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SELF-MANAGEMENT EDUCATION FOR ADOLESCENTS WITH HEADACHES: A PILOT STUDY

BY

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Dedication

This thesis is dedicated to my husband, Eric Whitley, whose emotional support has been essential during the difficult times of my academic journey. This accomplishment reflects your love and steadfast encouragement. Thank you for your presence, patience, and selfless sacrifices. Your support fueled my determination to achieve this milestone, and I could not have achieved it without you.

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“There is no such thing as a "self-made man". We are made up of thousands of others. Everyone who has ever done a kind deed for us, or spoken one word of encouragement to us, has entered into the makeup of our character and of our thoughts, as well as our success.”

— George Matthew Adams

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Abstract

Headache disorders affect around 25% of children in North America and are one of the most frequent health complaints. Pediatric headache disorders are associated with impairments in daily functioning, sleep problems and increased rates of anxiety and depression. Self-management plays an important role in chronic disease. In adults with headache disorders, self-management education has successfully improved self-efficacy. However, to our knowledge, no studies have evaluated this in a pediatric population. A pre-post comparison pilot study was conducted to evaluate the feasibility and acceptability of the protocol and intervention, including an assessment of the informed consent form, eligibility criteria, data collection method, recruitment rate, retention rate, and participant satisfaction. Participant-reported outcomes were collected to preliminarily evaluate changes in self-efficacy two weeks after attending an in-person, 90-minute, theory-guided headache self-management education session. Changes in behaviour related to sleep, caffeine intake, physical activity, and diet were also assessed. Seventy-five individuals met eligibility criteria and 37 signed informed consent, for a recruitment rate of 49%. Thirty participants received the intervention and 24 completed all the follow-up questionnaires, for a retention rate of 80%. Only 13 responses to the feedback survey were received, however, all responses were very satisfied. Headache self-efficacy increased following the intervention, while chronic illness self-efficacy was unchanged. The most common behavioural change was consuming less caffeine, followed by physical activity, diet, and sleep. Information from this pilot study can be used to refine the intervention, assess recruitment potential, and conduct a larger scale observational or randomized controlled trial.

Keywords: headache, migraine, pediatric, children, self-management, education, self-efficacy, behaviour

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List of Abbreviations

AU – Athabasca University

BOCF – Baseline observation carried forward

CDC – Centers for Disease Control

CHEO – Children's Hospital of Eastern Ontario

CGRP – Calcitonin gene-related peptide

CT – Controlled trial

HSES – Headache Self-Efficacy Scale

HSME – Headache self-management education

NSAID – Non-steroidal anti-inflammatory

NR – Not reported

PRCISE – Pediatric Rating of Chronic Illness Self-Efficacy

REB – Research Ethics Board

RCT – Randomized controlled trial

SCT – Social Cognitive Theory

TCPS2 – Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans

TTH – Tension-type headache

UK – United Kingdom

USA – United States of America

Chapter I: Introduction

Prevalence of Pediatric Headache

Headache disorders affect approximately one quarter of the pediatric population in North America, causing them to be one of the most frequent complaints encountered in medicine and neurology (Vides-Rosales, 2021). Approximately 15% of Canadian children aged 5 to 17 years report having headache attacks once per week or more (Statistics Canada, 2019). Migraine disease is diagnosed in roughly 10% of patients under 20 years old in North America (Vides-Rosales, 2021). The prevalence of headache disorders and migraine increases with age (Onofri et al., 2023; Togha et al., 2022). Before puberty, the prevalence of headache disorders and migraine is equal between sexes (Jasem Yousef Al-Hashel et al., 2019; Onofri et al., 2023). After the onset of puberty, both headache disorders and migraine are more common in females (Jasem Yousef Al-Hashel et al., 2019; Ursitti & Valeriani, 2023).

Headache Characteristics

Pediatric tension-type headache (TTH) is described as a pressing tightness in the head and/or neck muscles accompanied by mild to moderate non-pulsating bilateral pain (Nieswand et al., 2020). TTHs do not worsen with physical activity and are not typically associated with nausea or vomiting (Nieswand et al., 2020). They may be associated with sensitivity to light (photophobia) or sensitivity to sound (phonophobia), but not both (Nieswand et al., 2020). There are two subtypes of TTH: chronic and episodic. Chronic TTH is defined as a three-month history of 15 or more headache days per month, while episodic TTH is defined as a three-month history of fewer than 15 headache days per month (IHS Classification ICHD-3, 2021). The development of episodic TTH appears to be largely environmental, whereas genetic factors appear to be more important in the development of chronic TTH (Steel et al., 2021).

Pediatric migraine attacks are characterized by pulsating or throbbing moderate to severe head pain, that can occur all over the head, or be worse on one side of the head (Nieswand et al., 2020). Migraine attacks may be associated with other symptoms, such as nausea, vomiting, loss of appetite, abdominal pain, and fatigue (Nieswand et al., 2020). Symptoms may worsen with physical activity and exposure to light and sound (Nieswand et al., 2020). Approximately 25-30% of children living with migraine disease experience aura, a fully reversible set of nervous system symptoms, such as visual changes, speech disturbances, motor weakness, or sensory changes (Genizi et al., 2016; Taga et al., 2017). Visual changes are the most common type of aura, described as blurry or distorted vision, blind spots, or the appearance of flashing or moving lights (Aliano, 2020). Aura typically lasts 5 to 60 minutes and occurs 10 to 30 minutes before the onset of the headache, but can occur as early as the night before (Aliano, 2020; Rizzoli & Mullally, 2018). The etiology of pediatric migraine is not fully understood; however, most children with migraine have a positive family history (Eidlitz-Markus et al., 2014). It is believed that children with migraine disease have a genetic predisposition that is activated by environmental or physiological stimuli, such as exposure to drugs, diet, stress, or puberty (Al Khalili et al., 2023).

Comorbidities Associated with Pediatric Headache

Headache disorders in the pediatric population negatively influence quality of life and functioning. Pediatric headache disorders are associated with disturbed sleep patterns, such as insufficient total sleep, daytime sleepiness, difficulty falling asleep, restless sleep, and night wakings (Dosi et al., 2015). Headache characteristics such as frequency and intensity worsen with poor sleep habits (Dosi et al., 2015; Rabner et al., 2018). Moreover, higher levels of anxiety and depressive symptoms have been correlated with greater sleep disturbances in this population

(Rabner et al., 2018). Neut et al. (2012) found that 70% of children living with migraine disease identified lack of sleep as a trigger. The relationship is likely bidirectional, with headache attacks negatively impacting sleep and vice versa (Rabner et al., 2018).

Bullying is associated with frequent and recurrent headache attacks in children, with high-level data indicating that children who experience bullying are twice as likely to experience headache disorder compared with peers who have not experienced bullying (Gini et al., 2014; Nilles et al., 2023). Headache disorder is also associated with high rates of anxiety and depression. Anxiety and depressive symptoms are most common in children with migraine disease (15-44%), followed by TTH (7-28%), in comparison to healthy controls (3.5-8%) (Arruda & Bigal, 2012; Pavone et al., 2012). Children with migraine disease are twice as likely to have anxiety and depressive disorders compared to healthy peers (Falla et al., 2022). Additionally, children with headache disorders are more likely to experience suicidality (Nilles et al., 2023). The prevalence of suicidality increases with headache frequency (Nilles et al., 2023). Canadian youth with daily headache attacks are 4.7 times more likely to exhibit suicidality compared to non-headache peers (Nilles et al., 2023).

Headache disorders are associated with significant impairments in daily functioning in the pediatric population. Children with headache disorders are 2.7 times more likely to experience school absenteeism and 1.6 times more likely to experience school-reported problems than children without headache disorders (Turner et al., 2021). Furthermore, overall quality of life is lower with children suffering from headache disorders and migraine disease compared to healthy controls (Gozubatik-Celik & Ozturk, 2021).

Prevention of Pediatric Headache Attacks

Lifestyle Modifications

Most pediatric headache specialists take a multitiered approach to treating and preventing headache attacks. Initially, lifestyle modifications and integrative therapies are recommended. Lifestyle factors that have been proven to influence the burden of pediatric migraine include stress, sleep, and diet (Dasari et al., 2021). Stress-relieving interventions that are effective in children with headache disorders include cognitive behavioural therapy (Powers et al., 2013), yoga training (Hainsworth et al., 2014), and biofeedback (Dasari et al., 2021). Poor sleep habits are the second strongest trigger for migraine in children (Dasari et al., 2021; Neut et al., 2012). Poor sleep hygiene is associated with higher migraine-related disability (Bektaş et al., 2014) and more frequent headache attacks (Torres-Ferrus et al., 2018). In terms of diet, specific foods are rarely responsible for triggering migraine attacks in the pediatric population (Dasari et al., 2021). However, skipping meals is predictive of developing a migraine (Jasem Youssef Al-Hashel et al., 2021; Ragab et al., 2021; Seng et al., 2022). Caffeine intake has also been associated with higher migraine frequency (Bektaş et al., 2014) and migraine-related disability in children (Hikita et al., 2023).

Nutraceuticals

Preventative treatment with nutraceuticals is often explored in conjunction with or following recommended lifestyle modifications. Nutraceuticals are non-prescription dietary supplements such as vitamins and minerals (Chandra et al., 2022).

Magnesium. Magnesium is commonly recommended to children and adults for the preventative treatment of headache attacks (Kedia, 2016; Yamanaka et al., 2021). Magnesium deficiency can lead to neuronal dysfunction and are observed in individuals with migraine

(Kedia, 2016; Yamanaka et al., 2021). Two studies have investigated the use of magnesium as a preventative treatment for headache attacks in children, demonstrating an improvement in headache severity (Gallelli et al., 2014; Wang et al., 2003). Gallelli et al.(2014)conducted a controlled trial of 160 children aged 5-16 years, and found that magnesium pretreatment significantly reduced pain frequency. Wang et al. (2003) conducted a randomized controlled trial of 118 children aged 3-17 years, and found that daily magnesium significantly reduced headache days, but was not superior to placebo in reducing the frequency of migraine attacks. Further research on the efficacy of magnesium in preventing headache attacks in children is warranted; however, it continues to be widely recommended, given that it is easily accessible and has minimal side effects (Yamanaka et al., 2021).

Riboflavin. Current research indicates that riboflavin may be useful in preventing migraine attacks in children (Yamanaka et al., 2020). Randomized controlled trials have demonstrated that daily riboflavin is associated with a decrease in migraine frequency (Athaillah et al., 2012; Talebian et al., 2018), migraine attack duration (Athaillah et al., 2012; Talebian et al., 2018), and disability in children when compared to placebo (Athaillah et al., 2012). However, these studies contrast to two other randomized controlled trials in children, which showed no significant improvement with riboflavin supplementation compared to placebo on migraine attack frequency, severity, and duration (Bruijn et al., 2010; MacLennan et al., 2008). There is a lack of strong evidence, and further research into the use of riboflavin as a preventative treatment option for children with headaches disorders is warranted (Yamanaka et al., 2020). Similar to magnesium, riboflavin is widely recommended, given its availability and safety profile at low doses (Yamanaka et al., 2020).

Pharmaceuticals

Medications commonly prescribed for the preventative treatment of pediatric headache attacks are off-label use of antidepressants (e.g., amitriptyline), antihypertensives (e.g., calcium channel blockers, angiotensin II receptor blockers, beta-blockers, flunarizine), antiepileptics (e.g., topiramate), and antihistamines (e.g., cyproheptadine) (Koch & Oakley, 2018). There is a significant lack of high-quality pediatric clinical studies on acute and prophylactic medications (Langdon & DiSabella, 2017; Papetti et al., 2019). There is a high degree of variability in efficacy in the studies, which is attributed to high placebo rates and poor study designs (Langdon & DiSabella, 2017; Papetti et al., 2019) and it is unclear whether these preventative pharmaceuticals have any therapeutic gain over placebo (Locher et al., 2020; Powers et al., 2017).

Advanced research on the pathophysiology of migraine disease over the last two decades has led to a new class of medications, the first specifically designed to prevent migraine attacks (Wrobel Goldberg & Silberstein, 2015). Elevated levels of the neuropeptide calcitonin gene-related peptide (CGRP) are observed during the headache phase of a migraine attack and decrease with headache improvement (Arulmani et al., 2004; Goadsby et al., 1990). Additionally, infusion of human CGRP has been shown to trigger migraine attack in susceptible individuals (Lassen et al., 2002). These findings have led to the development of medications that inhibit CGRP pathways, many of which are approved by Health Canada for the preventative treatment of migraine attack in adults (Leroux, 2022). Clinical trials are ongoing to evaluate their safety and efficacy in children.

Treatment of Pediatric Headache Attacks

Abortive medications for pediatric headache attacks include non-steroidal anti-inflammatory drugs (NSAIDs), non-narcotic analgesics (e.g., acetaminophen), and triptans (Papetti et al., 2019). Abortive headache medications should be taken at the appropriate dose and at the first signs of a headache attack (Langdon & DiSabella, 2017). Triptans are prescription medications that have been shown to be safe and effective in children with migraine disease (Chanchlani et al., 2023). Medication overuse headaches arise as a result of the chronic and excessive use of abortive medications, leading to an escalation in headache frequency and severity (Genizi et al., 2023). The prevalence of medication overuse headaches in children with chronic headaches is as high as 40% (Genizi et al., 2023). Medication overuse headaches can be avoided by limiting NSAIDs and analgesics to less than 15 days per month, and triptans to less than 10 days per month (Langdon & DiSabella, 2017).

Self-Management of Chronic Illness

Self-management is described as an emphasis on both the patient and the provider actively treating a disease, with the patient managing the disease outside the clinical setting (Smith et al., 2010). Self-management requires confidence, knowledge, and motivation to make decisions and problem solve (Centers for Disease Control and Prevention [CDC], 2019). Current guidelines highlight the importance of self-management for chronic diseases such as headache disorders (CDC, 2019; Smith et al., 2010). An individual's confidence in managing their condition, known as self-efficacy, is an important factor influencing their ability to self-manage symptoms (Chan, 2021; Saxby et al., 2019). An individual's level of self-efficacy plays a key role in determining whether self-care actions are initiated, the amount of effort exerted, and how long the effort is sustained in the face of obstacles (Bandura et al., 1999; Chan, 2021). In the

pediatric population with chronic conditions (e.g., type one diabetes, juvenile rheumatoid arthritis, cystic fibrosis, urological conditions, and neuromuscular disorders), perceived self-efficacy has been positively associated with emotional, physical, and social quality of life (Cramm et al., 2013).

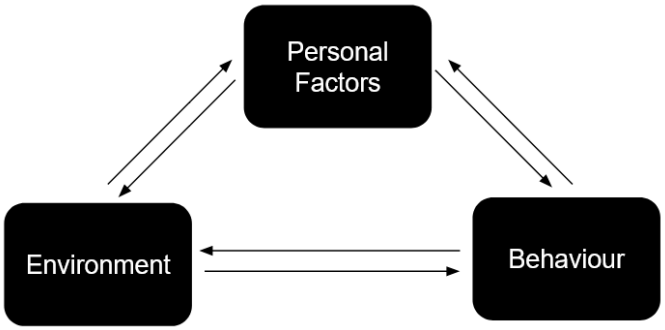
Headache-specific self-efficacy is defined as, "a patients' confidence that they can take actions that prevent headache episodes or manage headache-related pain and disability" (French et al., 2000). In the adult headache population, higher rates of self-efficacy have been associated with lower rates of anxiety and the use of positive psychological coping strategies to prevent and manage headache attacks (French et al., 2000). The current evidence suggests self-efficacy plays an important role in chronic illness management, including adults and children with headache disorders. Similarly, children with headache disorders who have higher pain self-efficacy and acceptance have less disability, better school functioning, and fewer depressive symptoms (Kalapurakkel et al., 2015).

Theoretical Framework

The theoretical framework of this study is centred around the construct of self-efficacy. Self-efficacy is a concept rooted in Social Cognitive Theory (SCT), which was developed by Canadian American psychologist Albert Bandura. SCT postulates that "learning occurs in a social context with a dynamic and reciprocal interaction of the person, environment, and behavior" (LaMorte, 2022). This triadic relationship is referred to as reciprocal determinism, displayed in **Figure 1** (Bandura, 1978).

Figure 1

Reciprocal Determinism



Self-efficacy is composed of two types of expectations: efficacy expectations and outcome expectations (Bandura et al., 1999). Efficacy expectations relate to beliefs about one's ability to successfully perform a particular behaviour (Bandura et al., 1999). If an individual with a headache disorder has confidence in their ability to improve their sleep hygiene, they are more likely to succeed. Outcome expectations are the beliefs that carrying out a specific behaviour will lead to a given outcome (Bandura et al., 1999). If an individual with a headache disorder believes that improving their sleep hygiene will improve their headaches, they will be more likely to do so. Both types of self-efficacy expectations play a central role in adopting and maintaining specific behaviours. However, efficacy expectations explain most of the variance in behaviour change (Bandura et al., 1999).

Bandura (1999) states that self-efficacy beliefs are formed by interpreting information about our own capabilities. This information is interpreted from four sources:

- Mastery experiences: provides information about ones' success and failures. Successful experiences increase self-efficacy, whereas failure lowers self-efficacy.
- Vicarious experiences: observing others successfully perform the target activity, thereby improving self-efficacy.

- Verbal/social persuasion: individuals can be convinced of their capabilities, especially if the persuasion comes from a credible source.
- Physiological and affective states: physiological and emotional arousal in situations where the capability is demonstrated. For example, in stressful situations, information on the somatic state is taken as an indicator of dysfunction, negatively impacting self-efficacy.

To effectively enhance self-efficacy beliefs in children living with headache disorder, interventions should be centred around, and incorporate aspects of, Bandura's self-efficacy theory. According to French et al. (2000), perceived self-efficacy influences cognitive, affective, and physiological responses to headache attacks. Self-efficacy is positively associated with the initiation and persistence of efforts to prevent headache attacks (French et al., 2000).

Rationale for the Study

Youth with headache disorders often have a long lag between being referred for headache care and being seen by the consultant. At the Children's Hospital of Eastern Ontario (CHEO), the time between the referral and the consultation can vary greatly, ranging from 2 weeks to 2 years. Specialists typically spend upwards of one hour during the initial consultation reviewing medical and headache history, educating patients on lifestyle factors associated with headache and reviewing treatment and prevention strategies. It is possible that patients will attend their consultation unprepared, with unreliable headache histories, a lack of information on their previous treatments, and not having implemented any lifestyle modifications or trials of nutraceuticals. These factors can result in longer, less effective consultation appointments.

Current literature supports using self-efficacy theory to improve patient outcomes related to headache disorders. To our knowledge, no studies measure the effect of headache self-

management education (HSME) on self-efficacy in the pediatric population. A pilot study is warranted to design and evaluate HSME at a large tertiary care hospital. Information and data from the pilot study can be used to refine the intervention, assess recruitment potential, and implement the intervention on a larger scale.

Pilot Study Objectives

The objectives of the pilot study were to evaluate the eligibility criteria, informed consent form, data collection method, recruitment rate, retention rate, and participant and caregiver acceptability of the HSME intervention. Pediatric studies with HSME interventions have reported recruitment rates ranging from 74-86% (Connelly et al., 2006; Hickman et al., 2015; Walter et al., 2020). It is hypothesized that the recruitment rate for the current study will align with this literature, with approximately 80% of eligible participants enrolling. A retention rate of 84-89% is observed in comparable pediatric studies (Connelly et al., 2006; Hickman et al., 2015; Walter et al., 2020). It is hypothesized that approximately 85% of participants will complete all follow-up questionnaires.

Participant-Reported Objectives

The participant-reported objectives are to determine the following in 12–17-year-olds referred to a large pediatric tertiary care hospital for headache:

1) Whether theory-guided HSME is associated with increased headache self-efficacy.
2) Whether theory-guided HSME is associated with increased chronic illness self-efficacy.
3) Whether theory-guided HSME is associated with behavioural change.
4) Whether sex is associated with headache self-efficacy, chronic illness self-efficacy, and positive behaviour change following HSME.

5) Whether age (i.e., younger versus older pediatric patients) is associated headache self-efficacy, chronic illness self-efficacy, and positive behaviour change following HSME.

Hypotheses

It is hypothesized that participation in HSME will be associated with increased headache self-efficacy, increased chronic illness self-efficacy, and positive behavioural change for 12–17-year-olds referred to a large pediatric tertiary care hospital for headache.

Chapter II: Literature Review

This chapter will highlight the relevant findings from peer-reviewed studies with an active headache self-management or education intervention arm. The mode, frequency and duration of the interventions and their success rates will be discussed. The learning theories guiding the intervention will be presented. The self-efficacy and behavioural change outcomes will be reviewed. There will be an emphasis on studies that enrolled pediatric participants.

Headache Self-Management Education Sessions: Mode, Frequency and Duration

A search of the peer-reviewed literature via Google Scholar and PubMed on prospective studies with an active intervention arm of headache management sessions identified 21 publications. Seventeen studies included 3,887 adult participants, and four studies included 184 pediatric participants. The sessions were most commonly facilitated by advanced practice nurses with specialization in headache care. Fourteen studies had in-person education interventions, three had remote interventions, and four had a combination of in-person and remote components. There was a combination of group (n = 9) and individual (n = 10) education sessions. Two studies had an initial group session, followed by individual sessions (Harpole et al., 2003; Schaetz et al., 2020). The duration of the education sessions ranged from a single session (n = 8) lasting 45 to 120 minutes, to multiple sessions (n =13) spanning two weeks to one year. A summary of the literature is presented in **Table 1**. Headache management sessions were highly successful, with 81% (17/21) identifying an improvement in their primary outcome measure and 95% (20/21) observing at least one outcome improve.

Table 1

Summary of the literature on studies with an active headache self-management or education intervention arm.

Authors	Country	Study Design	Population	N	Mode	Group or Individual	Frequency of HSME	Duration of HSME
(Holroyd et al., 1989)	USA	RCT	Adult	30	Combination	Individual	Multiple	NR
(Maizels et al., 2003)	USA	Pre-post	Adult	264	In-person	Group	Single	NR
(Blumenfeld & Tischio, 2003)	USA	Pre-post	Adult	497	In-person	Group	Single	120 mins
(Harpole et al., 2003)	USA	Pre-post	Adult	54	In-person	Combination	Multiple	90 - 120 mins
(Rothrock et al., 2006)	USA	RCT	Adult	100	In-person	Group	Multiple	3 × 90 mins
(Cady et al., 2008)[a]	USA	CT	Adult	180	In-person	Individual	Single	NR
(Matchar et al., 2008)	USA	RCT	Adult	614	In-person	Group	Single	NR
(Sauro & Becker, 2008)	Canada	Pre-post	Adult	132	In-person	Group	Multiple	6 × 120 mins
(Smith et al., 2010)[a]	USA	Pre-post	Adult	284	In-person	Individual	Single	NR
(Bromberg et al., 2012)[a]	USA	RCT	Adult	185	Remote	Individual	Multiple	8 × 20 min sessions over 4 weeks
(Leroux et al., 2018)[a]	Canada	CT	Adult	162	In-person	Individual	Multiple	4 × 45 mins
(Lagman-Bartolome et al., 2018)[a,b]	Canada	Pre-post	Adult	177	In-person	Group	Single	90 mins
(Thakur et al.,	USA	Pre-post	Adult	88	Remote	Individual	Single	60 mins

2018)								
(Schaetz et al., 2020)[a]	Switzerland	Pre-post	Adult	141	Combination	Combination	Multiple	monthly for 6 months
(Wells et al., 2021)	USA	Pre-post	Adult	44	In-person	Group	Multiple	8 × 120 mins
(Short, 2021)[a,b]	USA	Pre-post	Adult	15	Combination	Individual	Multiple	45 mins
(Underwood et al., 2023)	UK	RCT	Adult	736	In-person	Group	Multiple	NR (2-days, one week apart)
(Connelly et al., 2006)	USA	RCT	Pediatric	37	Remote	Individual	Multiple	4 × 60 mins
(Abram et al., 2007)	USA	RCT	Pediatric	81	In-person	Group	Single	60 mins
(Hickman et al., 2015)	USA	RCT	Pediatric	36	Combination	Combination	Multiple	7 weeks
(Walter et al., 2020)[b]	USA	RCT	Pediatric	30	In-person	Combination	Multiple	6 weeks

Note. CT = controlled trial, NR = not reported, RCT = randomized controlled trial.

[a]evaluated self-efficacy

[b]evaluated behavioural change

Outcomes and Outcome Measures

Self-Efficacy in Adult Studies

Six studies measured headache-related self-efficacy, and one measured overall health-related self-efficacy following HSME. An increase in self-efficacy was observed in 86% (n = 6) of studies. Of the six studies that observed an improvement in self-efficacy, two had a single session of in-person individual HSME (Cady et al., 2008; Smith et al., 2010), one had multiple sessions of in-person individual HSME (Leroux et al., 2018), one had multiple sessions of remote individual HSME (Bromberg et al., 2012), one had multiple individual HSME sessions that were both remote and in-person (Short, 2021), and one had multiple HSME sessions that were both remote, in-person, group, and individual (Schaetz et al., 2020). The study that did not observe an improvement in headache self-efficacy had a single session of in-person group HSME (Lagman-Bartolome et al., 2018). Three studies used unvalidated surveys that asked about the participants' confidence in performing tasks required to manage their headaches (Cady et al., 2008; Lagman-Bartolome et al., 2018; Smith et al., 2010). Three studies used the Headache Self-Efficacy Scale (Bromberg et al., 2012; Leroux et al., 2018; Short, 2021) and one study used the Patient Activation Measure (Schaetz et al., 2020).

Self-Efficacy in Pediatric Studies

None of the studies that enrolled pediatric participants evaluated self-efficacy.

Behaviour Change in Adult Studies

Positive behavioural changes were observed in the two studies that measured it. Lagman-Bartolome et al. (2018) saw an improvement in all three modifiable lifestyle behaviours evaluated, including routine sleep, hydration, and morning protein intake. This was measured using an unvalidated survey developed by the authors. Short (2021) had participants complete a

health behaviour survey pre- and post-intervention detailing morning protein intake, hydration, sleep amount and quality, use of relaxation techniques, and use of a headache diary app. Modest improvements were seen in morning protein intake, use of a sleep routine, practicing relaxation techniques, and use of a headache diary app.

Behavioural Change in Pediatric Studies

Walter et al. (2020) randomized 30 participants with a mean age of 14.8 years to either standard care (n=17) or a self-management intervention (n=13). They found that at six weeks, the self-management group demonstrated a greater magnitude of change in eating breakfast and lunch. No difference was observed in caffeine intake or sleep. The effect of HSME on behaviour change is limited in the literature; however, the available data indicates a positive association.

Learning Theory

Six studies used a theory-guided learning approach to headache management sessions. Seven distinct theories were presented: adult learning theory (Cady et al., 2008), acceptance and commitment theory (Underwood et al., 2023), theory of planned behaviour and reasoned actions (Underwood et al., 2023), symptom management theory (Walter et al., 2020), cognitive theory (Hickman et al., 2015), cognitive behavioural theory (Underwood et al., 2023), self-efficacy theory (Short, 2021) and social cognitive theory (Martin et al., 1993; Short, 2021; Underwood et al., 2023). Given the overall lack of information on theory-guided headache management interventions in the literature, particularly in the pediatric population, publications regarding other chronic health diagnoses were sought to identify theory-guided chronic condition self-management interventions in the pediatric population. Saxby et al. (2019) conducted a systematic review of chronic condition self-management educational interventions for children with asthma, cystic fibrosis, or diabetes. Of the 30 included studies, 21 mentioned specific developmental

theories. All 21 incorporated Bandura's *Social Learning and Cognitive Theories* either alone (n = 9) or in combination with Piaget's *Cognitive Constructivist Theory* (n = 12). Eight studies measured self-efficacy, and improvements were observed in all of them compared to usual care.

CHAPTER III: Methods

Research Design

A pre- post- comparison pilot study was utilized to assess the feasibility and acceptability of the study protocol, including an evaluation of the eligibility criteria, informed consent and data collection procedures, recruitment and retention rates and participant satisfaction. These data can be used to guide a large randomized controlled trial or observational study. Participant-reported outcomes were also assessed to determine whether participation in theory-guided HSME was associated with increased self-efficacy in 12 to 17-year-olds with a referral to CHEO for headache. Behaviour change was measured once following HSME. By nature of this being a pilot study, the focus was to assess the feasibility and acceptability of the study protocol, not to conduct hypothesis testing. Hypothesis testing with the pilot study data was conducted and interpreted with an understanding of the limitations.

Setting and Participant Population

Individuals aged 12 to 17 years with a referral to the CHEO Neurology Clinic between March and June 2024 for headache disorder were considered for participation. CHEO is a large, tertiary care children's hospital located in Ottawa, Canada. CHEO helps more than 500,000 children annually from Nunavut, Eastern Ontario, and Western Quebec (CHEO, 2024). To be included, those referred had to have the capacity to provide informed consent for themselves and speak and understand English. Potential participants were excluded if they were triaged to urgent consultation, which is defined as requiring a consultation within 14 days, or if they did not have a primary care physician. Since participants are awaiting consultation and are not actively being followed by the Neurology Clinic at the time of HSME, a primary care physician was essential to

ensure that participants were under the care of a physician for any follow-up questions or mental health concerns, which are discussed during HSME.

The triaging neurologist or nurse practitioner contacted potential participants by phone to briefly introduce the study and ask whether they were willing to be contacted by the research coordinator. If the potential participants agreed, their contact information was forwarded to the research coordinator. The research coordinator called potential participants to discuss consent and answer any study-related questions. The informed consent form was sent to potential participants via email. There is no legal age of consent in Ontario, and it is up to the research team to determine an individual's ability to understand the information in the consent form. The potential participant's capacity to consent was determined during the consent discussion by asking questions about their understanding of the study. If the potential participant demonstrated a comprehensive understanding of the study objectives, participant responsibilities, and risks of participation, they were deemed to have the capacity to consent for themselves. If potential participants were deemed incapable of providing informed consent, they were ineligible to participate. If a potential participant was interested in participating and deemed eligible by the research coordinator, informed consent was obtained via electronic written informed consent. All Research Ethics Board (REB)-approved versions of the electronic written informed consent were archived and retained for auditing purposes. The research coordinator sent the potential participant an email with the link to the consent form stored in REDCap. To verify the identity of the person giving their consent via electronic written informed consent, the research coordinator sent an additional email that includes a code that was unique to them. Before they submitted their response in the REDCap consent form, they were required to enter their unique code. Following their response submission, the research coordinator verified that they provided the correct code

before signing and submitting the survey. The informed consent form (**Appendix A**) details that participants may contact the principal investigator, or the CHEO REB should they have any questions and provides contact information (email address and phone number) for both entities. Once the participant provided their informed consent, the research coordinator sent them an electronic copy of the signed consent form.

The research coordinator documented the number of patients contacted and whether they agreed to participate. Identifiable information from individuals who declined participation was not retained.

Six workshops were scheduled biweekly over ten weeks. To facilitate group learning and collaboration, workshops were only run if there were a minimum of five participants. Enrollment into each workshop closed at 12 participants to manage time effectively (allow time for introductions and feedback) and comply with room capacity restrictions. CHEO neurology receives approximately 10 new headache referrals each week, and it was anticipated that there would also be a waitlist of referred patients to recruit from.

Intervention: Headache Self-Management Education

The intervention was a one-time, 90-minute, in-person, group workshop on HSME. Workshops took place on site at CHEO. To support recruitment and participant attendance, a total of six workshops were scheduled every other week over 10 weeks. Workshops were scheduled in the evenings to avoid participants missing school.

One of two nurse practitioners with specialized training in pediatric headaches or a pediatric neurologist facilitated the workshops. The pediatric neurologist led a 60-minute training session detailing how to facilitate the workshop. The training session began with a general overview of the workshop and the study objectives. This included: characteristics of attendees

(participants, caregivers), length of workshop, and modality of workshop. Next, the slides were presented one-by-one, and the purpose and context of each was discussed. A script was not provided, but general talking points were highlighted. The trainees had a chance to ask questions after each slide. There was additional time for questions at the end of the training session. The training session ended once all questions were answered. The author attended the training and all workshops in a supportive role.

Each workshop was separated into two phases and participants were required to attend both phases. Caregivers were welcome, but not required, to attend the first phase. The second phase was for participants only. The HSME slides are available in **Appendix B**.

1) The first phase took 45-60 minutes. The workshop began with introductions by the facilitator and support staff. Topics included:
    a. Headache types (TTH and migraine): pain quality, intensity, location of pain, and associated symptoms of each.
    b. Migraine aura.
    c. Preventing headache attacks: lifestyle modifications, supplements, and pharmacotherapy.
    d. Treating headache attacks: appropriate dosing and timing of rescue medications.
    e. Medication overuse headaches.
    f. How to use a headache diary.
2) The second phase took 30-45 minutes. This phase of the workshop focused on coping with the psychosocial impact of frequent headache attacks, including physical, emotional, social, and school-related challenges that children with frequent headache attacks face. The relationship between headache disorders and poor mental health was addressed, and

mental health support resources were provided. Next, an icebreaker activity was utilized to introduce the participants. Six case scenario questions were presented based on the content of the workshop. The facilitator and support staff prompted and encouraged group discussion to address the scenarios.

Caregivers were invited to network and enjoy refreshments in a separate room while the participants completed the second phase of the workshop. A second support staff was present in the room to answer questions.

Participants and caregivers were given the opportunity to provide their level of satisfaction and feedback at the end of the workshop. A QR code was available for participants and caregivers that linked to a REDCap satisfaction and feedback survey (**Appendix C**). Completion of the satisfaction and feedback survey was not mandatory, and it was anonymous.

Participants were provided with a portfolio with the following resources at the workshop (**Appendix D**): SMART goal worksheet, headache diary and medication history worksheets, community mental health resources, Migraine Canada pediatric dosing guidelines, Migraine Canada school letter templates, CHEO help with headaches handout, HSME additional resources page, and BounceBack for Youth 15-17.

Practical Implementation of Self-Efficacy Theory

The self-management education was guided by self-efficacy theory. In addition to didactic learning, the following was implemented into the HSME:

a) Realistic goal setting and hands-on experience: Participants were provided with a SMART goal worksheet and encouraged to set a goal for themselves based on the content of the workshop. Examples were provided, and participants had time to set a goal during the workshop.

b) Problem solving: At the end of the workshop, case scenarios were presented. These included determining which type of headache(s) the individual experiences, calculating their recommended dose of supplements, identifying whether they are experiencing medication overuse headaches, and brainstorming ways to implement lifestyle changes practically.
c) Collaborative learning environment: Participants were encouraged to discuss the case scenarios as a group.
d) Provide constructive feedback: The facilitator provided positive and constructive feedback on the case scenario responses.
e) Promoting autonomy: The second phase of the workshop was only open to participants in an effort to promote their autonomy, and highlight the importance of their role in identifying, managing, and treating headache attacks, and communicating with their support system.

Sample Size

If interest in participating in the study was high, a maximum of 72 participants would have been enrolled (six workshops with 12 participants in each). If interest in participating in the study was low, it was anticipated that a minimum of four workshops would be run with five participants in each, for a total sample size of 20. Given that this was a pilot study, the sample size should allow for the identification of any issues with the workshop design and provide an estimate of recruitment potential. Four workshops would be enough to highlight issues with the workshop design. If patient interest was low, it would be valuable information to consider before initiating the workshop on a large scale. If participant interest was high, the study may be powered to answer the primary research question. Regardless of the sample size recruited, the

results of this pilot study can be used to estimate effect sizes to determine the sample size needed for a larger scale RCT or observational study.

Data Collection

The following data were collected for administrative purposes but were not included in the study data for analysis: full name, medical record number, phone number, email address, and date of the consultation appointment. Participant demographics included in data analysis were age at the time of the workshop and sex at birth.

Outcome Measures

Outcomes measures are included in **Appendix E**.

Headache Self-Efficacy Scale

The headache self-efficacy scale (HSES) was used as the primary outcome measure. The HSES is a validated, 25-item questionnaire that measures an individual's confidence in headache prevention, headache pain management, and headache-related disability (French et al., 2000). Responses range on a scale of 1 – strongly disagree, to 7 – strongly agree (French et al., 2000). The HSES has not been validated in the pediatric population. However, the readability of the HSES was evaluated using the Automated Readability Index and Flesch Reading Ease (*Readability Scoring System*, n.d.). The Automated Readability Index considers the average number of characters per word and the average number of words per sentence (*Readability Scoring System*, n.d.). The Automated Readability Index rates the HSES as "easy" in terms of reading difficulty, at a fourth-grade level, and for individuals 9-10 years old (*Readability Scoring System*, n.d.). The Flesch Reading Ease considers the average syllables per word and the average words per sentence (*Readability Scoring System*, n.d.). The HSES was deemed "easy" in terms of reading difficulty, at a sixth-grade level, and for 11 to 12-year-olds (*Readability Scoring System*,

n.d.). Therefore, the HSES is considered readable for the participant population (12 years of age and older).

Pediatric Rating of Chronic Illness Self-Efficacy

The Pediatric Rating of Chronic Illness Self-Efficacy (PRCISE) is a 15-item Likert-style questionnaire. Participants are required to circle a number from zero (not at all sure) to 10 (very sure) that best describes how sure they are in managing their illness, mood, symptoms, exercise, obtaining help, and recreational activities (Emerson et al., 2018). The PRCISE questionnaire has been preliminary validated as a reliable measure of self-efficacy in 7-20 year olds (Emerson et al., 2018).

Behavioural Change Survey

The behavioural change survey is an unvalidated 4-item survey developed by the authors to determine whether participants modified their behaviour following the workshop. Questions are related to changes in diet, physical activity, and sleep (**Appendix E**).

Timepoints & Retention Strategy

Participants completed questionnaires at two timepoints: prior to HSME, and two weeks after HSME, but prior to their consultation appointment. Three days prior to HSME, enrolled participants received an email link to complete the initial set of questionnaires: HSES and PRCISE. If participants did not complete the pre-HSME questionnaires after the first email, a reminder email was sent the day before HSME.

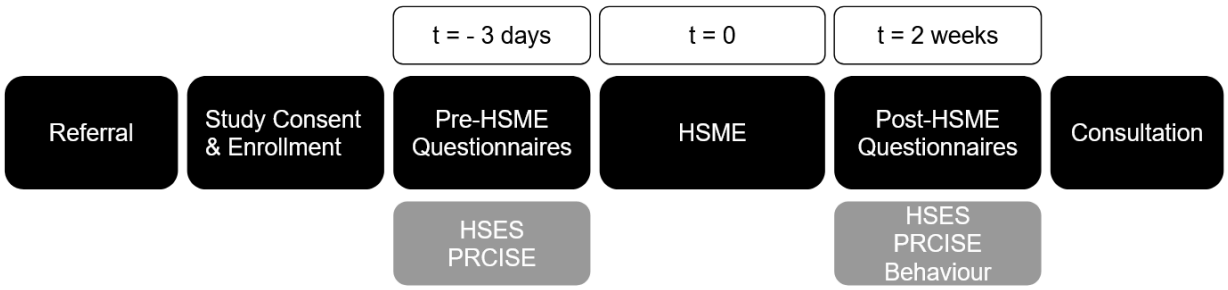
Two weeks following the HSME, the participants received an email link to complete the second set of questionnaires: HSES, PRCISE, and behavioural change survey. The second set of questionnaires were completed prior to the participant's consultation appointment, which was scheduled no earlier than two weeks after HSME. Following the initial email two weeks after

HSME, if the questionnaire had not been completed and the consultation appointment had not occurred, reminder emails were sent (up to a maximum of two total emails per week). If the questionnaires had not been completed prior to the consultation appointment, the research coordinator would meet participants in the clinic to facilitate questionnaire completion on a tablet prior to their appointment. If questionnaires were not completed six weeks following HSME, the data would be considered missing, and no further attempts were made to have the participant complete the questionnaires. A visual depiction of the study flow is displayed in **Figure 2**.

Participants were provided with parking passes at the HSME. There was a total of two pre-HSME questionnaires with a combined 31 questions. There was a total of three post-HSME questionnaires with a combined 35 questions. It was estimated that questionnaire completion would take approximately ten minutes at each timepoint, which would not be overly burdensome on participants. The workshop was a one-time event that lasted 90 minutes.

Figure 2

Study Flow Diagram



Note. HSME = headache self-management education; HSES = headache self-efficacy scale; PRCISE = pediatric rating of chronic illness self-efficacy; Behaviour = behavioural change survey.

Questionnaire Administration and Data Storage

Study data were stored securely in REDCap. REDCap is a secure, web-based application designed exclusively to support data capture for research studies. The application and data are stored on CHEO servers located in Canada. Study data will be stored for seven years after the completion of the study and then destroyed. Electronic files will be permanently deleted, and hardcopy files will be shredded.

Participants directly inputted questionnaire responses into REDCap. Participants provided an email to facilitate the distribution of the questionnaires, which was stored with study data in REDCap. This field was marked as an identifying field in REDCap and removed from data export.

Study administrative data are stored on a master list, linking the subject ID from REDCap and identifying information. The master list is stored on the secure CHEO Microsoft 365 server. Only the study staff have access to this list.

Pilot Study: Feasibility and Acceptability of the Protocol

The pilot study evaluated the eligibility criteria, informed consent forms and data collection method. During the recruitment phase of the study, the research coordinator identified whether the eligibility criteria met the objectives of the study and whether revisions or additions to the inclusion and exclusion criteria were warranted. This was assessed on a case-by-case basis with the triaging neurologist. To assess the informed consent form, the research coordinator documented the consent process for each participant. During the consent process, the study coordinator documented if participants asked questions about information in the consent form that highlighted sections to add, delete, or revise. If there were any required changes to the informed consent form during the study, the research coordinator would submit an amendment to

the REB. The study coordinator also documented any issues with data collection on the REDCap system.

To assess the recruitment rate, the total number of participants who enrolled in the study during the recruitment phase was tracked. The retention rate is presented as the percentage of enrolled participants that attended the HSME and the percentage of participants that completed the post-intervention questionnaires. Participant and caregiver acceptability of the HSME was evaluated based on responses to the anonymous satisfaction and feedback survey.

Ethical Considerations

REB approval was obtained from the CHEO and Athabasca University (AU). (**Appendix F and Appendix G**, respectively). Initial CHEO REB approval was granted on February 7, 2024. A minor modification was submitted and approved on February 22, 2024, to add the PRCISE questionnaire pre- and post-HSME. No participants were contacted prior to the approval of the minor modification. Ethical considerations included the principles of informed consent, voluntary participation, participant confidentiality, and the burden on participants (financial, time at the workshop, and completing the questionnaires).

All informed consent procedures aligned with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS2 (2022) (Canadian Institutes of Health Research et al., 2022). Informed consent was obtained through electronic informed consent on CHEO REDCap. CHEO REB provides a guidance document on the use of electronic written informed consent that was followed to obtain e-consent in accordance with TCPS2.

Data Analysis

Descriptive statistics (mean and standard deviation) were calculated for the participants age, pre- and post-intervention HSES, and PRCISE scores. The Shapiro-Wilk test was used to

check for normality. Paired samples t-tests were conducted for pre-post (time) comparisons of the HSES and PRCISE scores.

Missing Data

If an HSES was missing responses to six or more questions (>23%), the questionnaire was deemed missing. If a post-HSME HSES had one to five missing responses, the baseline observation carried forward (BOCF) method was utilized. BOCF is a common method used to handle missing data in clinical trials (Liu-Seifert et al., 2010). Using this method, the baseline observation is treated as the final response from the participant, indicating no treatment effect following an intervention (Liu-Seifert et al., 2010). If a PRCISE was missing responses to four or more questions (>26%), the questionnaire was deemed missing. If a post-HSME PRCISE had one to three missing responses, the BOCF method was utilized. Since the Behaviour Modification Survey analyzed each question individually, partially completed surveys were included.

If a pre-HSME HSES and PRCISE was completed, but the post-HSME HSES and PRCISE were missing, analysis was conducted twice: once utilizing the BOCF method and once utilizing pairwise deletion. Best practice for handling missing data in longitudinal studies is highly dependent on the context of the study and study objectives (Little et al., 2012). In this study, it is reasonable to assume that the HSME intervention will not reduce a participant's self-efficacy. However, as the time between referral and consultation increases, the participant's condition may worsen, and self-efficacy may decrease despite HSME. The BOCF will not account for potential reductions in self-efficacy during this period, but it will also not allow for any assumptions of an improvement. Pairwise deletion involves calculating the statistical analyses using all cases who provide data relevant to each estimate (Newman, 2014). Pairwise

deletion will reduce the sample size by excluding incomplete data sets, which may bias the results, since the reason for not completing the post-HSME questionnaires will be unclear (Newman, 2014). Therefore, the results of both the analyses will be reported. All analyses were performed using SPSS v. 29 (IBM Corp., 2023).

Chapter IV: Results

Participant Characteristics

A total of 95 individuals aged 12 to 17 years were assessed for study eligibility between March and June 2024. Fifty-eight were excluded because they did not meet eligibility criteria (n = 20) or they were not interested in participating (n = 38). The remaining 37 signed informed consent, and 30 attended HSME. Forty-nine percent of potentially eligible participants signed informed consent, and 81% of participants who signed consent attended HSME. Seven signed consent but did not attend HSME, either because they did not show up for their scheduled workshop (n = 4), or their workshop was cancelled due to low enrollment (n = 3). A summary of participant screening, enrollment, and follow-up is presented in a CONSORT flow diagram (**Figure 3)**. The mean (SD) age of the sample was 14.7 (1.5) years and 73% were female (**Table 2**). For all analyses, the assumption of normality was met for all data sets based on independent Shapiro-Wilk tests.

Figure 3

CONSORT Flowchart of Participants

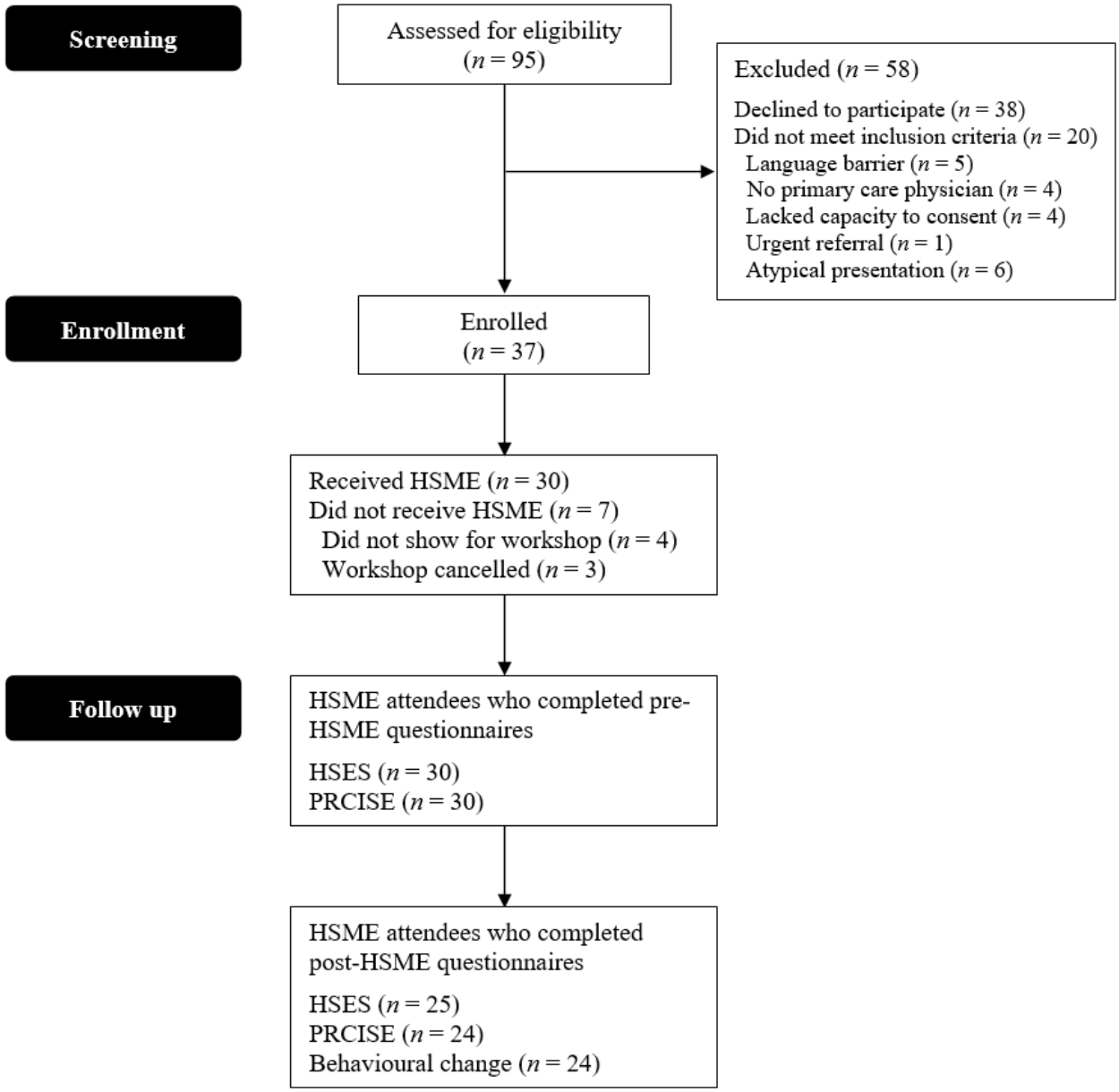


Table 2

Demographic information of the HSME attendees.

	Mean (SD)	%	N
Age	14.7 (1.5)		
Age group			
12 – 14 years		43	13
15 – 17 years		57	17
Sex			
Female		73	22
Male		27	8

Pilot Study Results

Recruitment and Retention Rate

A total of 75 patients were deemed eligible for participation in the HSME study, of which 37 (49%) enrolled. Eighty-one percent (n = 30) of the enrolled participants received the intervention by attending the HSME. Twenty-four HSME attendees completed all the post-HSME questionnaires (80%), and 25 (83%) partially completed the post-HSME questionnaires.

Six workshops were scheduled biweekly between April and June 2024. Workshops were cancelled if fewer than five participants enrolled. This occurred twice, causing workshops four and six to be cancelled. Four workshops were run, with six to nine participants in each.

Assessment of Informed Consent Form

The informed consent form was found to be largely thorough and detailed. However, information was missing in the informed consent form and protocol regarding the cancellation of HSME workshops. It was decided that a minimum of five participants were required to run a workshop; however, there was no information on when the decision to cancel a workshop would occur, and when or how participants would be notified. The following statement should be added to the informed consent form, “A minimum of five participants are needed to run a workshop. There is a chance that the workshop you sign up for will be postponed or cancelled due to not

having enough participants. You will be notified by email at 12:00 pm the day before the workshop with a cancellation notice if this occurs".

Assessment of Eligibility Criteria

The proposed eligibility criteria were generally acceptable; however, one additional exclusion criterion was required which excluded six of the 95 participants assessed for eligibility. This exclusion was for an "atypical presentation, in the opinion of the triaging neurologist". Three of the six patients who were excluded for this were noted to have "too many comorbidities." These were serious or life-threatening comorbidities, in which the HSME was felt to be inappropriate. The other three excluded patients had an atypical presentation of headaches, which indicated to the triaging neurologist that the information in the HSME would not be suitable.

Assessment of the Data Collection Method

No issues were noted with the REDCap platform for obtaining informed consent or questionnaire data.

Behavioural Change Survey

The behavioural change survey is an unvalidated 4-item survey developed by the authors to determine whether participants modified their behaviour following the HSME. At the data analysis stage, it was determined that more appropriate response options would have been agree and disagree, as the difference between neutral and disagree is unclear.

Participant and Caregiver Acceptability of HSME

Thirteen responses to the participant and caregiver anonymous feedback survey were received. Three respondents were patient participants, and 10 were parents or caregivers. Detailed responses to the survey are displayed in **Table 3.**

Table 3

Responses to feedback survey.

Responder	Satisfaction Rate	Feedback
Participant	5	it was very nice to finally see and actually meet other people around my age that feel the same things i do almost everyday. it was also very nice to learn how to manage and catch headaches more often before they get too bad.
Participant	5	
Participant	5	it was very informative
Caregiver	5	Excellent information for parents to work with and explore with the child and caregivers. Knew none of this prior, thank you!
Caregiver	5	I am sooooo happy that this study exists. Thank you.
Caregiver	5	Excellent presentation. Very informative. The handouts will be very useful.
Caregiver	5	learned a lot, glad we attended 👍🏾
Caregiver	5	Very informative
Caregiver	5	
Caregiver	5	Very informative, thank you
Caregiver	5	Great information! Enthusiastic nurses! Thank you!
Caregiver	5	This was a very informative presentation! We learned a lot about preventative and treatment. We are beginning our preventative treatment this week. Thank you!
Caregiver	5	The pharmacological list is helpful to share with the MD for ongoing headaches that are not responding to the current treatment regime. Also started taking supplements to monitor for improvement.

Note. Satisfaction rate options were 1 = very dissatisfied, 2 = dissatisfied, 3 = neither satisfied nor dissatisfied, 4 = satisfied, and 5 = very satisfied.

Participant-Reported Objective Results

Missing Data

Headache Self-Efficacy

A paired samples t-test was conducted to compare pre- and post-HSES scores. There was a significant increase in headache self-efficacy using the HSES tool (pre = 72.6 ± 21.5 to post = 78.8 ± 23.3; t(29)=3.1, p = 0.002). Similar results were observed when the analysis was restricted to complete cases only (pre = 74.8 ± 20.3 to post = 82.0 ± 21.7; t(24)=3.1, p = 0.002).

To compare differences in pre- and post-HSES between sexes, two paired samples t-tests were conducted: one with only female participants, and one with only male participants. For female participants, there was a statistically significant increase (pre = 69.3 ± 19.3 to post = 74.9 ± 21.3; t(21)=2.9, p = 0.004). However, for male participants, no significant change was observed (pre = 81.8 ± 25.8 to post = 88.6 ± 27.2; t(7)=1.3, p = 0.116). Similarly, to compare differences in pre- and post-HSES between age groups, two paired sample t-tests were conducted: one with participants aged 12 to 14 years and one with participants aged 15 to 17 years. There was a significant increase for participants 12 to 14 years (pre = 77.9 ± 18.8 to post = 84.8 ± 22.9; t(11)=2.3, p = 0.020). A significant increase was also observed for participants 15 to 17 years (pre = 71.3 ± 21.7 to post = 76.9 ± 21.5; t(16)=2.0, p = 0.030). A summary of the HSES scores are displayed in **Table 4.**

Table 4

Headache self-efficacy scale pre- and post-headache self-management education.

Measure	N	Pre	Post	p-Value
HSES[a]	25	74.8 (20.3)	82.0 (21.7)	0.002*
HSES[b]	30	72.6 (21.5)	78.6 (23.3)	0.002*
Female[b]	22	69.3 (19.3)	74.9 (21.3)	0.004*
Male[b]	8	81.8 (25.8)	88.6 (27.2)	0.116
Aged 12 -14 years[b]	13	77.9 (18.8)	84.8 (22.9)	0.020*
Aged 15 – 17 years[b]	17	71.3 (21.7)	76.9 (21.5)	0.030*

[a]Pairwise deletion method.
[b]BOCF method.
* Significance set at $p < 0.05$.

Chronic Illness Self-Efficacy

A paired samples t-test was conducted to compare pre-and post-PRCISE. There was no statistically significant change observed (pre = 93.7 ± 23.9 to post = 94.0 ± 25.4; t(29)=0.1, p = 0.445). Similar results were observed when incomplete data sets were excluded (pre = 95.5 ± 23.0 to post = 95.9 ± 24.8; t(23)=0.1, p = 0.446).

To compare differences in pre- and post-PRCISE between sexes, two paired samples t-tests were conducted: one with female participants and one with male participants. For female participants, there was no significant change (pre = 89.2 ± 23.9 to post = 92.8 ± 26.7; t(21)=1.6, p = 0.067). For male participants, PRCISE scores significantly decreased (pre = 106.1 ± 97.3 to post = 97.3 ± 22.4; t(7)=-2.7, p = 0.016). Similarly, to compare differences in PRCISE between age groups, two paired sample t-tests were conducted: one with participants aged 12 to 14 years and one with participants aged 15 to17 years. There was no difference for participants 12 to 14 years (pre = 96.1 ± 21.4 to post = 98.2 ± 19.7; t(12)=0.5, p = 0.303). Similar results were observed for participants 15 to 17 years (pre = 91.9 ± 26.1 to post = 90.8 ± 29.1; t(16)=-0.4, p = 0.333). A summary of the PRCISE scores are displayed in **Table 5.**

Table 5

Pediatric rating of chronic illness self-efficacy scale pre- and post-headache self-management education.

Measure	N	Pre	Post	p-Value
PRCISE[a]	24	95.5 (23.0)	95.9 (24.8)	0.446
PRCISE[b]	30	93.7 (23.9)	94.0 (25.4)	0.445
Female[b]	22	89.2 (23.9)	92.8 (26.7)	0.067
Male[b]	8	106.1 (20.3)	97.3 (22.4)	0.016*
Aged 12 -14 years[b]	13	96.1 (21.4)	98.2 (19.7)	0.303
Aged 15 – 17 years[b]	17	91.9 (26.1)	90.8 (29.1)	0.333

[a]Pairwise deletion method.
[b]BOCF method.
* Significance set at $p < 0.05$.

Behavioural Change

Of the 24 respondents, 10 (42%) stated that they drink less caffeine, eight (33%) were more physically active and skipped fewer meals, and six (25%) kept a more regular sleep schedule following HSME (**Table 6)**. Of the respondents, 18 were female (75%) and nine were 12 to 14 years old (38%). Male participants were more likely to improve their sleep schedule (43% vs 17%), skip fewer meals (43% vs 28%), and drink less caffeine (57% vs 33%) compared to female participants. A greater proportion of younger participants improved their sleep schedule and skipped fewer meals, but a greater proportion of older participants were more physically active following HSME. The results are displayed in **Table 7**.

Table 6

Changes in behaviour following headache self-management education (n = 24).

Since the workshop, I …	Agree N (%)	Neutral N (%)	Disagree N (%)
Have a more regular sleep schedule	6 (25)	14 (58)	4 (17)
Skip fewer meals	8 (33)	14 (54)	3 (13)
Drink less caffeine	10 (42)	12 (50)	2 (8)
Am more physically active	8 (33)	14 (58)	2 (8)

Table 7

Agree responses displayed by sex and age group.

Since the workshop, I **agree** that I…	Total N	Female %	Male %	12-14 years %	15-17 years %
Have a more regular sleep schedule	6	17	43	33	20
Skip fewer meals	8	28	43	56	20
Drink less caffeine	10	33	57	44	40
Am more physically active	8	33	29	22	40

Chapter V: Discussion

The primary objective of our pilot study was to assess the feasibility and acceptability of the protocol. Our study had a recruitment rate of 49% and retention rate of 80%. The informed consent form, eligibility criteria, and data collection methods were largely sufficient. Participants and caregivers were highly satisfied with the HSME intervention, however, the response rate to the satisfaction survey was low. The participant-reported objectives of our study were to determine whether theory-guided HSME was associated with an increase in headache self-efficacy and chronic illness self-efficacy, and positive behaviour change in 12 to 17-year-olds referred for headache to a large pediatric tertiary care hospital. Our study found that headache self-efficacy, measured using the HSES, significantly increased following theory-guided HSME. Our study found no change in chronic illness self-efficacy and moderate behavioural change following HSME. Our study also sought to determine whether sex and age were associated with greater increases in headache self-efficacy, chronic illness self-efficacy, and behavioural change. Female sex at birth was associated with greater increases in self-efficacy but not behavioural change. Changes in self-efficacy were similar between age groups. A greater proportion of older participants reported more physical activity following HSME than younger participants, but a greater proportion of younger participants improved all other behaviours.

Recruitment and Retention Rate

Half of the eligible participant population signed consent to attend HSME. This is lower than the hypothesized recruitment rate of 80%, which was based on comparable studies in the pediatric population. Walter et al. (2020), Hickman et al. (2015), and Connelly et al. (2006) had enrollment rates of 86%, 84% and 74%, respectively. There are several reasons the enrollment rate was low. CHEO has a wide catchment area from Nunavut, Eastern Ontario, and Western

Quebec. Therefore, some referred patients live hundreds of kilometres from the hospital, and attending an in-person workshop was not feasible. Additionally, only a small number of workshops were held over a relatively short period of time, which may have logistically limited the number of participants that could attend. A focus group or interview study including all individuals that met eligibility criteria is warranted to further elicit reasons for the relatively low recruitment rate, and ways it could be improved in a future study.

In the current study, 80% of HSME participants fully completed the follow-up questionnaires. This is slightly lower to the hypothesized retention rate of 85%, but similar to the rates seen by Hickman et al. (2015) (89%), Walter et al. (2020) (87%), and Connelly et al. (2006) (84%). It is also notable that there was no incentive for participants to complete the follow-up questionnaires, as it did not impact the scheduling of their consultation appointments, there was no financial incentive, and they would receive no further HSME. When designing and budgeting for a larger-scale study, a reasonable financial incentive in the form of a gift card, stipend, or entrance into a draw for a prize may improve the retention rate (Abdelazeem et al., 2023).

Acceptability

While the responses to the satisfaction survey were overwhelmingly positive, the response rate was low, with only three out of 30 potential participant responses and 10 caregiver responses. The satisfaction and feedback survey could not be mandatory, since it was important to allow for anonymity. The survey was presented during the workshop, at the end of Phase 1, and provided in the participant handouts. However, in hindsight, more effort should have been invested in promoting a higher response rate. A follow-up email to all participants with a link to the survey should have been sent the day after their workshop requesting feedback. Prior to developing an RCT, it would be beneficial to invite participants and caregivers from the current

study to attend focus groups to gather more feedback on the enrollment process, mode, duration, and content of the HSME, as well as follow-up procedures.

Headache Self-Efficacy

Baseline headache self-efficacy scores of 72.6 ± 21.5 observed in our pediatric population were low compared to published literature in adult headache patients, in which baseline scores range from 97 – 114 (Bromberg et al., 2012; Leroux et al., 2018; Wells et al., 2021). However, the HSES has only been validated in the adult population making comparisons to the pediatric population difficult. While the readability of the HSES appears appropriate (*Readability Scoring System*, n.d.), it is possible that it does not provide a valid measure of headache self-efficacy in the pediatric population. Alternatively, it is likely that HSES is a valid measure but that headache self-efficacy is lower in the pediatric population compared to the adult population. Self-efficacy in the pediatric population may be lower as they are more likely to rely on their caregivers to aid in their care and advocate for them. As detailed below, chronic illness self-efficacy is also lower in our study group compared to other pediatric populations, supporting the notion that our study population lacks self-efficacy.

The HSES score increased by six points two weeks after HSME, which was statistically significant. However, the pre-post study design makes it difficult to determine whether this increase is related to the HSME. Further data collection in this participant population is necessary to assess whether the increase is clinically meaningful. For example, an assessment and comparison of improvements in of headache frequency, headache-related disability, or quality of life to improvements in headache self-efficacy would provide insight to determine a clinically meaningful increase in the HSES. In a prospective controlled trial of adult headache participants, a self-management education intervention was compared to standard of care

(Leroux et al., 2018). The intervention was in-person, one-on-one goal setting and motivational interviewing with a nurse over four visits. The total in-person time with the nurse was approximately three hours per participant over 12 months, in addition to unrestricted and unrecorded phone calls. Headache self-efficacy was measured using the HSES, and at 12 months the standard of care group increased by 8.4 points, while the intervention group increased by 16.8 points (Leroux et al., 2018). Similarly, in a randomized controlled trial of 185 adult participants, headache self-management education was compared to standard of care (Bromberg et al., 2012). The intervention was fully remote, with participants being required to complete eight 20-minute modules in the first four weeks, followed by one 20-minute module monthly for five months. The modules involved completing self-assessments, using interactive tools, reading articles, and using a pain tracker. Headache self-efficacy was measured using the HSES, and at six months the standard of care group increased by eight points, while the intervention group increased by 18 points. Short (2021) performed a pre-post headache self-management education study in adults. The intervention was introduced in-person with participant education via a series of short videos (10 minutes total), followed by verbal information tailored to the participant's feedback and questions. The videos highlighted statistics about chronic migraine, use of migraine diary, and the importance of specific lifestyle behaviours. Following the in-person education, participants were provided with a self-management toolkit website to access outside the clinical setting. The website included patient education videos, tips, resources, articles, podcasts, and website links. They observed a 19-point increase in HSES at eight weeks post-intervention. These studies indicate that the observed increase in HSES may not be clinically meaningful, given that the increase aligns with that of control groups in other studies (Bromberg et al., 2012;

Leroux et al., 2018). Additionally, the current study had a short follow-up period, so it is not possible to determine whether the increase in HSES would be sustainable over time.

Chronic Illness Self-Efficacy

The baseline PRCISE score in the study population was 94.7 ± 23.9. In the preliminary validation study of the PRCISE scale, the mean score was 114 ± 32 for children with various chronic diseases and 114 ± 33 for the subgroup comprising children with neurological disorders (Emerson et al., 2018). Gürcan & Turan (2022) conducted a validation and reliability study of the PRCISE in 220 Turkish children with various chronic illnesses and observed a mean PRCISE of 106 ± 18. The PRCISE scores were slightly lower in the subgroup analysis for children with neurological disorders, at 105 ± 22. Öncel & Solmaz (2022) evaluated PRCISE scores in a group of children with multiple sclerosis, and the mean score was 102 ± 22. Similar to HSES, our baseline score is lower than scores published in the literature. In our study, males have a higher baseline PRCISE score than females (106.1 ± 20.3 compared to 89.2 ± 23.9). However, Gürcan & Turan (2022) found no significant relation between self-efficacy score and age or sex. This result may be due to our small sample size (n = 30), and our limited number of male participants (n = 8).

There was no change in PRCISE scores following HSME, contrasting with the increase observed in HSES. The HSES measures headache-specific self-efficacy, whereas the PRCISE measures chronic illness self-efficacy. Pediatric headaches are associated with an elevated risk of several conditions, including attention-deficit hyperactivity disorder, depression, anxiety, epilepsy, obesity, atopic disorders, inflammatory bowel disease, and irritable bowel syndrome (Jacobs et al., 2016). The HSME intervention primarily focuses on headaches, with some information and resources on psychological comorbidities, including depression and anxiety.

However, it is possible that our study population was highly comorbid, and there was little benefit to their overall chronic illness self-efficacy.

Behavioural Change

Analysis of the behavioural change survey revealed that changes to the response options are warranted. Participants were provided directional statements (e.g., Since the workshop, I am more physical active) and the response options were agree, neutral, and disagree. It is difficult to interpret the difference between neutral and disagree responses. Therefore, the neutral response option should be removed if the survey is used in a larger scale study.

Behavioural modifications, including drinking less caffeine, skipping fewer meals, being more physically active, and keeping a more regular sleep schedule, were observed in 42%, 33%, 33%, and 25%, of the participants, respectively. Walter et al. (2020)'s RCT assessed changes in diet, caffeine, and sleep following a headache self-management education intervention in a pediatric population. They observed a significant improvement in diet in the intervention group, but no notable improvement in sleep or caffeine. This is a notable difference from the current study, where just under half the participants drank less caffeine following the intervention. To our knowledge, this is the only other study that has measured changes in caffeine intake following a HSME intervention. Short (2021) and Lagman-Bartolome et al. (2018) performed pre-post studies on the adult population and observed modest improvements in morning protein intake and use of a sleep routine, aligning with the results observed in our study. Behaviours are often difficult to modify; therefore, we did not anticipate that our intervention would significantly improve any of the behaviours measured.

Limitations

The limitations of this study include the lack of a control group, the use of unvalidated surveys, participant self-selection, and a short follow-up period. Participants who chose to participate may have enhanced motivation for practicing self-management and improving self-efficacy, compared to those who declined participation. The population is likely not representative of the general pediatric headache population, given that they were referred to a tertiary care hospital, and that they were more likely to have the time, resources, and proximity to attend an in-person workshop. It is unknown whether increases in self-efficacy and behavioural changes are sustained over time since there was a single follow-up timepoint two weeks after HSME. Additionally, the response rate to the anonymous feedback survey was low, with only three participant and ten caregiver responses.

Strengths

To our knowledge, this is the first study to prospectively evaluate the association between HSME and self-efficacy in a pediatric population. The sample size is adequate for a pilot study and provides valuable evidence to support the future development of a large observational study or randomized controlled trial.

Chapter VI: Conclusion

The findings from our study indicate that a single, in-person headache self-management education intervention is generally feasible and acceptable in this pediatric population. A focus group or interview study is warranted to elicit extensive and thorough feedback to decipher ways to explain and improve the relatively low recruitment rate, and to further assess the protocol and intervention. The participant reported outcomes suggest that pediatric headache patients awaiting consultation with a neurologist may benefit from HSME. A single, 90-minute HSME workshop increased headache self-efficacy and modestly improved behaviour during the waiting period. To distinguish whether HSME is causatively related to increased headache self-efficacy in this population, an RCT is warranted. Our pilot study provides valuable guidance to develop a successful RCT in this population, including expected recruitment and retention rates and changes in HSES scores to estimate sample size.

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Appendix A: Informed Consent Form

Informed Consent Form for Participation in a Research Study

Study Title: Self-management education for adolescents with headaches: a pilot study

Principal Investigator: Dr. Daniela Pohl, Division of Neurology
613-737-7600 ext. 3504

Sponsor/Funder(s): Children's Hospital of Eastern Ontario Research Institute

INTRODUCTION

You are being invited to participate in a research study. You are invited to participate in this study because you have been referred to the Children's Hospital of Eastern Ontario (CHEO) for headache. This consent form provides you with information to help you make an informed choice. Please read this document carefully and ask any questions you may have. All your questions should be answered to your satisfaction before you decide whether to participate in this research study.

Please take your time in making your decision. You may find it helpful to discuss it with your friends and family.

Taking part in this study is voluntary. You have the option to not participate at all or you may choose to leave the study at any time. Whatever you choose, it will not affect the usual medical care that you receive outside the study.

IS THERE A CONFLICT OF INTEREST?

There are no conflicts of interest to declare related to this study.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to see whether a headache self-management education workshop is helpful for patients newly referred to CHEO for headaches.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

It is anticipated that about 40 participants will take part in this study. This study should take 6 months to complete, and the results should be known in about 10 months.

WHAT WILL HAPPEN DURING THIS STUDY?

Headache Self-Management Education Workshop

You will be asked to participate in one headache self-management education workshop in person at CHEO. The workshop will be facilitated by a neurology healthcare provider (i.e. nurse practitioner or neurologist). There will be 4-11 other participants in the workshop. The workshop will be divided into two parts, described below.

Part One: Instructional Learning (45 minutes)
Attendance: Participants are required to attend. Up to a maximum of two caregivers are invited to attend, however, their attendance is not mandatory.
Content: Types of headaches, headache prevention and treatment.
Part Two: Collaborative Learning (45 minutes)
Attendance: Participants are required to attend independently. During this period, a separate room will be available for caregivers to review resources and enjoy refreshments.
Content: Coping with headaches, goal setting, and collaborative problem solving through case scenario questions.

Questionnaires
You will be provided with one questionnaire before the workshop and two questionnaires 2 weeks after the workshop. The purpose of the questionnaires is to understand how the workshop affects your self-efficacy and behaviour. The questionnaires will take about 15 minutes to complete. The information you provide is for research purposes only.

A link to the pre-workshop questionnaire will be sent to your email three days prior to the workshop. The link can be used to complete questionnaires electronically through a web browser on a smartphone or computer. If the questionnaires are not completed that day, a reminder email will be sent the following day. If you prefer to complete the questionnaire over the phone with the research coordinator, you can call them at 613-737-7600 extension 4261.

A link to the post-workshop questionnaires will be sent to your email two weeks after the workshop. The link can be used to complete questionnaires electronically through a web browser on a smartphone or computer. If you prefer to complete the questionnaire over the phone with the research coordinator, you can call them at 613-737-7600 extension 4261. If the questionnaires are not complete, a reminder email will be sent twice weekly. If the questionnaires are not complete at the time of your in-person consultation appointment at the CHEO Neurology Clinic, you will be asked to complete the questionnaires in-person prior to the start of your appointment. If you have not completed the questionnaires four weeks after the workshop, you will no longer be contacted to complete the questionnaires.

WHAT ARE THE RESPONSIBILITIES OF STUDY PARTICIPANTS?
If you choose to participate in this study, you will be expected to:

- Attend a headache self-management education workshop.
- Complete the questionnaires before the workshop and 2 weeks after the workshop.

HOW LONG WILL PARTICIPANTS BE IN THE STUDY?
Your participation in this study will last for about 4 weeks.

CAN PARTICIPANTS CHOOSE TO LEAVE THE STUDY?
You can choose to end your participation in this research (called withdrawal) at any time without having to provide a reason. If you choose to withdraw from the study, you are encouraged to contact the research team.

You may withdraw your permission to use information that was collected about you for this study at any time by letting the research team know. However, this would also mean that you withdraw from the study.

CAN PARTICIPATION IN THIS STUDY END EARLY?
Your participation on the study may be stopped early, and without your consent, for reasons such as:

- New information shows that the research is no longer in your best interest.
- The research team decides to stop the study.
- The research ethics board withdraws permission for this study to continue.

If you are removed from this study, the research team will discuss the reasons with you.
WHAT ARE THE RISKS OR HARMS OF PARTICIPATING IN THIS STUDY?
You may become uncomfortable while discussing your experiences. You may refuse to answer questions or leave the workshop at any time if you experience any discomfort.

While the study team will take precautions to protect your confidentiality, we cannot guarantee that other members of the workshop will respect your privacy or keep the discussions of the workshop confidential.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?
You may benefit from the information learned and experience attending the workshop. However, you may not receive direct benefit from participating in this study. We hope the information learned from this study will help other people with headaches in the future.

HOW WILL PARTICIPANT INFORMATION BE KEPT CONFIDENTIAL?
If you decide to participate in this study, the research team will only collect the information they need for this study.

Records identifying you at this centre will be kept confidential and, to the extent permitted by the applicable laws, will not be disclosed or made publicly available, except as described in this consent document.

Authorized representatives of the following organizations may look at your original (identifiable) medical records, to check that the information collected for the study is correct and follows proper laws and guidelines.

- The research ethics board who oversees the ethical conduct of this study *at this location*
- This institution and affiliated sites, to oversee the conduct of research at this location

Information that is collected about you for the study (called study data) may also be sent to the organizations listed above. Your name, address, email, or other information that may directly identify you will not be used. The records received by these organizations may contain your disclose identifiers e.g., participant code, sex, and age.

The following organizations may also receive study data:
- Athabasca University

Communication via e-mail is not absolutely secure. We do not recommend that you communicate sensitive personal information via e-mail.

If the results of this study are published, your identity will remain confidential. It is expected that the information collected during this study will be published/ presented to the scientific community at meetings and in journals.

Even though the likelihood that someone may identify you from the study data is very small, it can never be completely eliminated.

Study data will be retained by the research team for 7 years and then be destroyed.

Any information that may indicate that a child is being harmed or at risk of harm (including self-harm) would not be kept confidential and instead be disclosed to appropriate authorities.

Other future research
Your coded study data may be used or shared with other researchers (inside and outside of Canada) for future studies. “Coded” means that directly identifying information (such as your name and date of birth) will be replaced by a randomly generated number, which will be applied to the study data. This may include storing the coded study data in controlled-access databases, for which access is limited to researcher(s) who submit a study plan and who sign an agreement to use the coded study data and/or coded samples only for that research. Very limited coded study data may also be placed in an open access, publicly accessible database. The goal of sharing is to make more research possible. However, the code matching your study data with your name and other directly identifying study data will not be shared. You will not be asked if you agree to take part in future research studies using your study data. You

or your study doctor will not be told what type of research will be done. You will not be given reports or other information about any research that is done with your study data.

WHAT IS THE COST TO PARTICIPANTS?
Participation in this study will not involve any additional costs to you or your private health care insurance.

ARE STUDY PARTICIPANTS PAID TO BE IN THIS STUDY?
If you decide to participate in this study, you will receive a parking pass to cover the cost of parking during the workshop.

WHAT ARE THE RIGHTS OF PARTICIPANTS IN A RESEARCH STUDY?
You will be told, in a timely manner, about new information that may be relevant to your willingness to stay in this study.

You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of the results of this study, please contact the research team.

Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected.

By signing this form you do not give up any of your legal rights against the researcher or involved institutions for compensation, nor does this form relieve the researcher or their agents of their legal and professional responsibilities.

You will be given a copy of this signed and dated consent form prior to participating in this study.

WHOM DO PARTICIPANTS CONTACT FOR QUESTIONS?

If you have questions about taking part in this study, or if you suffer a research-related injury, you can talk to the research team, or the person who is in charge of the study at this institution. That person is:

Dr. Daniela Pohl	613-737-7600, extension 3504
Name	Telephone

If you have questions about your rights as a participant or about ethical issues related to this study, you can talk to someone who is not involved in the study at all. That person is:

The CHEO Research Ethics Board	613-737-7600, extension 3272
Name	Telephone

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SIGNATURES

- All of my questions have been answered,
- I understand the information within this informed consent form,
- I allow access to medical records and related personal health information as explained in this consent form,
- I do not give up any of my legal rights by signing this consent form,
- I agree that my data collected for this research may be used in future research within or beyond the general area of research of the current study,
- I agree to take part in this study.

Signature of Participant	PRINTED NAME	Date
Signature of Person Conduction Consent Discussion	PRINTED NAME	Date

Appendix B: Headache Self-Management Education

1/19/2024

HEADACHE WORKSHOP

Part 1: Headache Education

Facilitators: Name 1
Name 2

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Agenda

Part 1: Headache Education

- **Patients and Caregivers**
- 45 minutes
- Topics:
  - Types of headaches
  - Preventing headaches
  - Treating headaches
  - Headache diary

Part 2: Managing Headaches

- **Patients**
- 45 minutes
  - Coping with headaches
  - Goal setting
  - Problem solving
  - Collaboration
- Caregivers: Room X

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Types of Headaches

Tension-type headache

Migraine

Wojaczyńska-Stanek, 2008, *Journal of Child Neurology*

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Typical Presentation

Tension-type headache

- Mild to moderate
- Dull

Migraine

- Moderate to severe
- Pulsating / throbbing

Stafstrom, 2002, *Pediatrics*

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Typical Presentation

Tension-type headache

- Both sides of the head
- Often band-like

Migraine

- May be worse on one side

Wojaczyńska-Stanek, 2008, *Journal of Child Neurology*

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Typical Presentation

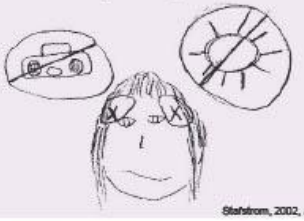
Tension-type headache

- Physical activity may help
- May be sensitive to light or sound, but not both

Wojaczyńska-Stanek, 2008, *Journal of Child Neurology*

Migraine

- Worse with activity
- Nausea, vomiting
- Sensitivity to light AND sound



Stafstrom, 2002, *Pediatrics*

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Typical Presentation: Summary

	Tension-type headache	Migraine
Pain Intensity	+/++	++/+++
Pain Quality	Dull	Pulsating or throbbing
Location of pain	Both sides	One or both sides
Nausea	-	+
Vomiting	-	+
Sensitivity to light and sound	NOT both	Both
Worse with physical activity	-	+

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Migraine Aura

Fully reversible neurological symptoms:

- Visual: dots, zigzags, blurred or distorted vision, blind spots
- Ringing in ears
- Dizziness
- Slurred speech

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Migraine Aura

- 10% of youth with migraine
- Up to 60 minutes before headache
- Typically lasting less than 1 hour



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Managing Headaches

Preventing headaches	Treating headaches
• Lifestyle • Supplements • Medications	• Medications • Environment

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Preventing Headaches

Sleep hygiene

- Regular sleep
- No screen-time 1 hour before bedtime
- 8-11 hours of sleep
- Melatonin can help

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Preventing Headaches

Diet

- **Do not skip meals!**
- 3 meals daily with 1-3 snacks in-between
- High-protein breakfast within 1 hour of waking

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Preventing Headaches

Diet

- **Avoid caffeine!**

8-ounce cup of coffee	8-ounce can of energy drink	12-ounce can of soda	8-ounce cup of tea
			
80-100 milligrams	40-250 milligrams	30-40 milligrams	30-50 milligrams

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Preventing Headaches

Physical activity

- 30 minutes of moderate to vigorous physical activity every day
- Moderate: talk, but not sing
- Vigorous: only say a few words

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Preventing Headaches

Supplements: Magnesium

Membrane stabilizer

Dose:
9 mg/kg/day of elemental Mg
divided into 2-3 daily doses

Side effects:
Diarrhea at higher doses – if persistent reduce dose

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Preventing Headaches

Supplements: Riboflavin (Vitamin B2)

Reduces oxidative stress and inflammation of nerves

Dose:
200 – 400 mg
once per day

Side effects:
Bright yellow or orange urine (not harmful)

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Preventing Headaches

Supplements: Coenzyme Q10

Improves the energy metabolism of brain cells

Dose:
1-3 mg/kg
once per day

Side effects:
Upset stomach - take with food

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Preventing Headaches

Supplements: Frequently Asked Questions

Should I start all 3 supplements at the same time? If not, which one should I start first?

You can start all 3 at the same time, but you don't have to.

Consider your personal needs:

Mg	B2	CoQ10
• Least expensive • Can help with constipation, muscle aches	• More expensive $8-18/month	• Most expensive $25 – 40/month

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Preventing Headaches

Supplements: Frequently Asked Questions

I calculated my dose, but it doesn't exist.

What should I do?

Round down and/or speak to the pharmacist.

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Preventing Headaches

Supplements: Frequently Asked Questions

What type of Mg should I take?

- Glycinate recommended
- If you can't find glycinate, oxide is a good alternative
- Citrate not recommended

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Preventing Headaches

Supplements: Frequently Asked Questions

What time of day should I take supplements?

Mg	First dose in the morning or early afternoon Second dose at bedtime
B2	Does not matter
CoQ10	Morning

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Preventing Headaches

Supplements: Frequently Asked Questions

When can I expect to notice an improvement?

1 to 3 months

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Preventing Headaches

Medications

No clear-cut evidence for medications to prevent headaches in children (only for adults)

- Amitriptyline
- Topiramate
- Beta-blockers (e.g. propranolol)

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Preventing Headaches

Medications

CGRP-inhibitors

- Approved for adults
- Ongoing studies in children
  - Subcutaneous injection every 4 weeks:
    - Fremanezumab, Erenumab
  - Oral disintegrating tablet every other day:
    - Rimegepant

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Preventing Headaches

Medications

Botox

- Approved for adults
- Used off-label for teenagers
- 31 intramuscular scalp injections
- Every 4 months

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Treating Headaches

Ibuprofen (Advil®, Motrin®)

Dose:
10 mg/kg/dose (max. 800 mg/dose)
repeat every 6 hours

Total per day:
40 mg/kg/day (max. 3,200 mg/day)

Side effects:
Upset stomach (ideally take with food)

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Treating Headaches

Acetaminophen (Tylenol®)

Dose:
15 mg/kg/dose (max. 1,000mg/dose)
repeat every 4 hours

Total per day:
75 mg/kg/day (max. 4,000mg/day)

Side effects:
Upset stomach (ideally take with food)

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Treating Headaches

Naproxen (Aleve®)

Dose:
5-7 mg/kg per dose (max 500 mg/dose)
repeat every 8-12 hours

Total per day:
10 mg/kg/day (max 1000 mg/day)

Side effects:
Upset stomach (ideally take with food)

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Treating Migraines

Triptans

Prescription acute migraine medication

- Oral tablets, nasal spray
- Almotriptan (Axert®)[Δ]
- Rizatriptan (Maxalt®)
- Sumatriptan (Imitrex®)
- Zolmitriptan (Zomig®)

[Δ] approved for children

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Treating Migraine

Nausea associated with migraine

Dimenhydrinate (Gravol ®)

Dose:
50 to 100 mg
repeat every 4-6 hours

Total per day:
max 400 mg/day

Side effects:
Drowsiness

Ondansetron

Prescription only

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Treating Headaches

Timing of medication

When?

- The earlier the better!
- No later than 1 hour after onset

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Treating Headaches

Medication overuse headaches

Headaches from taking pain medication too often

- Do NOT use pain medications on more than 14 days per month.
- Do NOT use triptans on more than 9 days per month.

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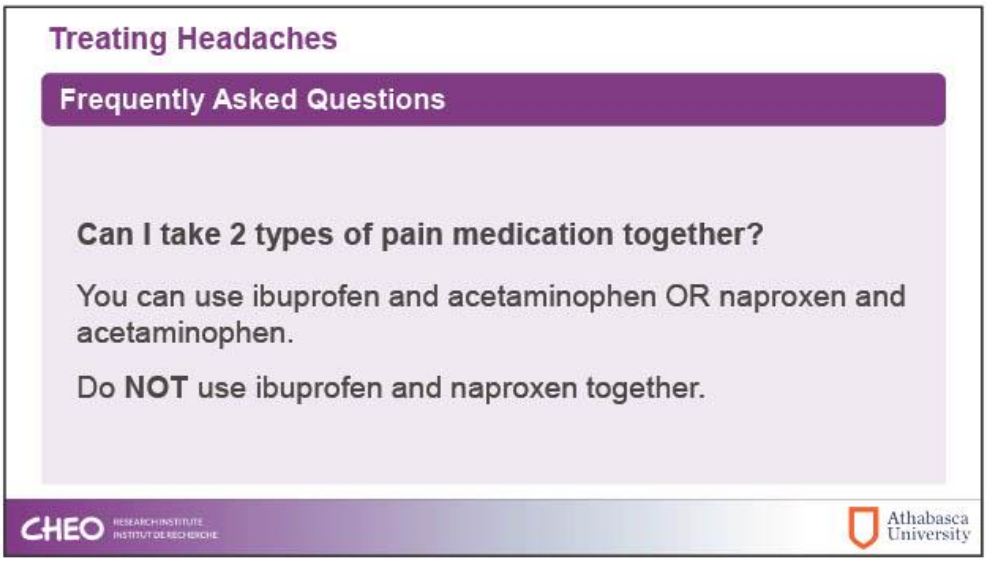
Treating Headaches
Frequently Asked Questions
Can I take 2 types of pain medication together?
You can use ibuprofen and acetaminophen OR naproxen and acetaminophen.
Do NOT use ibuprofen and naproxen together.
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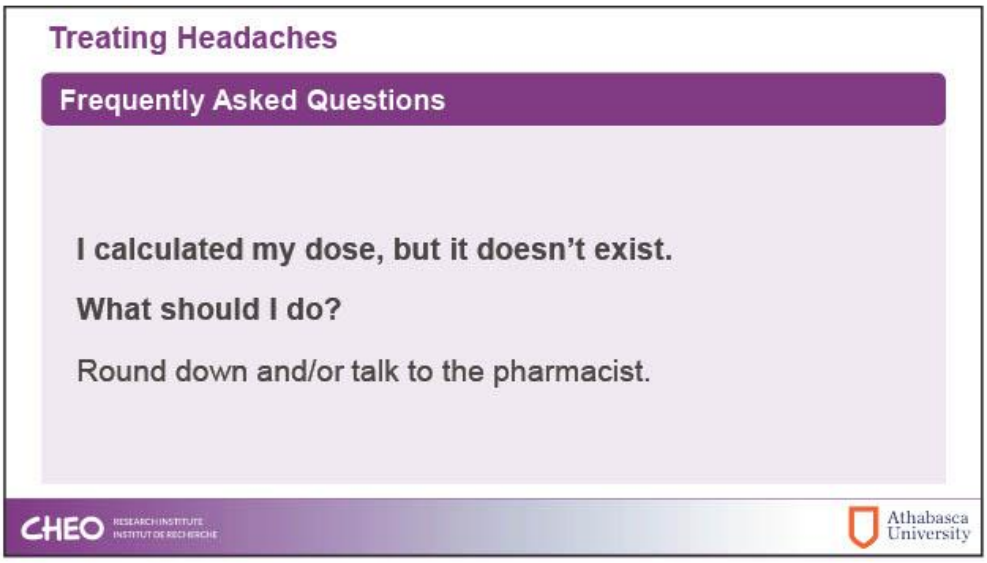
Treating Headaches
Frequently Asked Questions
I calculated my dose, but it doesn't exist.
What should I do?
Round down and/or talk to the pharmacist.
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Treating Headaches

Frequently Asked Questions

I think I overuse medication. How long after I stop will I see an improvement?

Expect a 2–10 day withdrawal period.

Start before a weekend or holiday.

Improvement within 2-6 weeks.

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Headache Diary

Why is it important?

- Identify triggers
- Provide your doctors with accurate information
- Prevention strategies working?
- Avoid medication overuse

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Headache Diary

What information is important?

- **Whether you had a headache**
- Type of headache
- Duration
- Pain intensity
- Medications taken and response
- Associated symptoms
- Triggers

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Headache Diary

Where should you track your headaches?

Electronic:

- Canadian Migraine Tracker
- Migraine Buddy

Canadian Migraine Tracker

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Headache Diary

Where should you track your headaches?

On paper: Headache diary in your portfolio

DATE	START TIME	DURATION		SEVERITY (0-10)	ASSOCIATED SYMPTOMS					MEDICATION TAKEN	NOTES
		< 4 hrs	> 4 hrs		N	V	StL	StS	Wpa		
12	2 pm	X		8	X		X	X		Sumatriptan	Medication provided some relief.

< = less than, > = greater than, N = nausea, V = vomiting, StL = Sensitivity to Light, StS = Sensitivity to Sound, Wpa = Worse with physical activity

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Prepare for your Consultation

- Complete follow-up questionnaires (in 2 weeks via email)
- Complete headache diary- at least 1 month
- Complete “My Medication History” worksheet
- Trial supplements
- Bring all medication and supplement bottles
- Write down your questions

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Prepare for your Consultation Appointment

My Medication History worksheet

INSTRUCTIONS: INCLUDE ALL CURRENT MEDICATIONS (FOR ANY INDICATION) AND ALL PAST MEDICATIONS YOU HAVE TAKEN FOR HEADACHE. INCLUDE MEDICATIONS TO PREVENT HEADACHES AND TO TREAT HEADACHES ONCE THEY HAVE ALREADY STARTED. IF YOU HAVE TAKEN THE SAME MEDICATION AT DIFFERENT DOSES, MAKE A NEW FOR EACH DOSE.

BRING THIS WITH YOU TO YOUR CONSULTATION APPOINTMENT

MEDICATION	INDICATION	DOSE	FREQUENCY	START DATE	STOP DATE	NOTES
Amitriptyline	*Headache prevention*	*20 mg*	*Daily*	*19 Oct 2023*		*Currently taking, a little bit helpful.*
Amitriptyline	*Headache prevention*	*10 mg*	*Daily*	*15 Aug 2023*	*18 Oct 2023*	*Increased dose because it was not helping at this dose.*
Advil	*Headache treatment*	*600 mg*	*As needed*	*Sep 2022*		*Helps sometimes*
Tylenol	*Headache treatment*	*800 mg*	*As needed*	*Sep 2022*		*Helps sometimes*

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We value your feedback!

Satisfaction Survey

QR code to anonymous satisfaction survey on REDCap will be placed here.

REDCap URL to anonymous satisfaction survey on REDCap will be placed here.

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HEADACHE WORKSHOP

Part 2: Managing Headaches

Facilitators: Name 1
Name 2

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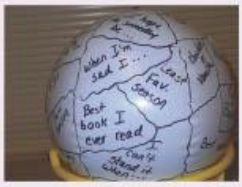
Icebreaker Activity

Talking Ball Toss



Toss the ball to someone in the room.

Catcher:

State your name,

answer the question closest to your right thumb,

and toss the ball to someone else.

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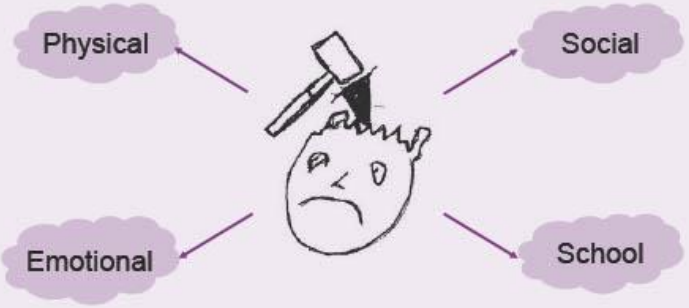
Recognizing the impact of headaches

Headaches can affect many aspects of your life…



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Headaches and mental health

More likely to have symptoms of anxiety and depression, and thoughts of suicide

Anxiety	Depression
• Feeling restless or on edge	• Feeling hopeless
• Being irritable	• Loss of interest in activities
• Difficulty concentrating	• Feeling worthless
• Difficulty sleeping	• Self-criticism

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Headaches and mental health

Resources

1Call1Click.ca

- Match youth with the right mental health support
- Answer questions about mental health services
- Self referral (online or by phone)

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Headaches and mental health

Resources

Kids Help Phone – Texting

Text CONNECT To 686868

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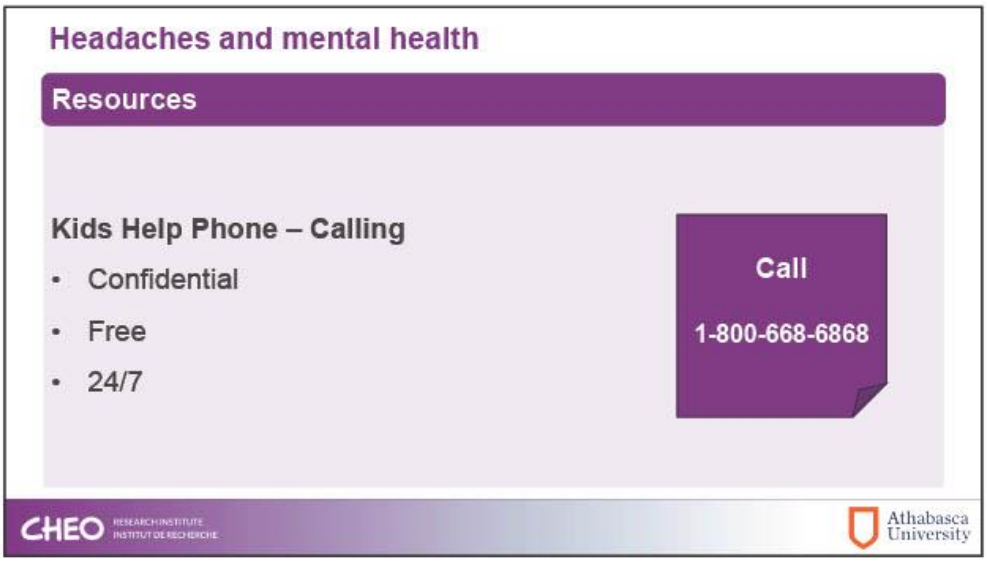
Headaches and mental health
Resources
Kids Help Phone – Calling
• Confidential
• Free
• 24/7
Call
1-800-668-6868
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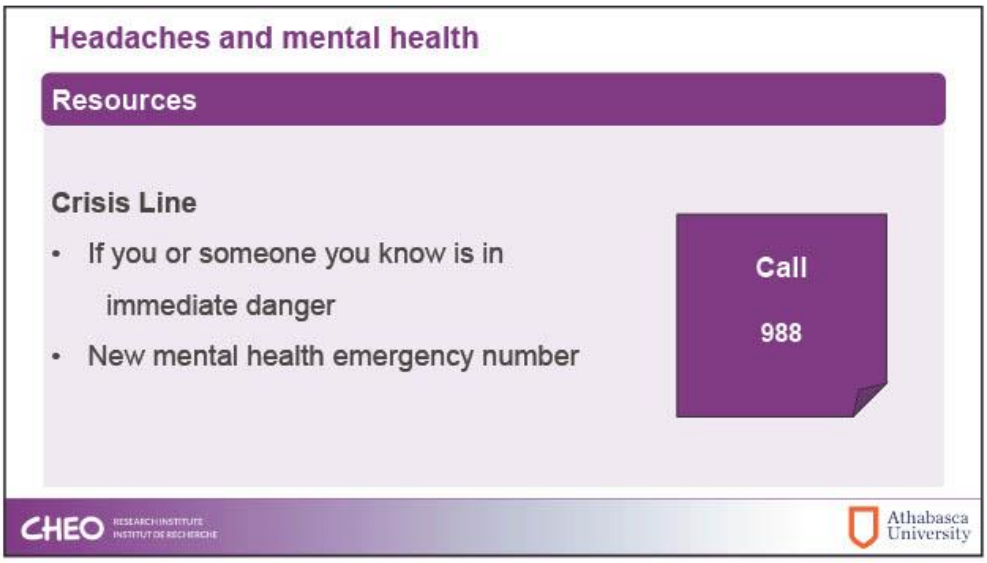
Headaches and mental health
Resources
Crisis Line
• If you or someone you know is in immediate danger
• New mental health emergency number
Call
988
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Coping with Headaches

Develop a support system

Parents

Teachers

Coaches

Siblings

Friends

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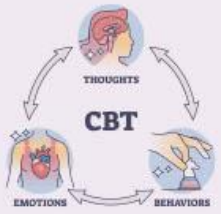
Coping with Headaches

Managing stress and anxiety

It's important to learn to cope with stress and anxiety.

Cognitive behavioural therapy (CBT)

- Our **thoughts** influence how we **feel** which influences how we **act**.



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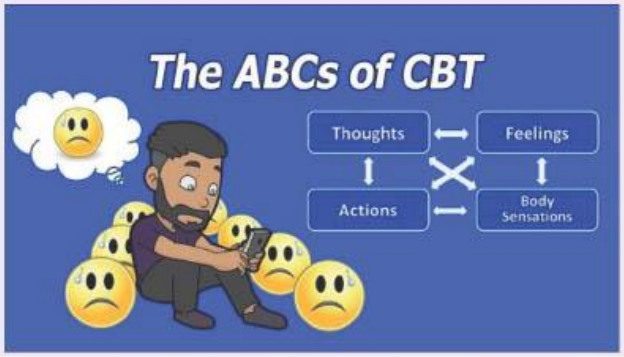
Coping with Headaches

Cognitive Behavioural Therapy



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Coping with Headaches

CBT Resources: MindShift® App

MindShift® CBT

- Free
- Evidence-based anxiety relief
- Developed by Anxiety Canada
- Available on IOS and Android

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Coping with Headaches

CBT Resources: BounceBack® (15 – 17 years)

BounceBack® Coaching

- Free
- Work with a trained coach
- Up to six telephone sessions

Canadian Mental Health Association
Mental health for all

BounceBack® Today Videos

- Online video series
- Pick and choose topics

BounceBack®
reclaim your health

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Case Scenarios

Discuss with the people next to you!

We are now going to go through 6 case scenarios. Please discuss with the people next to you and share your thoughts with us.

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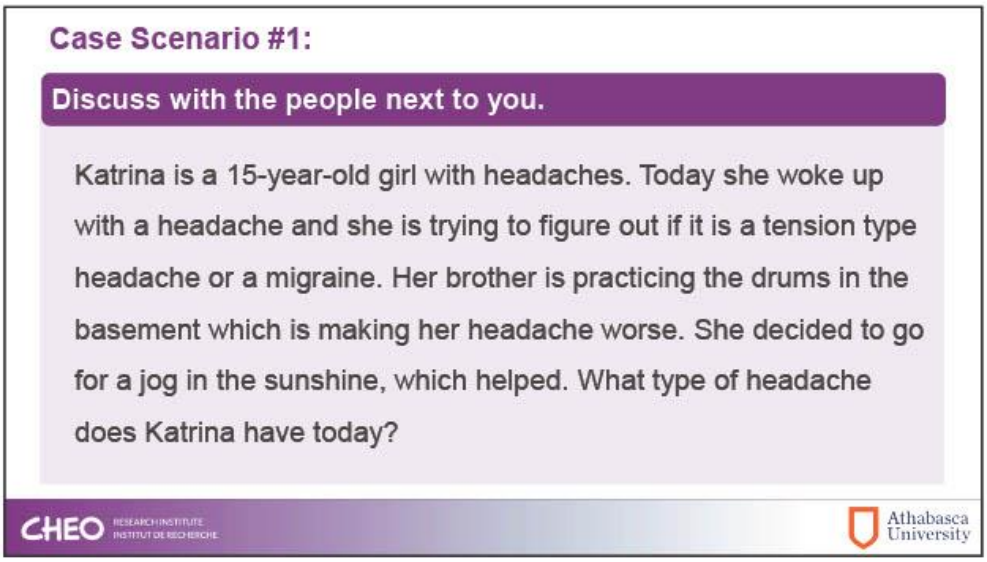
Case Scenario #1:
Discuss with the people next to you.
Katrina is a 15-year-old girl with headaches. Today she woke up with a headache and she is trying to figure out if it is a tension type headache or a migraine. Her brother is practicing the drums in the basement which is making her headache worse. She decided to go for a jog in the sunshine, which helped. What type of headache does Katrina have today?
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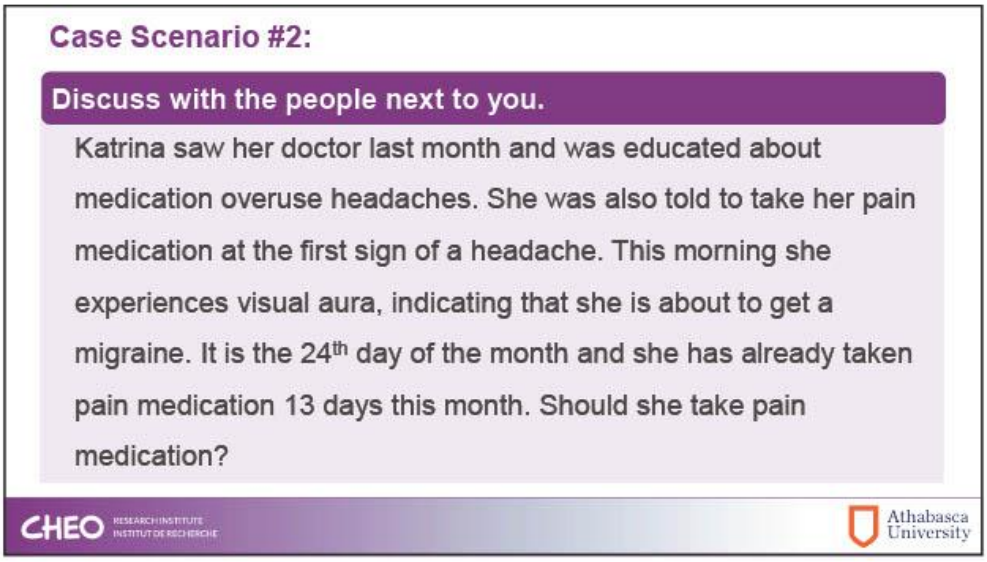
Case Scenario #2:
Discuss with the people next to you.
Katrina saw her doctor last month and was educated about medication overuse headaches. She was also told to take her pain medication at the first sign of a headache. This morning she experiences visual aura, indicating that she is about to get a migraine. It is the 24th day of the month and she has already taken pain medication 13 days this month. Should she take pain medication?
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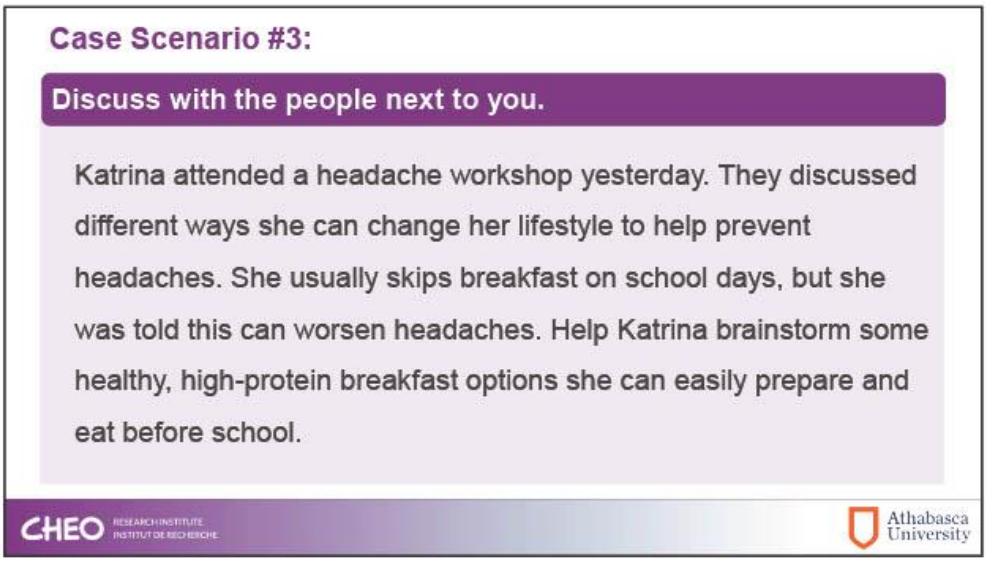
Case Scenario #3:
Discuss with the people next to you.
Katrina attended a headache workshop yesterday. They discussed different ways she can change her lifestyle to help prevent headaches. She usually skips breakfast on school days, but she was told this can worsen headaches. Help Katrina brainstorm some healthy, high-protein breakfast options she can easily prepare and eat before school.
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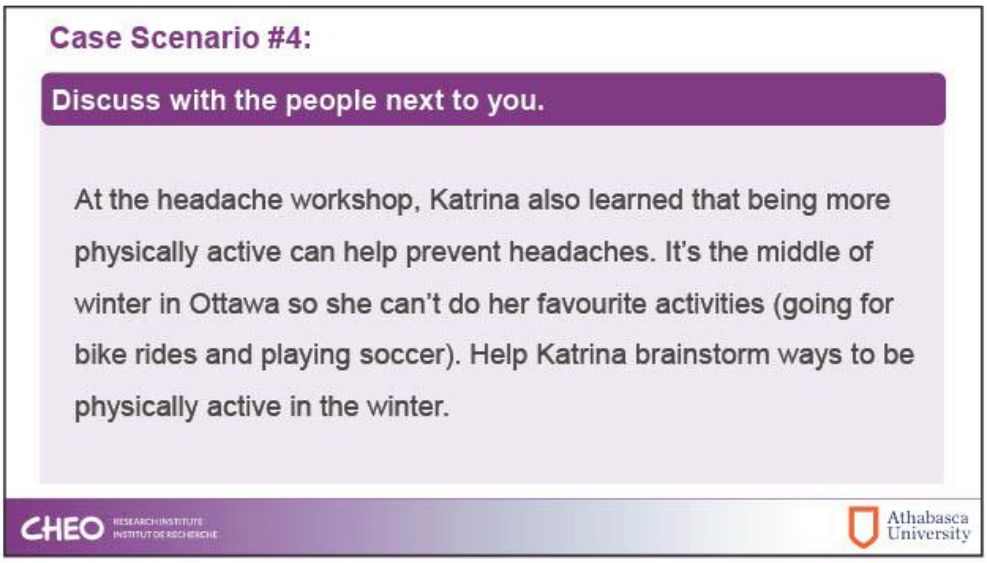
Case Scenario #4:
Discuss with the people next to you.
At the headache workshop, Katrina also learned that being more physically active can help prevent headaches. It's the middle of winter in Ottawa so she can't do her favourite activities (going for bike rides and playing soccer). Help Katrina brainstorm ways to be physically active in the winter.
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Case Scenario #4:
Physical activities in the winter
• Snowboard, ski, skate, toboggan
• Indoor rock climbing
• Dance
• Shovel snow
• Swimming
• Indoor sports: volleyball, basketball
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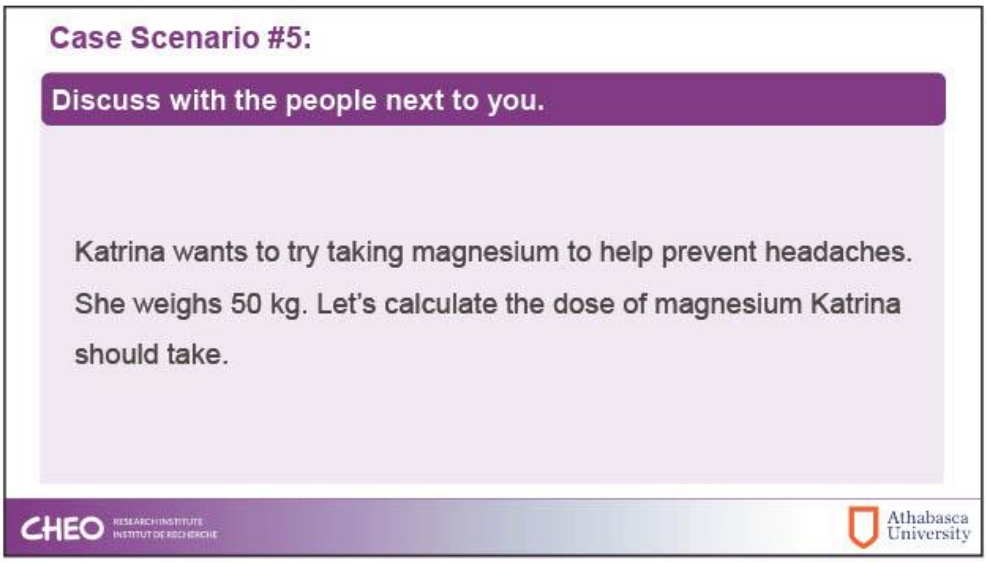
Case Scenario #5:
Discuss with the people next to you.
Katrina wants to try taking magnesium to help prevent headaches. She weighs 50 kg. Let's calculate the dose of magnesium Katrina should take.
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Case Scenario #5:

Discuss with the people next to you.

Dose = 9 mg/kg/day of elemental Mg divided into 3 daily doses

9 mg × 50 kg = 450 mg per day

450 mg ÷ 3 = 150 mg 3 times per day

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Case Scenario #6:

Discuss with the people next to you.

Katrina often forgets to take daily medications. Brainstorm some ways that she can remind herself to take the magnesium three times a day.

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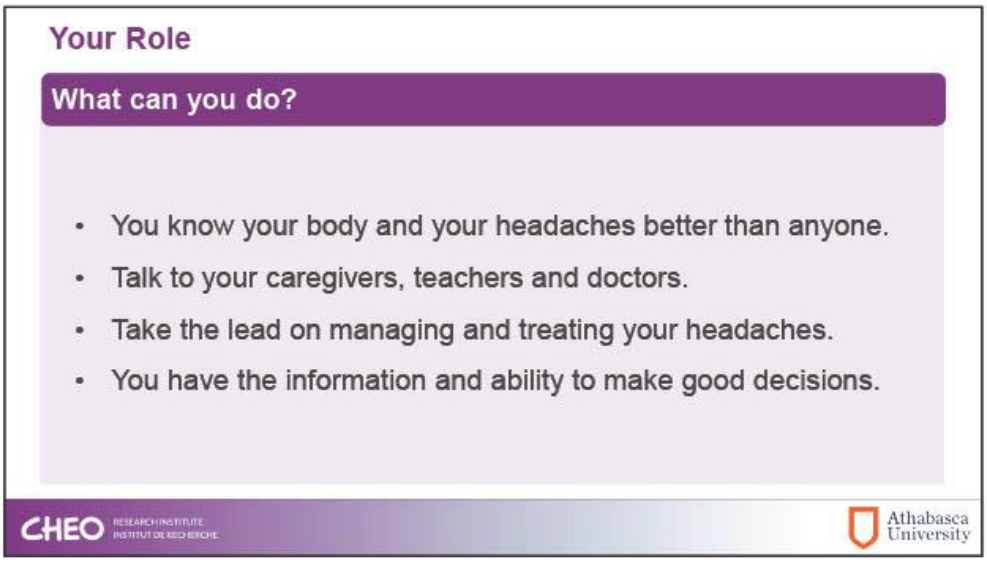
Your Role
What can you do?
• You know your body and your headaches better than anyone.
• Talk to your caregivers, teachers and doctors.
• Take the lead on managing and treating your headaches.
• You have the information and ability to make good decisions.
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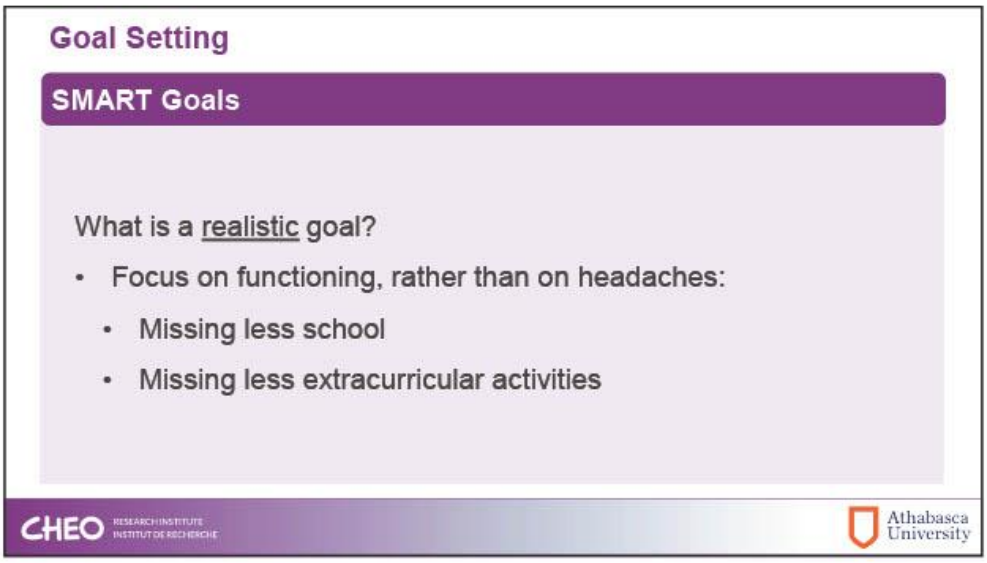
Goal Setting
SMART Goals
What is a realistic goal?
• Focus on functioning, rather than on headaches:
• Missing less school
• Missing less extracurricular activities
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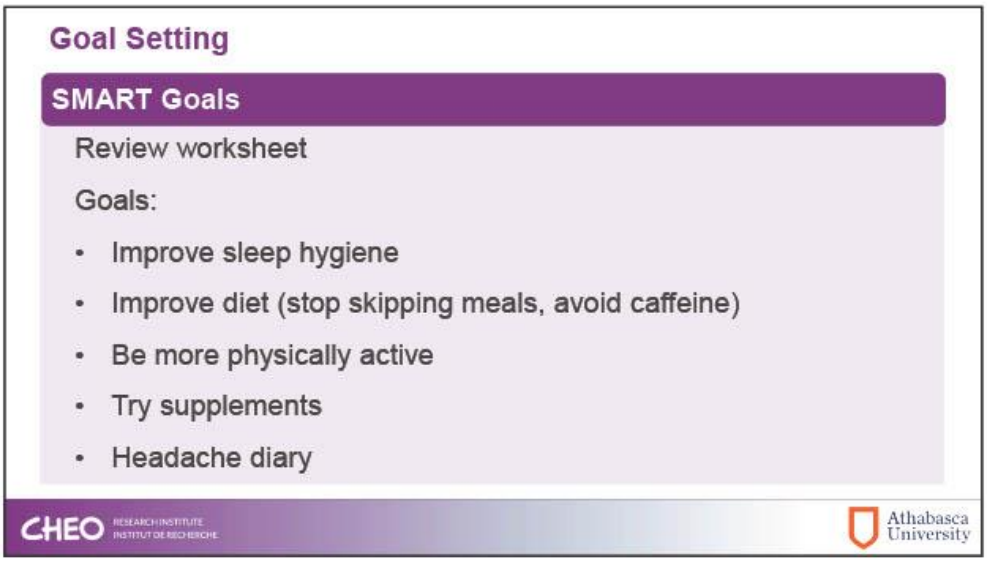
Goal Setting
SMART Goals
Review worksheet
Goals:
• Improve sleep hygiene
• Improve diet (stop skipping meals, avoid caffeine)
• Be more physically active
• Try supplements
• Headache diary
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Appendix C: Anonymous Satisfaction Survey

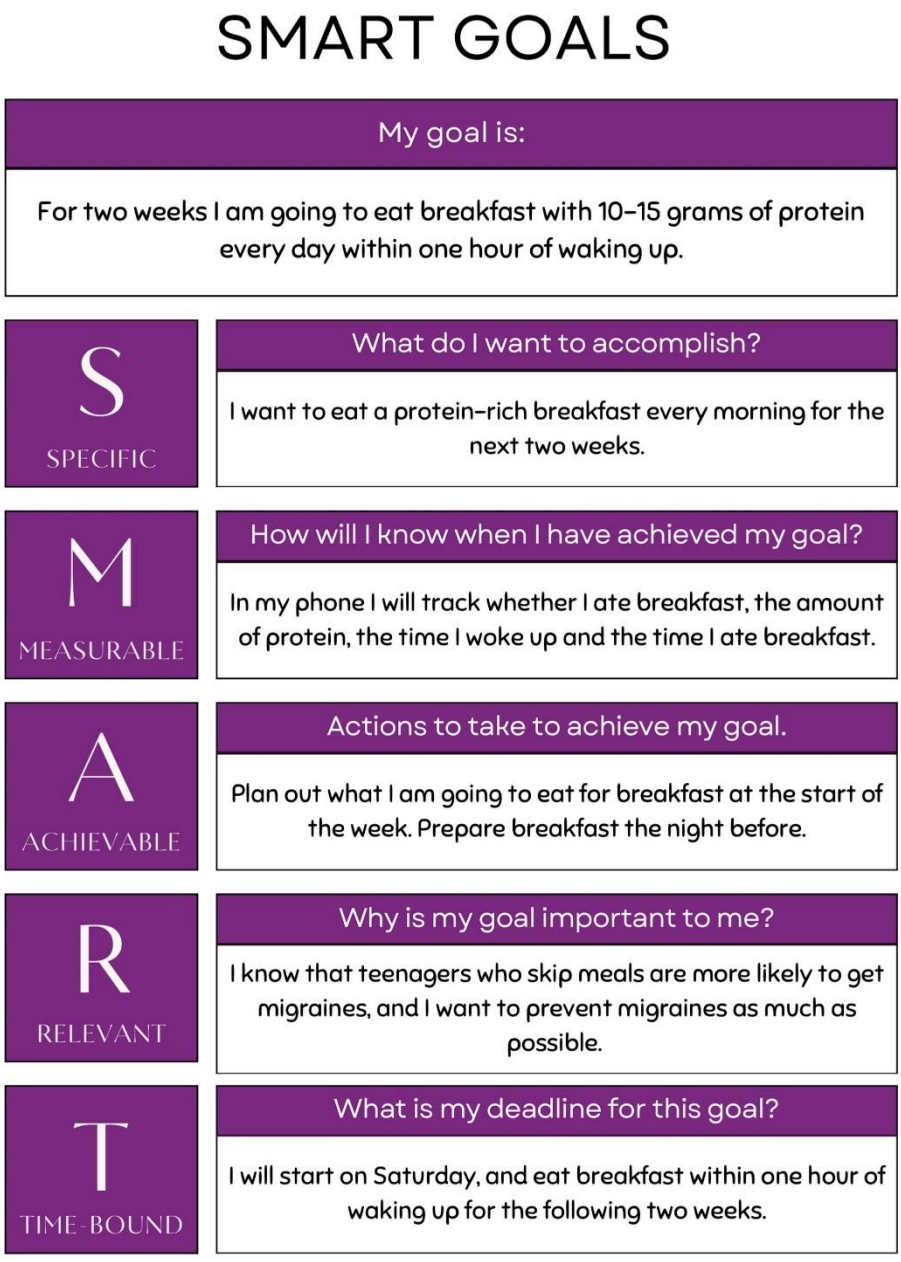
Satisfaction Survey

1. I am a:
   - ❑ Patient
   - ❑ Parent/guardian/caregiver

2. How satisfied were you with the headache self-management workshop?
   - ❑ Very satisfied
   - ❑ Somewhat satisfied
   - ❑ Neither satisfied nor dissatisfied
   - ❑ Somewhat dissatisfied
   - ❑ Very dissatisfied

3. What else would you like to share with us about your experience?

Appendix D: Participant Materials



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SMART GOALS

My goal is:

S SPECIFIC	What do I want to accomplish?
M MEASURABLE	How will I know when I have achieved my goal?
A ACHIEVABLE	Actions to take to achieve my goal.
R RELEVANT	Why is my goal important to me?
T TIME-BOUND	What is my deadline for this goal?

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MY HEADACHE DIARY

MONTH:_____ **YEAR:**_____

DATE	START TIME	DURATION		SEVERITY (0-10)	ASSOCIATED SYMPTOMS					MEDICATION TAKEN	NOTES
		< 4 hrs	> 4 hrs		N	V	StL	StS	Wpa		
12	*2 pm*	*X*		*8*	*X*		*X*	*X*		*Ibuprofen*	*Medication provided some relief.*

< = less than, > = greater than, N = nausea, V = vomiting, StL = Sensitivity to Light, StS = Sensitivity to Sound, Wpa = Worse with physical activity

MY HEADACHE DIARY

MONTH:_____ YEAR:_____

DATE	START TIME	DURATION		SEVERITY (0-10)	ASSOCIATED SYMPTOMS					MEDICATION TAKEN	NOTES
		< 4 hrs	> 4 hrs		N	V	StL	StS	Wpa		

< = less than, > = greater than, N = nausea, V = vomiting, StL = Sensitivity to Light, StS = Sensitivity to Sound, Wpa = Worse with physical activity

MY MEDICATION HISTORY

NAME: _____

INSTRUCTIONS: INCLUDE ALL CURRENT MEDICATIONS AND SUPPLEMENTS (FOR ANY INDICATION) AND ALL PAST MEDICATIONS AND SUPPLEMENTS YOU HAVE TAKEN FOR HEADACHE. INCLUDE MEDICATIONS AND SUPPLEMENTS TO PREVENT HEADACHES AND TO TREAT HEADACHES ONCE THEY HAVE ALREADY STARTED. IF YOU HAVE TAKEN THE SAME MEDICATION OR SUPPLEMENT AT DIFFERENT DOSES, MAKE A NEW FOR EACH DOSE.

BRING THIS WITH YOU TO YOUR CONSULTATION APPOINTMENT

MEDICATION	INDICATION	DOSE	FREQUENCY	START DATE	STOP DATE	NOTES
Amitriptyline	*Headache prevention*	*20 mg*	*Daily*	*19 Oct 2023*		*Currently taking, a little bit helpful.*
Amitriptyline	*Headache prevention*	*10 mg*	*Daily*	*15 Aug 2023*	*18 Oct 2023*	*Increased dose because it was not helping at this dose.*
Advil	*Headache treatment*	*600 mg*	*As needed*	*Sep 2022*		*Helps sometimes*
Tylenol	*Headache treatment*	*800 mg*	*As needed*	*Sep 2022*		*Helps sometimes*
Vitamin D	*General health*	*1000 IU*	*Daily*	*1 Sep 2023*		
Magnesium	*Headache prevention*	*600 mg*	*Three times per day*	*1 Aug 2023*		*Not sure if helping or not.*

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MY MEDICATION HISTORY

NAME: _____

INSTRUCTIONS: INCLUDE ALL CURRENT MEDICATIONS AND SUPPLEMENTS (FOR ANY INDICATION) AND ALL PAST MEDICATIONS AND SUPPLEMENTS YOU HAVE TAKEN FOR HEADACHE. INCLUDE MEDICATIONS AND SUPPLEMENTS TO PREVENT HEADACHES AND TO TREAT HEADACHES ONCE THEY HAVE ALREADY STARTED. IF YOU HAVE TAKEN THE SAME MEDICATION OR SUPPLEMENT AT DIFFERENT DOSES, MAKE A NEW FOR EACH DOSE.

BRING THIS WITH YOU TO YOUR CONSULTATION APPOINTMENT

MEDICATION	INDICATION	DOSE	FREQUENCY	START DATE	STOP DATE	NOTES

Mental Health Community Resources

Support at CHEO

- **CHEO's centralized Intake Service**
- **Social Worker attached to the Neurology Clinic**

Youth Service Bureau (www.ysb.ca| 613-729-1000)

Intensive Family Support (supports families with youth (aged 12-18) who are at risk of out-of-home placement to foster care, a group hoe, or a correctional facility)

- **Contact:** Michelle Earle | mearle@ysb.ca | 613-288-1588 ext. 227

Wraparound Ottawa (works with existing supports and services to help families, children, and youth find solutions and work towards a better life.

- **Contact:** Michelle Earle | mearle@ysb.ca | 613-288-1588 ext. 227

Youth Mental Health Walk-In Clinic

- **Hours:** Tuesdays and Thursdays, 12 noon to 8 pm (last session is at 6 pm)
- **Contact:** counselling@ysb.on.ca | 613-562-3004 | 2301 Carling Avenue (2nd floor)

Youth and Family Counselling

- **Contact:** 613-562-3004

The Counselling Group (http://thecounsellinggroup.com/services/)

- Counselling for children and youth aged 3-18
- Clients may self-refer or be referred by others. All inquiries about counselling will be directed to the Director of Counselling Services or to the Intake Worker, who will assist with service options.

Youth Net (http://ynra.ca/)

- Focus and support groups to talk about mental health issues and healthy ways they can make changes in their life and in the mental health system.

App: Toutematete | healthyminds (http://www.healthymindsapp.ca/)

- Created by the Royal Ottawa and D.I.F.D.
- Self-help app to help students guide themselves through stressors and sad points
- Provides information and proposes solutions

Walk-In Clinics in Ottawa – No Appointments or referral necessary

Catholic Family Services (Non-denominational) (www.cfsottawa.ca | 613-233-8478 | 310 Olmstead)

- **Hours:** Thursdays 12 noon to 8:00 pm (last walk-in session is at 6:30 pm)
  Fridays 12 noon to 5:00 pm (last walk-in session is at 3:30 pm)

Family Services Ottawa (www.familyservicesottawa.org | 613-725-3601 | 312 Parkdale Ave)

- **Hours:** Thursdays 12 noon to 8:00 pm (last walk-in session is at 6:30 pm)
  Saturdays: 12 noon to 5:00 pm (last walk-in session is at 3:30 pm)

Jewish Family Services of Ottawa (Non-sectarian) (www.jfsottawa.com | 613-722-2225 | 300-2255 Carling Ave

- **Hours:** Wednesdays 12 noon to 8:00 pm (last walk-in session is at 6:30 pm)
  Sundays 12 noon to 5:00 pm (last walk-in session is at 3:30 pm)

Somerset West Community Health Centre (English and Chinese only) (55 Eccles St)

- **Hours:** Tuesdays 11:00 am to 5:30 pm (last walk in session at 4:00 pm)

these above organizations also offer scheduled counselling for a sliding fee

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Mental Health Community Resources

Other Counselling Services (Fees for service)

- **Christian Counselling Ottawa (www.christiancounsellingottawa.ca)**
  Contact: 613-729-8454 Ext. 0 (Sliding fee scale)
- **Cornwall and area: Child and Youth Counselling Services (CYCS)-ENGLISH ONLY**
  Cornwall Community Hospital provides assessment, therapy, and counselling.
  Contact: 613-932-1558
  Limited outreach services in Winchester office
- **Lanark County: Open doors for Lanark Children and Youth (www.opendoors.on.ca)**
  Contact: 613-283-8260
  Offices in Carleton Place, Smith Falls, and Perth
- **Leeds and Grenville County: Children's Mental Health of Leeds and Grenville (www.cmhlg.ca)**
  Contact: 613-498-4844
  Offices in Brockville, Elgin, Gananoque, and Prescott
- **Ottawa University – Centre for Psychological Services and Research**
  (http://socialsciences.uottawa.ca/psychology/centre-psychological-services-research)
  Contact: 613-562-5289
- **Renfrew County: Phoenix Centre for Children, Youth, and Families (https://phoenixctr.com/)**
  Contact: 613-735-2374 | 1-800-1870
  Offices in Renfrew and Pembroke
- **Stormont, Dundas, Glengarry, and Akwesasne (Cornwall Island): Single Point Access**
  For all child, youth, family, and mental health services
  Contact: 613-938-9909 | 1-888-286-5437
  Satellite offices in Winchester
- **St. Paul's University Counselling Centre (https://ustpaul.ca/en/counselling-and-psychotherapy-centre-home_360_120.htm)**
  Contact: 613-782-3022 | counselling@ustpaul.ca

Crisis Lines

- **Youth Service Bureau** (613-230-2360 | 1-877-377-7775)
  There is also a 24/7 online chat at https://www.ysb.ca/services/ysb-mental-health/24-7-crisis-line/
- **Kids Help Phone** (1-800-668-6868)
- **Mental Health Crisis Line 16+ year olds** (613-722-6914 | 1-866-966-0991)
- **Distress Centre of Ottawa** (613-238-3311 | www.dcottawa.on.ca)

Community Resources – Specific for Individuals with Cognitive Impairment

- **Citizen Advocacy of Ottawa** (613-230-6305 | info@citizenadvocacy.org)
  Everyday Champions: Provides youth with disabilities one-on-one, long term supportive relationship.
- **Coordinated Access** (www.coordinatedaccess.ca | 613-729-0577 Ext. 251)
  Helps determine the best course of care for youth with complex needs.
- **Roberts/Smart Centre** (www.robertssmartcentre.com)
  Contact: 613-728-1946 | info@rsc-crs.com | 1199 Carling Ave
  Serving specifically high needs adolescents
  * Group psychotherapy are also available on a fee-for-service basis
- **Service Coordination** (https://scsonline.ca | 613-748-1788)
  Community-based support for children and youth (<18 y.o) who have developmental delay

Version: 17 Jan 2024

Therapeutic Management of an Acute Migraine Attack in Pediatrics (6-17 years)

International Classification of Headache Disorders diagnostic criteria for migraine

- Must have had at least 5 headaches
- The headache must last 2-72 hours long

The headache must have **ONE** of the following:

- Nausea **AND/OR** vomiting
- Light **AND** noise sensitivity

The headache must have **TWO** out of the 4 criteria:

- Pain that is unilateral or bilateral (typically frontotemporal)
- Pulsating quality
- Moderate or severe pain
- Worsened by, or causes avoidance of routine physical activity

Rules of treatment

1. Treat early, as soon as the attack starts.
2. Repeat 1 dose prn within 24h if attack persists after 1st dose in appropriate interval.
3. Maximum doses: 2 days/week for triptans; 3 days/week for NSAIDs.
4. For patients with a lot of emesis/early emesis, consider nasal spray or ODT format.
5. Medications from different classes may be used in combination.

Recommendations

Non-specific treatment of migraine attacks

TREATMENT	DOSAGE	INTERVAL	MAXIMUM
Ibuprofen	10 mg/kg/dose	q6-8h prn	600 mg/dose, 40 mg/kg/day or 2400 mg/day
Naproxen	5-7 mg/kg/dose	q8-12h prn	500 mg/dose, 10 mg/kg/day or 1000 mg/day
Acetaminophen	15 mg/kg/dose	q4-6h prn	1000 mg/dose, 75 mg/kg/day or 4000 mg/day

Specific treatment of migraine attacks for patients

TREATMENT	DOSAGE	INTERVAL	MAXIMUM	
Rizatriptan Tablets & ODT	< 40 kg: 5 mg ≥ 40 kg: 10 mg	Can repeat in 2 hours, max 2 doses/24 hours	< 40 kg: 10 mg ≥ 40 kg: 20 mg	5 mg ODT approved by FDA for ≥ 6 yo
Zolmitriptan Tablets, ODT & nasal spray	< 40 kg: 2.5 mg PO ≥ 40 kg: 5 mg PO	Can repeat in 2 hours, max 2 doses/24 hours	< 40 kg: 5 mg ≥ 40 kg: 10 mg	2.5 mg nasal spray approved by FDA for ≥ 12 yo
Sumatriptan nasal spray	< 40 kg: 5 mg ≥ 40 kg: 20 mg	Can repeat in 2 hours, max 2 doses/24 hours	< 40 kg: 10 mg ≥ 40 kg: 40 mg	10 mg nasal spray approved by European Medicines Agency for ≥12 yo
Almotriptan	< 40 kg: 6.25 mg PO ≥ 40 kg: 12.5 mg PO	Can repeat in 2 hours, max 2 doses/24 hours	< 40 kg: 12.5 mg ≥ 40 kg: 25 mg	6.25 mg and 12.5 mg tablets approved by Health Canada and FDA for ≥ 12 yo
Sumatriptan/Naproxen combined tablet	< 40 kg: Do not use due to the 500mg naproxen dose which is too high ≥ 40 kg: 85mg Sumatriptan/500 mg Naproxen once per day			85/500 mg tablets approved by FDA for ≥ 12 yo

Anti-nausea medication

TREATMENT	DOSAGE	INTERVAL	MAXIMUM
Ondansetron liquid, tablets and ODT	0.15-0.2 mg/kg/dose PO	q8h prn	8 mg/dose
Metoclopramide liquid, tablets	0.1-0.3 mg/kg/dose PO	q6h prn	10 mg/dose
Prochlorperazine tablets and suppositories	0.1 mg/kg/dose PO/PR	q6-8h prn	10 mg/dose

PeCaHN CHEO Migraine Canada

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1

Over-the-counter preventive treatment

TREATMENT	DOSAGE	INTERVAL	MAXIMUM
Magnesium (elemental)	9 mg/kg/day	BID or qHS	600 mg/day
Coenzyme Q10 or ubiquinol	1-3 mg/kg/day	Daily to BID	200 mg/day
Vitamin B2 (riboflavin)	200-400 mg/day	Daily to BID	400 mg/day

Pharmacological preventive treatment

TREATMENT	DOSAGE	INTERVAL	MAXIMUM
Topiramate	2 mg/kg/day	BID	200 mg/day
Propranolol	2-4 mg/kg/day	TID	120 mg/day
Amitriptyline	1 mg/kg/day	HS	75 mg/day

SUGGESTIONS FOR PREVENTIVE TREATMENT

1. Therapeutic trials should be a minimum of 6-8 weeks at the target dose.
2. Titration of pharmacologic preventive interventions to the target dose should start low and go slow, over 4-8 weeks.
3. Screen for contraindications to treatments prior to starting them.
4. Treatment decisions need to be individualized based on the patient's preferences and medical profile.

SELF-MANAGEMENT RECOMMENDATIONS

Non-pharmacological recommendations for daily headache prevention

Exercise
- Moderate to high intensity physical exercise 30 minutes to 60 minutes a day.

Sleep
- Establish a regular sleep routine (consistent sleep/wake schedule) and ensure adequate amounts of sleep. Avoid screens and other stimulating activities 1 hour prior to sleep.

Food and Diet
- Regular meals and fluid intake throughout the day (goal of 8 cups of water/day) is recommended.
- Avoid skipping meals; include protein rich foods in every meal.
- Limit or reduce the amount of caffeine in the diet to avoid caffeine withdrawal headaches. Caffeine includes iced tea, caffeinated soda, energy drinks, chocolate, coffee, tea.
- A small number of people may have specific food triggers (e.g. tyramine, histamine). Triggers can be identified by keeping a headache diary and eliminated if identified.
- It is NOT recommended to undertake multiple elimination diets.

Mind and Body Connection
- Daily mindful exercises (meditation, visualization, deep breathing, biofeedback) and body relaxation techniques (yoga, massage, physiotherapy exercises) can be used for prevention of a headache attack and to lower pain/prevent escalation of pain during a headache attack.
- Activity pacing is a helpful tool to support patients to stay engaged in daily activities and limit activity avoidance.
- Anxiety and depressive symptoms are common in children and adolescents with migraine. It is recommended to screen for these and ensure that patients have access to resources for mental health support if symptoms are present.

References available at www.migrainecanada.org/Pediatrics

The recommendations and all other information in this leaflet are based on published guidelines and on the expert consensus endorsed by the Pediatric Canadian Headache Network (PeCaHN). The advice is intended solely for insured medical professionals and Migraine Canada expressly disclaims any direct or indirect liability to any patient.

MEDICAL NOTE

Date: _____

To whom it may concern,

_____ has been a patient of mine since _____ and has been diagnosed with _____. This letter is intended to be a formal medical note.

Migraine is a disabling medical condition characterized by attacks of headache and neurological symptoms. The attacks can typically be treated effectively if treated early. Many children and adolescents can identify when a migraine is starting and may request to be allowed to take their medication(s) as prescribed, even if they do not yet appear to be in pain. If they are made to wait until the headache is severe, the medication(s) may not work well, thus resulting in increased school absence and decreased school performance.

There are several symptoms of migraine including head pain, nausea, vomiting, visual changes, dizziness, abdominal upset, and a host of other neurological symptoms such as tingling of the face, arms, or legs. Treatments for migraine include preventive medication, acute medication, and coping techniques such as relaxation and breathing techniques.

When _____ begins to feel the onset of a migraine, acute medication must be taken VERY QUICKLY to prevent worsening and a prolonged headache. It would be helpful if there is somewhere quiet and dark _____ can go to rest for 30 – 60 minutes after taking medication. With successful early treatment of a migraine attack, the goal is that [_____ can return to school activities after this time.

At migraine onset, please administer the following medication(s) as I have prescribed:
1. NSAID: _____
2. TRIPTAN: _____
3. Analgesic: _____
4. Anti emetic: _____

This medical note is valid until the end of the current school year.

If you require any additional information, please contact me at the telephone number or email below. More information on migraine can be found at www.migrainecanada.org.

Thank you. I appreciate your cooperation in helping support children with migraine.

Sincerely,

_____

This medical note is endorsed by:

Migraine Canada

PaCHN

Version: 19 Jan 2024

MEDICAL NOTE

Date: _____

To whom it may concern,

_____ has been a patient of mine since _____ and has been diagnosed with _____ . **This letter is intended to be a formal medical note.**

Migraine is a disabling medical condition characterized by attacks of headache and neurological symptoms. The attacks can typically be treated effectively if treated early. Many children and adolescents can identify when a migraine is starting and may request to be allowed to take their medication(s), even if they do not yet appear to be in pain. If they are made to wait until the headache is severe, the medication(s) may not work well, thus resulting in increased school absence and decreased school performance.

There are several symptoms of migraine including head pain, nausea, vomiting, visual changes, dizziness, abdominal upset, and a host of other neurological symptoms such as tingling of the face, arms or legs. Treatments include preventive medication, acute medication, and coping techniques such as relaxation and breathing techniques.

When _____ begins to feel the onset of a migraine, acute medication must be taken VERY QUICKLY to prevent worsening and a prolonged headache. It would be helpful if there is somewhere quiet and dark _____ can go to rest for 30 – 60 minutes after _____ takes medication. With successful early treatment of a migraine attack, the goal is to return to school activities after this time.

At migraine onset, please administer the following medication(s) as I have prescribed. The name of the medication and dosing is included:

1. NSAID: _____
2. TRIPTAN: _____
3. Analgesic: _____
4. Anti emetic: _____

Migraine can significantly impact school participation in different ways for each individual. In particular, migraine can impact attendance, ability to concentrate, and ability to focus on schoolwork for an extended period of time. It is requested that appropriate accommodations be put in place to ensure a successful school year for _____ . If _____ is having a migraine attack or frequent attacks, they should have a plan in place to help them with school activities at their own pace. Some people may require flexibility for deadlines, extended periods of time for tests, and a quiet space during the school day to take a break or rest. If a student has missed school, they should be supported to help them to catch up at their own pace.

Support from the social worker or guidance counsellor may help [insert name] deal with social and/or academic stressors in school which can be significant triggers for migraine. This type of support may also help [insert name] to develop their own unique individualized plan for school and missed work.

This medical note is valid until the end of the current school year. If you require any additional information, please contact me at the telephone number or email below. More information on migraine can be found at www.migrainecanada.org.

I appreciate your cooperation in helping support children living with migraine.

Sincerely,

This medical note is endorsed by:

Version: 19 Jan 2024

Help with headaches

How to prevent headaches

Proper lifestyle can help prevent headaches before they start

Get better sleep

- Make sure to have regular sleep schedule every day, even on weekends.
- Make the bedroom a screen-free zone for at least one hour before bedtime (this means charging devices overnight in another room!).
- Make sure to get between 8-11 hours of sleep every night.
- Melatonin is a supplement that can be taken before bedtime to help with sleep.
    - Preschool-age: 1 to 2 milligrams
    - School-age: 2 to 3 milligrams
    - Adolescents: 5 milligrams

Keep a balanced diet

- Start your day with a high protein breakfast (yogurt, cheese, and milk are good options) within one hour of waking up — this prevents sudden drops in blood sugar.
- Keep your blood sugar levels stable by eating 3 meals a day with 1-3 snacks in between.
- Include protein, carbohydrates, and vegetables or fruit at each meal.
- Drink plenty of water throughout the day and avoid sugary, or caffeinated beverages like Kool-Aid®, coffee, tea, pre-workout, and energy drinks.

Stay active

- Ensure you have at least 60 minutes of moderate to vigorous physical activity every day.

Learn to manage stress

- Try participating in relaxation exercises like yoga or a mindfulness practice — you can find some suggested apps for mobile devices on our **Headaches resource page.**

Take supplements

+ Magnesium

Dose:

- 9 mg/kg/day of elemental magnesium divided into three daily doses
- Start at a low dose and slowly increase

Available in:

- Capsules (e.g., magnesium glycinate containing 165 mg magnesium) — may be sprinkled on food
- Tablets (e.g., magnesium oxide containing 242 mg magnesium)

Side effects:

- Diarrhea at higher doses — if persistent reduce the dose

+ Coenzyme Q10

Dose:

- 1 to 3 mg/kg/day once a day

Available in:

- Capsules (30 mg, 60 mg) — may be sprinkled on food
- Soft gels (50 mg, 100 mg, 150 mg)

Side effects:

- Upset stomach - take with food

+ Vitamin B2 (Riboflavin)

Dose:

- 50-400 mg once a day

Available in:

- Tablets (50 mg, 100 mg)

Side effects:

- Bright yellow or orange urine - not harmful

How to treat headaches

CHEO

HELP WITH HEADACHES

Medications work best if given at first signs of a headache. Pain medications should not be given on more than 15 days per month to avoid medication overuse headaches.

Let your healthcare provider know if you need to take your medications 3+ times per week or if this plan isn't working.

+ Ibuprophen (Advil®, Motrin®, etc.)

Dose:

- 10 mg/kg/dose (max 800 mg/dose) – may repeat the dose in 6 hours.

Total per day:

- 40 mg/kg/day (max 3200 mg/day)

Available in:

- Tablets, chewable tablets, soft gels, and liquid

Side effects:

- Upset stomach – take with food

+ Acetaminophen (Tylenol®)

Dose:

- 15 mg/kg/dose (max 1000 mg/dose) – may repeat the dose in 4 hours.

Total per day:

- 75 mg/kg/day (max 4000 mg/day)

Available in:

- Tablets, chewable tablets, and liquid

Side effects:

- Upset stomach – take with food

Keep a headache diary

A headache diary will help identify triggers and which treatments are helping you. Please bring your headache diary to your appointments. You can find suggested headache diary apps on our **Headaches resource page.**

#BestLife for every child and youth

2022-09-14 | P6153

Additional Resources

Anonymous Satisfaction & Feedback Survey

https://redcap.cheori.org/surveys/?s=HPWJ7M8X3EMK8NAM
OR
1) **Go to this web address:** https://redcap.cheori.org/surveys/
2) **Then enter this code:** KD4HE37KR

Headache Diary Apps

Canadian Migraine Tracker

https://migrainetracker.ca/

Migraine Buddy

https://migrainebuddy.com/

Cognitive Behavioural Therapy App

MindShift

https://www.anxietycana.da.com/resources/mindshift-cbt/

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Clinical Trials at CHEO

The studies below can be found by searching the ClinicalTrials.gov identifier (NCT followed by 8 numbers), or by scanning the QR code.

Clinical trials have a list of eligibility criteria, which are the key requirements that people who want to participate in a clinical study must meet or the characteristics they must have. Eligibility criteria consist of both inclusion criteria (which are required for a person to participate in the study) and exclusion criteria (which prevent a person from participating).

Some of the eligibility criteria are listed on www.clinicaltrials.gov, however, it is not a complete list. There is a possibility that you will not qualify for the clinical trials.

To learn more about these clinical trials, you can contact the Research Coordinator:
Nicole Whitley
nwhitley@cheo.on.ca
613-737-7600 x 4164

Study Title	ClinicalTrials.gov Identifier	QR Code
A Study to Test if Fremanezumab is Effective in Preventing Chronic Migraine in Patients 6 to 17 Years of Age	NCT04464707	
Efficacy and Safety Study of Rimegepant for the Preventative Treatment of Migraine in Pediatric Subjects	NCT05156398	
Efficacy and Safety of Erenumab in Pediatric Subjects With Chronic Migraine (OASIS(CM))	NCT03832998	
Efficacy and Safety of Erenumab in Pediatric Participants With Episodic Migraine (OASIS(EM))	NCT03836040	

Version: 3 Feb 2024

BounceBack® reclaim your health

Canadian Mental Health Association Ontario

Youth Booklets

Booklet 1. Write all over your bathroom mirror

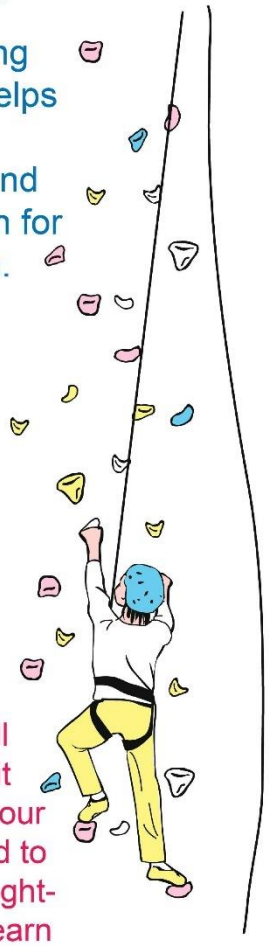
This booklet makes the others work better. Learn 15 great tips on how to work with the other booklets and feel better sooner.

Booklet 2. Why do I feel so bad?

Want to know what makes you tick? This booklet helps you understand how your responses to outside events can affect your thoughts and feelings. It shows how just a single altered thought can lead to sadness, tiredness, and even illness.

Booklet 3. I can't be bothered doing anything

We've all said this to ourselves when feeling down. This booklet helps you break out of the cycle of low activity and sets out a simple plan for getting back in action.



Booklet 4. Why does everything always go wrong?

If that thought sounds familiar, this booklet will teach you how to stop it from taking control of your life. You'll be introduced to the Amazing Bad-Thought-Busting program and learn how to swap bad thoughts for helpful ones.

Version: 23 Feb 2018

Booklet 5. I'm not good enough

How come other people seem so confident? Learn their secrets and get to like yourself again, with practical suggestions about how to build your self-esteem.

Booklet 6. How to fix almost everything

This booklet introduces the Easy 4-Step Plan — a straightforward way to fix your problems and achieve your goals that has worked for thousands of people. Do you know how to go up a climbing wall? This booklet will show you how.

Booklet 7. The things you do that mess you up

When you're feeling low you can start to lean on things to get you through a bad time. This booklet helps you get back in control of hiding away, spending too much time on social media, or watching TV.

Booklet 8. 1, 2, 3, breathe

This booklet teaches you the 1, 2, 3 breathe! system — everything you need to control your temper and improve your happiness and relationships. No complicated terms, no theory, just practical help.

Booklet 9. 10 things you can do to feel happier straight away

The booklet sums everything up and then shows you how to be happier, more active, and able to see the positive side of life every day.

Version: 23 Feb 2018

Appendix E: Outcome Measures

HSES

To create a total HSE score reverse score starred (*) items. Higher scores will be associated with higher self-efficacy. Efforts to create subscales that would yield separate scores for self-efficacy for the prevention of headaches and self-efficacy for the management of headache pain have not proven successful. That is, factor analyses conducted in samples that have been examined to date do not support the existence of separate subscales.

Name _____ **Date** _____

Instructions: You will find below a number of statements related to headaches. Please read each statement carefully and indicate how much you agree or disagree with the statement by circling a number next to it. Use the following scale as a guide:

Strongly Disagree	Moderately Disagree	Slightly Disagree	Neither Agree or Disagree	Slightly Agree	Moderately Agree	Strongly Agree
1	2	3	4	5	6	7

1)	I can keep even a *bad* headache from disrupting my day by changing the way I respond to the pain.	1	2	3	4	5	6	7
2)	When I'm in some situations, nothing I do will prevent headaches.*	1	2	3	4	5	6	7
3)	I can reduce the intensity of a headache by relaxing.	1	2	3	4	5	6	7
4)	There are things I can do to reduce headache pain.	1	2	3	4	5	6	7
5)	I can prevent headaches by recognizing headache triggers.	1	2	3	4	5	6	7
6)	Once I have a headache there is nothing I can do to control it.*	1	2	3	4	5	6	7
7)	When I'm tense, I can prevent headaches by controlling the tension.	1	2	3	4	5	6	7
8)	Nothing I do reduces the pain of a headache.*	1	2	3	4	5	6	7
9)	If I do certain things every day, I can reduce the number of headaches I will have.	1	2	3	4	5	6	7
10)	If I can catch a headache before it begins I often can stop it.	1	2	3	4	5	6	7

Please complete reverse side

SE Scale 2/23/95

Strongly Disagree	Moderately Disagree	Slightly Disagree	Neither Agree or Disagree	Slightly Agree	Moderately Agree	Strongly Agree
1	2	3	4	5	6	7

11)	Nothing I do will keep a mild headache from turning into a bad headache.*	1	2	3	4	5	6	7
12)	I can prevent headaches by changing how I respond to stress.	1	2	3	4	5	6	7
13)	I can do things to control how much my headaches interfere with my life.	1	2	3	4	5	6	7
14)	I cannot control the tension that causes my headaches.*	1	2	3	4	5	6	7
15)	I can do things that will control how long a headache lasts.	1	2	3	4	5	6	7
16)	Nothing I do will keep a bad headache from disrupting my day.*	1	2	3	4	5	6	7
17)	When I'm not under a lot of stress I can prevent many headaches.	1	2	3	4	5	6	7
18)	When I sense a headache is coming, there is nothing I can do to stop it. *	1	2	3	4	5	6	7
19)	I can keep a *mild* headache from disrupting my day by changing the way I respond to the pain.	1	2	3	4	5	6	7
20)	If I am under a lot of stress there is nothing I can do to prevent headaches.*	1	2	3	4	5	6	7
21)	I can do things that make a headache seem not so bad.	1	2	3	4	5	6	7
22)	There are things I can do to prevent headaches.	1	2	3	4	5	6	7
23)	If I am upset there is nothing I can do to control the pain of a headache.*	1	2	3	4	5	6	7
24)	I can control the intensity of headache pain.	1	2	3	4	5	6	7
25)	I can do things to cope with my headaches.	1	2	3	4	5	6	7

SE Scale 2/23/95

SE Scales

Prevention

Note: We do not use these subscales but use the total score; however negative items need to be reverse scored.

Positive

5) I can prevent headaches by recognizing headache triggers.
7) When I'm tense I can prevent headaches by controlling the tension.
9) If I do certain things every day I can reduce the number of headaches I will have.
10) If I can catch a headache before it begins I often can stop it.
13) I can prevent headaches by changing how I respond to stress.
17) When I'm not under a lot of stress I can prevent many headaches.
22) There are things I can do to prevent headaches.

Negative

2) When I'm in some situations nothing I do will prevent headaches.
14) I cannot control the tension that causes my headaches.
18) When I sense a headache is coming there is nothing I can do to stop it.
20) If I am under a lot of stress there is nothing I can do to prevent headaches.

Pain Management /Disability

Positive

1) I can keep even a *bad* headache from disrupting my day by changing the way I respond to the pain.
3) I can reduce the intensity of a headache by relaxing.
4) There are things I can do to reduce headache pain.
13) I can do things to control how much my headaches interfere with my life.
15) I can do things that will control how long a headache lasts.
19) I can keep a *mild* headache from disrupting my day by changing the way I respond to the pain.
21) I can do things that make a headache seem not so bad.
24) I can control the intensity of headache pain.
25) I can do things to cope with my headaches.

Negative

6) Once I have a headache there is nothing I can do to control it.
8) Nothing I do reduces the pain of a headache.
11) Nothing I do will keep a mild headache from turning into a bad headache.
16) Nothing I do will keep a bad headache from disrupting my day.
23) If I am upset there is nothing I can do to control the pain of a headache.

SE Scale 2/23/95

The Pediatric Rating of Chronic Illness Self-Efficacy (PRCISE)

Even though you have a health condition…

Exercise	**Circle the number that best describes how sure you are:**
1. How sure are you that you can exercise regularly?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
Obtain Help from Family, Friends and Doctors	**Circle the number that best describes how sure you are:**
2. How sure are you that you can get help from family with tasks and activities such as homework or chores?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
3. How sure are you that you can get family to help you when you are feeling sad or worried (such as listening or talking about problems)?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
4. How sure are you that you can get friends to help you when you are feeling sad or worried (such as listening or talking about problems)?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
5. How sure are you that you can ask your doctor questions when you are worried or unsure about your health?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
Illness Management	**Circle the number that best describes how sure you are:**
6. How sure are you that you can follow your doctor's advice everyday?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
7. How sure are you that you can tell when feelings in your body mean that you should see a doctor again?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
8. How sure are you that you stay away from things that make you feel bad?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
Chores, Hobbies and Recreation	**Circle the number that best describes how sure you are:**
9. How sure are you that you can complete your household chores?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
10. How sure are you that you can continue to do your hobbies and things you enjoy?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
11. How sure are you that you can go to school without having your health get in the way of your learning?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
Symptoms	**Circle the number that best describes how sure you are:**
12. How sure are you that you can reduce your physical discomfort or pain?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
13. How sure are you that you can make yourself better when you feel sick?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
14. How sure are you that you can keep your health problems from getting in the way of what you want to do?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
Mood	**Circle the number that best describes how sure you are:**
15. How sure are you that you can keep from feeling sad about your health?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure

For office use only.	*Total Score: _____*
Study ID:_____	*Gender: _____*
Date: _____	*Ethnicity: _____*
Age: _____	*Primary Medical Diagnosis: _____*

Emerson, N. D., Morrell, H. E. R., Mahtani, N., Sanderson, L., Neece, C., Boyd, K. C., & Distelberg, B. (2018). Preliminary validation of a self-efficacy scale for pediatric chronic illness. *Child: Care, Health and Development*, *44*(3), 485-493.

Behavioural Change

Since the headache self-management education workshop, I...

	Agree	Neutral	Disagree
have a more regular sleep schedule			
skip fewer meals			
drink less caffeine			
am more physically active			

Version: 1 Jan 2024

Appendix F: CHEO REB Approval Letters

Whitley, Nicole

From: do-not-reply-cheo@researchservicesoffice.com
Sent: Wednesday, February 7, 2024 3:16 PM
To: Pohl, Daniela
Cc: Whitley, Nicole; Tagliapietra, Sarah
Subject: REB Protocol No 24/10X - Final Approval - Delegated Review

EXTERNAL MAIL*

CHEO REB
Letter of Approval

REB Protocol No: 24/10X
ROMEO File No: 20240020
Principal Investigator: Dr. Daniela Pohl
Protocol Title: CHEOREB# 24/10X - Self-management education for adolescents with headaches: a pilot study

Protocol Status: Active

Approval Date: February 07, 2024
Approval Expiry Date: January 15, 2025

The CHEO REB has conducted a delegated review and determined that the conditions of approval have been satisfied for the above-named study. Approval is valid for the period indicated above. This research study is to be conducted by the investigator noted above. Annual renewals or study closures must be completed before the expiry date noted above.

REB members involved in the study do not participate in the review, deliberations, or decision.

Documents Approved:

Document Name	Comments	Version Date
Other Document	Mental Health Incidental Findings Flowsheet	2024/02/06
Protocol	Protocol v3, Clean	2024/02/03
Other Document	Participant Resource: Help with Headaches	2022/09/14
Other Document	Participant Resource: Medication History Worksheet	2024/01/18
Other Document	Participant Resource: BounceBack Youth 15-17	2018/02/23
Other Document	Workshop URLs for REB review	2024/01/19
Other Document	Participant Resource: Migraine Canada School Letter Template w Accomodation	2024/01/19
Other Document	Participant Resource: Migraine Canada School Letter Template	2024/01/19
Other Document	Participant Resource: Migraine Canada Ped Dosing Guide	2024/01/19

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Other Document	Workshop, Part 1	2024/01/18
Other Document	Workshop, Part 2	2024/01/18
Other Document	Email Templates	2024/02/03
Consent Form	Consent Form, v6Feb2024, Clean	2024/02/06
Questionnaire/Survey	HSES Questionnaire	2024/02/01
Other Document	Additional Resources (Clean)	2024/02/03
Questionnaire/Survey	Anonymous Satisfaction Survey	2024/01/11
Other Document	Participant Resource: Community Mental Health Resources	2024/01/17
Other Document	Participant Resource: SMART Goal Worksheet	2024/01/18
Other Document	Participant Resource: Headache Diary Worksheet	2024/01/18
Questionnaire/Survey	Behavioural Change Survey v1 (1 Jan 2024)	2024/01/01

Documents Acknowledged:

Document Name	Comments	Version Date
Case Report Form	Case Report Form	2024/01/19

Any modifications made to the study must be reviewed and approved by the REB prior to implementation, except when necessary to eliminate immediate danger or hazard(s) to study participants or when the change(s) involves administrative aspects of the study. Investigators must promptly alert the REB of any changes that increase the risk to participants or affect the safety of participants, all unanticipated and harmful events that occur, and new information that significantly impact the conduct of the study.

The CHEO REB operates in compliance with, and is constituted in accordance with, the requirements of the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans (TCPS 2); the International Conference on Harmonization Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; and Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The CHEO REB is registered with the U.S. Department of Health and Human Services (DHHS) Office for Human Research Protection (OHRP).

Please do not hesitate to contact the Research Ethics Office if you have any questions.

Best wishes for the successful conduct of your research.

Cécile Bensimon, MA, PhD
Chair, Research Ethics Board
Présidente, Comité d'éthique de la recherche

Whitley, Nicole

From: do-not-reply-cheo@researchservicesoffice.com
Sent: Thursday, February 22, 2024 3:09 PM
To: Pohl, Daniela
Cc: Whitley, Nicole; Anderson, Natalie
Subject: REB Protocol No 24/10X - Approval of Minor Modification

EXTERNAL MAIL*

CHEO REB
Letter of Approval

REB Protocol No: 24/10X
ROMEO File No: 20240020
Principal Investigator: Dr. Daniela Pohl
Protocol Title: CHEOREB# 24/10X - Self-management education for adolescents with headaches: a pilot study

Protocol Status: Active

Approval Date: February 22, 2024

The CHEO REB has conducted a delegated review and approved the minor modification for the above-named study.

REB members involved in the study do not participate in the review, deliberations, or decision.

Documents Approved:

Document Name	Comments	Version Date
Consent Form	ICF v22Feb2024 (Clean)	2024/02/22
Protocol	Protocol v22Feb2024 (Clean)	2024/02/22
Other Document	Email templates v22Feb2024 (Clean)	2024/02/22

Documents Acknowledged:

Document Name	Comments	Version Date
Questionnaire/Survey	PRCISE Questionnaire	2024/02/22

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Chair, Research Ethics Board
Présidente, Comité d'éthique de la recherche

Appendix G: AU REB Approval Letter

Athabasca University

CERTIFICATION OF ETHICAL APPROVAL

The Athabasca University Research Ethics Board (REB) has reviewed and approved the research project noted below. The REB is constituted and operates in accordance with the current version of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) and Athabasca University Policy and Procedures.

Ethics File No.: **25635**

Principal Investigator:
Ms. Nicole Whitley, Graduate Student
Faculty of Health Disciplines\Master of Nursing

Supervisor/Project Team:
Dr. Steven Johnson (Co-Supervisor)
Dr. Jennifer Knopp-Sihota (Co-Supervisor)

Project Title:
Self-management education for adolescents with headaches: a pilot study

Effective Date: February 23, 2024 **Expiry Date**: February 22, 2025

Restrictions:

Any modification/amendment to the approved research must be submitted to the AUREB for approval prior to proceeding.

Any adverse event or incidental findings must be reported to the AUREB as soon as possible, for review.

Ethical approval is valid *for a period of one year*. An annual request for renewal must be submitted and approved by the above expiry date if a project is ongoing beyond one year.

An Ethics Final Report must be submitted when the research is complete *(i.e. all participant contact and data collection is concluded, no follow-up with participants is anticipated and findings have been made available/provided to participants (if applicable))* or the research is terminated.

Approved by: **Date: February 23, 2024**

Paul Jerry, Chair
Athabasca University Research Ethics Board

Athabasca University Research Ethics Board
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