wade SL, Wolfe C, Brown TM, Pestian JP. Putting the pieces together: preliminary efficacy of a web-based family intervention for children with traumatic brain injury. J Pediatr Psychol. 2005; 30(5): 437–442. [PubMed: 15944171]
- Wu YP, Thompson D, Aroian KJ, McQuaid EL, Deatrick JA. Commentary: Writing and evaluating qualitative research reports. J Pediatr Psychol. 2016; 41(5):493–505. [PubMed: 27118271]

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Table 1

Characteristics of RCTs testing CBT for pediatric headache (Study 1).

Study	Z	Age in Years (M, SD)	Headache Type	Pre-Treatment Headache Frequency	Number of Sessions	Treatment Duration	Treatment Format	Comparator
Face-to-Face								
Fichtel 2001	36	15.4(1.55)	M; M+T	7 /month	8–10	6hrs - 8 hours, 30mins	Individual + Group	Wait list
Griffiths 1996	51	11.3(0.58)	M; T	4/month	8	12 hours	Individual + Group	Self-monitoring
Labbe 1984	28	10.8	M	5/month	10	6 hours, 40mins	Individual	Wait list
Labbe 1995	46	12.0	M	2/month	10	7 hours, 30mins	Individual	Wait list
Larsson 1987	46	Unknown	M; T; M+T	6/month	6	6 hours, 45mins	Group	Self-monitoring
Larsson 1996	26	Unknown	Т	5/month	6	3 hours, 20mins	Group	Wait list
Osterhaus 1997	39	15.2(3.3)	M; T; M+T	18/month	8	9 hours, 20mins	Individual + Group	Wait list
Sartory 1988	43	11.3 (2.1)	M	1.78/week	10	10 hours	Individual	Beta-blocker
Scharff 2002	34	12.8(2.4)	M	11/month	4	4 hours	Individual	Attention control
Powers 2015	135	14.4 (2.0)	M	21.3/month	8 + 5 booster	8 hours + 5 hours booster	Individual	Education
Internet								
$\mathrm{Hicks}2006^*$	42	11.7 (2.1)	M; T; M+T	Unknown	7	Unknown	Individual	Standard care
Blinded 2009*	48	14.8 (2.0)	Unknown	Unknown	8	5 hours	Individual	Education
Trautmann 2010	55	12.7(2.2)	M; T; M+T	11/month	9	Unknown	Individual	Education

Notes:

For headache type, M = Migraine; T = Tension-type; M+T = Combined migraine and tension-type.

 $\stackrel{*}{\ast}$  Intervention developed for children with mixed chronic pain conditions.

Table 2

Law et al.

Component profile analysis (Study 1).

		Core Treatn	Core Treatment Components		Seco	Secondary Treatment Components	ents
	Headache Education	Relaxation Training	Cognitive Skills Training	Biofeedback Training	Parent Interventions	Lifestyle Interventions	School Interventions
Face-to-Face CBT							
Fichtel 2001	Х	X					
Griffiths 1996	Х	X	X				
Labbe 1984; 1995	Х	X		X			
Larsson 1987; 1996		X					
Osterhaus 1997	X	X	X				
Sartory 1988	X	X	X	X			
Scharff 2002	X	X	X	X			
Powers 2015	X	X	X	X	X	X	
Internet CBT							
Hicks 2006	X	X	X		X	X	X
Authors Blinded 2009	X	X	X		X	X	
Trautmann 2010	X	X	X				

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# Table 3

Operational definitions of treatment components (Study 1).

Core Treatment Components	nents
Headache education	The purpose of headache education is to help families understand how cognitive and behavioral skills can improve the body's ability to regulate pain signaling and support adaptive behavioral responses to headache. For example, Osterhaus, Linssen, & Passchier (1997) provided education about headache symptoms, headache triggers, and biopsychosocial factors that influence pain processing in the body.
Relaxation training	Relaxation methods (e.g., progressive muscle relaxation, guided imagery, deep breathing) can help children to achieve physiological changes that promote a relaxation response in the body by slowing heart rate and breathing, increasing blood flow to muscles, and reducing muscle tension. These physiologic changes can reduce stress and anxiety, and support children in coping with pain sensations.
Cognitive skills training	Cognitive skills training (e.g., cognitive restructuring, thought stopping, problem solving) addresses maladaptive thoughts that may contribute to headache and related disability. Cognitive restructuring involves identifying automatic maladaptive thoughts and then changing those thoughts to become more adaptive. Ruminative thoughts can be addressed using thought stopping, in which negative thoughts are paired with an image of a stop sign, and then replaced with a more adaptive alternative (e.g., Hicks et al., 2006). Problem solving training involves a structured approach to identifying problems, generating solutions, selecting a solution, trying it out, evaluating the results and revising the plan (e.g., Scharff, Marcus, & Masek, 2002).
Biofeedback training *	During biofeedback, patients are taught relaxation skills while wearing sensors that provide a visual representation of the body's physiological response to relaxation practice such as skin temperature, heart rate, breath rate, or muscle tension. Among the protocols we reviewed, all used thermal biofeedback combined with autogenic relaxation training.
Secondary Treatment Components	omponents
Parent interventions	Parent interventions focus on operant training where parents are taught to ignore pain behaviors, and to use praise and reward systems to increase the child's pain self-management and participation in daily activities. In one protocol (Authors blinded, 2009), parents also received training in modeling, cognitive skills, and communication skills.
Lifestyle interventions	Lifestyle interventions address nutrition, physical activity, and sleep hygiene. Nutrition intervention includes education about the benefits of activity participation on pain management and strategies for increasing physical activity. For example, children are instructed to intersperse a target activity (e.g., taking a walk) with scheduled breaks and then decrease the breaks as endurance improves (e.g., Hicks et al., 2006). Sleep intervention includes sleep hygiene education, such as keeping a regular sleep schedule, and instruction in applying relaxation methods to help facilitate sleep onset (e.g., Authors blinded, 2009).
School interventions	School interventions include planning for using pain self- management skills in the school setting, and communicating with school staff about accommodations to support attendance and performance (e.g., Authors blinded, 2009).

Notes:

<sup>\*</sup> Among the protocols we reviewed, biofeedback training was a core treatment component only in face-to-face protocols.

Law et al.

# Table 4

Example quotes from qualitative interviews of patient perspectives on Internet CBT for pediatric headache (Study 2).

Patient Perceptions of Treatment Components	nents
Core Treatment Components	
The content of the pain education component is too broad (reported by 2 children and 4 parents)	"[The information] wasn't catered towards my headache. It was hard because it was catered towards a wider audience. And because of that I wasn't as confident that it would help my problem."—IDI, child, treatment non-responder "The thing we struggled with a lot is medications and how to do that. It would [have been] helpful to know about medications and things to expect around medications."—ID2, parent, treatment non-responder
The relaxation training component includes beneficial strategies (reported by 9 children and 4 parents)	Deep breathing "And I know that [child name] uses the deep breathingand she's made that part of her routine, just because it worked for her."—ID4, parent, treatment non-responder non-responder The taske make fout of the situation and just go sit somewhere else just by myself and focus on breathing, that helps a lot."—ID5, child, treatment responder Progressive muscle relaxation "just closing my eyes and trying to focus on different parts of my body. So, I focus on my head, and try to individually relax muscles. Then I move down, like into my arms. Focusing on individual muscles to make sure I am properly relaxing them all is very helpful."—ID3, child, treatment responder
The cognitive skills component teaches skills that are used and considered to be beneficial (reported by 5 children and 3 parents)	Thought stopping "I like the yelling one. I really love that one. It's empowering, I think. You're taking control back." –ID4, child, treatment non-responder Cognitive restructuring "I use a lot of self-talk. I do that quite a bit." –ID7, child, treatment responder
Secondary Treatment Components	
The parent intervention component results in parents setting consistent expectations and using attention to increase desired behavior (reported by 10 parents)	Operant training  'I learned that attitude shift of being more positive with her and encouraging her [when she was doing things I wanted her to do]. Also, some of the things I realized in myself, being a parent, were, like the times where I was probably empowering her to be weak. [I learned to say] 'you do need to go to school, so what do we need to do to make that work?'" –ID8, parent, treatment non-responder "I had to learn not to run every time she said 'Ow!' Now, even if it kills me, I [remember] that lesson. I say 'You got to do this yourself. You have to learn to manage your pain.' So, it has been learning not to be the overbearing, overprotective mom." –ID6, parent, treatment responder
Lifestyle interventions are used and considered to be beneficial (reported by 6 children and 4 parents)	Nutrition  "One thing I did take away was getting her to eat healthier. So I started to put water on the table instead of making her get it herself, because then it will happen." —IDI, parent, treatment non-responder  Physical activity  "There was something about how physical activity really helps to relieve some of that stresskind of help you deal with the pain and put it in perspective. After I heard that, I started training in track and cross country. Running training me emotionally and training me in terms of dealing with my pain, too. It was a really awesome gift, actually, to be able to learn that. It has really changed everything." — IDII, child, treatment responder  "We ve seet tremendous benefit from exercise. It's about finding a balance between getting enough exercise to benefit and not overdoing it so much." —ID3, parent, treatment responder  Sleep  "Some of the relaxation exercises are helpful in particular for sleep, which is hard when there is a lot of pain." —ID3, child, treatment responder
The school intervention component is considered to be helpful (reported by 1 child)	"Learning about the different types of ways to deal with school was helpful." –ID8, child, treatment non-responder
General Program Structure and Components	
A desire for a family-based treatment approach (reported by 6 parents)	"[Program name] treats the child as well as the parent. Prior to that, my biggest frustration was not having access to any one place that had [treatment] for both of us."—ID4, parent, treatment non-responder  "The parent version and the child version of the program is very beneficial. [We] came together via the different activities and the parallel things that the program has [for parents and children]."—ID6, parent, treatment responder

Patient Perceptions of Treatment Components	ents
Appreciation for multiple treatment components (reported by 6 children and 7 parents)	"There are a couple good skills that I can go into when the pain gets really bad that can be helpful." —D12, child, treatment non-responder "It gave a lot of good and different ways of trying to manage. Definitely some of the techniques on certain days are more helpful than others." —D9, parent, treatment responder
Dissatisfaction with the focus of the treatment program (reported by 2 children and 4 parents)	"It seemed very tailored to kids who had only pain going on. [My child] has other things in addition to painshe's got fatigueanxiety." – ID4, parent, treatment non-responder "I just felt as ifit wasn't really applicable to our [headache] situation." –ID10, parent, treatment non-responder "It wasn't really for me because it seemed to be catered more towards people who would have to have a long time dealing with their pain and there was no end in sight for their pain." – ID2, child, treatment non-responder
Suggestions for New Treatment Components	
Social support interventions (reported by 2 children and 3 parents)	"If there had been a way for parents to connect. As parents of kids dealing with chronic headache, you feel isolated." –ID3, parent, treatment responder "I would have skyped with other teenagers [and] younger kids with my same condition." –ID9, child, treatment responder
Booster sessions (reported by 4 parents)	"Getting people to continue in what you learn. I saw my daughter doing some things and it would help her, and then you lose your flow with that. [For example,] a once a month tip or reminder for those people who graduated." –ID8, parent, treatment non-responder