HEADACHE EXPERIENCE OF THE CHILD AND THE ADOLESCENT WITH SHUNTED HYDROCEPHALUS

by

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Abstract

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Hydrocephalus is a common pediatric neurosurgical condition affecting the body’s ability to regulate cerebral spinal fluid. Treatment commonly involves insertion of a ventriculoperitoneal (VP) shunt re-establishing cerebral spinal fluid flow. Shunts are prone to malfunction, with headache being a common symptom. Headache has predominantly been recognized as a sign of shunt malfunction and not seen as a pain event. While headache is common in pediatric hydrocephalus patients with an apparently functional shunt, it has not been rigorously investigated putting them at risk for the consequences of unresolved pain. Researchers have not addressed headache within this patient population outside of shunt functioning or the impact of headache from the child and adolescent perspective. Drawing on the Gate Control Theory, the Neuromatrix Theory of Pain and the International Headache Societies Headache Classification system, a mixed methods study design was undertaken to (a) determine the prevalence, frequency and nature of headaches, (b) describe potential child factors associated with headaches and (c) evaluate the impact of headaches on the child’s and adolescent’s’ school, social and family life. Sixty six percent of children and adolescents reported headache within a one month period. Based on the modified International Headache Society’s criteria, 13.0% of headaches were tension-like, 13.2% were unclassifiable 33.5% were migraine-like and 38.8% were mixed.
Etiology was significant with children diagnosed with tumour and congenital without myelomeningocele having a decreased tendency to report headache compared to children diagnosed with congenital with myelomeningocele. Children and adolescents described hidden emotions and missing out on many of their school, social and family activities. The main themes from the qualitative analysis were invisibility, normalcy and control/out of control. Etiology and multiple psychosocial and psychological factors potentially influence the headache experience in children and adolescents with shunted hydrocephalus. Future studies are required to further explore and delineate factors impacting headache within this study population.
Table of Contents

Abstract........................................................................................................................................... ii
List of Tables ...................................................................................................................................... vii
List of Figures .................................................................................................................................... viii
List of Appendices .............................................................................................................................. ix
Acknowledgements ............................................................................................................................ x

Chapter 1: Introduction ...................................................................................................................... 1
  Problem .............................................................................................................................................. 4
  Purpose of the Study .......................................................................................................................... 5

Chapter 2: Literature Review ............................................................................................................ 7
  Acute Headache and the Child with Shunted Hydrocephalus ......................................................... 7
  Recurrent/Chronic Headache and the Child with Shunted Hydrocephalus ................................. 10
  Pain and Headache in the Spina Bifida Population ........................................................................ 18
  Headache within the General Pediatric Population ........................................................................ 20
  Summary of Literature Review ........................................................................................................ 24

Chapter 3: Conceptual Framework .................................................................................................. 25
  Theoretical Perspectives on Pain ...................................................................................................... 25
      Gate control theory of pain ........................................................................................................... 25
      Neuromatrix theory of pain ......................................................................................................... 27
  International Headache Society Criteria ......................................................................................... 30
  Proposed Framework for Headache for the Child and Adolescent with Shunted Hydrocephalus ............................................................................................................................................................................. 30

Chapter 4: Methods ........................................................................................................................... 35
  Research Questions .......................................................................................................................... 35
  Definitions ......................................................................................................................................... 36
  Inclusion/Exclusion Criteria ............................................................................................................. 39
  Assumptions ...................................................................................................................................... 39
      Philosophical assumptions ........................................................................................................... 41
  Study Design ..................................................................................................................................... 43
Diagnosis of hydrocephalus .................................................................137
Importance placed on neurosurgical context of headache ..................140
Psychological challenges and emotional factors ....................................141
Predisposition to stress and stressful events ........................................142
Frequency of Headache ........................................................................144
Nature of Headache .............................................................................145
Child Factors .......................................................................................148
Age and sex ........................................................................................148
Etiology .................................................................................................150
Description of Headache .......................................................................153
Emotions in Relation to Headache Pain ................................................157
Impact of Pain ......................................................................................161
Pain Management and Maintaining Normalcy ........................................164

Chapter 8: Implications, Future Directions, Knowledge Translation and
Study Summary .....................................................................................168
Significance of Study ...........................................................................168
Study Strengths .....................................................................................169
Study Limitations ................................................................................172
Implications for Research ....................................................................177
Implications for Clinical Practice .........................................................181
Knowledge Translation .........................................................................184
Study Summary .....................................................................................190
References ............................................................................................192
Appendices ............................................................................................215
List of Tables

Table 1. Strengths and Weaknesses of Qualitative/Quantitative Methodologies for Child and Adolescents’ Headache ................................................................. 45
Table 2. Demographic Data and Child Factors....................................................... 71
Table 3. Prevalence and Frequency of Headaches for all Study Participants.............. 73
Table 4. Frequency of Reported Headache Days by Headache Classification............... 75
Table 5. Frequency of headache days by sex, age and etiology .................................. 76
Table 6. Summary of Participants Headache Characteristics Reported by Children and Adolescents ............................................................................. 77
Table 7. Summary of Participants Headache Characteristics Reported by Children and Adolescents ............................................................................. 78
Table 8. Bivariate Analysis of Categorical Variables Crossed with Presence or Absence of Headache........................................................................... 82
Table 9. Bivariate Analysis of Continuous Factors Crossed with Presence or Absence of Headache........................................................................... 83
Table 10. Multivariable Regression Analysis of Etiologies and Sex............................. 84
Table 11. Summary of Child Factors for Qualitative Sample by Age and Sex............... 87
Table 12. Qualitative Themes and Subcategories.................................................... 102
List of Figures

Figure 1. Flow Diagram of Study Sample ..............................................................................69
Figure 2. Number of Headache Days Reported by Children and Adolescents
          over the Last Month ..................................................................................................74
List of Appendices

Appendix A. International Headache Societies Classification of Headache Disorders .......................................................... 215
Appendix B. Assent and Consent Forms .......................................................... 218
Appendix C. Refusal Log ............................................................................ 223
Appendix D. Demographic Data Collection Sheet ......................................... 224
Appendix E. Interview Guide for Screening Questions .................................. 225
Appendix F. Interview Guide for Interview #1 .............................................. 227
Appendix G. Interview Guide for Interview #2 .............................................. 231
Appendix H. Consent for Audiotaping .............................................................. 235
Appendix I. Numerical Rating Scale ............................................................ 237
Appendix J. Example of Matrix: Pain Descriptors by Sex ............................ 238
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Chapter 1

Introduction

Hydrocephalus is predominantly a pediatric neurosurgical condition with an estimated incidence of 0.9-1.2 per 1000 children (Kestle et al., 2000). This condition interferes with the brain’s ability to produce or absorb cerebral spinal fluid (CSF). As a result, there is a build-up of CSF within the brain causing increased intracranial pressure (ICP). If left untreated, it will lead to death. There are multiple etiologies for hydrocephalus, which can be congenital or acquired, that include tumours, aqueductal stenosis, trauma, spina bifida, infection, and intraventricular haemorrhage. The most common treatment involves insertion of a ventriculoperitoneal shunt, which diverts CSF fluid from the ventricle to the peritoneal cavity to allow CSF to be reabsorbed within the circulatory system. Shunts are prone to malfunction and headache is a common presenting symptom of shunt malfunction (Barnes, Jones, Hayward, Harkness & Thompson, 2002; McClone, 2001).

Parents of children with shunted hydrocephalus and children with shunts are educated about the importance of recognizing headache as a symptom of shunt malfunction in the prevention of neurological morbidity and mortality associated with raised ICP. Therefore, headache within the neurosurgical context has been predominantly associated with shunt malfunction with little consideration for pain. Children with shunted hydrocephalus presenting with headache are often investigated with a variety of diagnostic modalities including (a) Computed Tomography (CT) imaging of the brain to assess ventricular changes, (b) skull, chest and abdominal X-rays to assess the integrity of the shunt, and (c) ICP monitoring to assess fluctuations in the CSF pressure dynamics. Results of this testing indicate that some children
with shunted hydrocephalus presenting with headache have a functional shunt. Therefore, there is limited understanding of headache with respect to these children outside of ICP.

The neurosurgical perspective of headache fails to recognize headache as a manageable pain problem. From a pain perspective, the etiology of headache for the child and the adolescent with shunted hydrocephalus is likely complex and multifactorial, but is currently unknown. Pain, as defined by the International Study of Pain (IASP), is an “unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (Mersky & Bogduk, 1994). This definition of pain acknowledges the complexity of pain and illustrates that pain is not purely determined by tissue damage. The experience of pain incorporates a personal and subjective component. Therefore, within the neurosurgical context, interpreting headache as a symptom of shunt function leaves the child vulnerable to the physiological and psychosocial implications of unresolved pain.

In the research literature, there are no reports of the child’s or adolescent’s perspective of their headache experience associated with shunt function and ICP. The concept of headache is an important part of these children’s and adolescents’ lives, yet we know little about the child’s experience of headache in relation to their hydrocephalus.

There are multiple factors inherent in the child with hydrocephalus that can precipitate headache. First, due to the nature of shunts and their predisposition for malfunction, the child and the adolescent with hydrocephalus appear more likely to undergo stressful events such as surgery and clinic appointments than their peers. These children and adolescents are constantly being observed and being asked whether or not they are having headaches. As part of the teaching on hydrocephalus, the health care team emphasizes the importance of headache as a sign of shunt malfunction. The emphasis of headache during clinic visits and within patient
education draws attention to headache, potentially sensitizing the child to their headache experience. Secondly, these children are often coping with learning difficulties, which are subtle and unrecognized in a mainstream school environment (Stellman-Ward & Hewison, 2002). Hence, the varying degrees of intellectual, cognitive, and communication deficits can cause stress and influence their ability to cope with stress. Finally, children with a chronic physical condition show a higher proportion of social and emotional problems than their peers (Stellman-Ward & Hewison), which can impact their social relationships and sports and leisure activities. These children may have a biological vulnerability to a condition affecting the central nervous system. This biological vulnerability may predispose these children and adolescents to greater reactivity to the physiological effects of stress and anxiety (Stellman-Ward & Hewison) either congenitally, or related to sequelae of increased ICP.

There is also evidence that repeated acute pain events cause central sensitization (Porter, Grunau, & Anand, 1999; Woolf & Salter, 2000). Central sensitization is a physiological process that occurs peripheral to the spinal cord and in higher brain centres following repeated injury or inflammation. Central sensitization manifests at the single cell level as a change in receptive field properties, reducing the pain threshold, increasing pain responsiveness, spatial extent, and recruitment of novel inputs (Woolf, 1996). These changes may increase the magnitude of perceived pain and contribute to the development of chronic pain syndromes (Connelly, 2003; Marcus, 2003). Sixty percent of children and adolescents with shunted hydrocephalus have their initial shunt insertion at less than 6 months of age (Glinianaia & Rankin, 1999). As shunts are prone to failure requiring surgical intervention, these children and adolescents are at risk of multiple acute pain episodes related to shunt failure and surgical intervention, which can potentially increase their susceptibility to developing a recurrent pain condition.
In the general pediatric headache research literature on migraine and tension type headaches, age (Forsyth & Farrell, 1999; McGrath & Hillier, 2001; Lewis, 2004; Lipton, Goadsby, & Silberstein, 1999), sex (McGrath et al.; Ayatollahi, Moradi, & Ayatollahi, 2002), and stress (Bandell-Hoekstra, Abu-Saad, Passchier, & Knipschild, 2000; McGrath et al.) have been reported as factors influencing the child’s headache. Increased prevalence of headache has been associated with adolescent females (Laurell, Larsson, & Eeg-Olofsson, 2004; Zwart, Dyb, & Holm, 2004).

Common sources of stress for children with headache include social relationships with peers, school, sports and leisure activities, and family (McGrath et al., 2001; Eccleston, Wastell, Crombez, & Jordan, 2008). Headache pain in the general pediatric literature has been associated with increased functional impairment, increased somatic complaints, and decreased quality of life (Kernick & Campbell, 2009; Unalp, Dirik, & Kurul, 2007; LeResche, Mancl, Drangsholt, Saunders, & Von Korff, 2005; Nyame et al., 2010). Headache related morbidities inevitably affect the child’s and adolescent's daily activities and their ability to function in school and social environments (Eccleston et al., 2008).

**Problem**

Present assessment and management of headache pain is suboptimal for the child and adolescent with shunted hydrocephalus, leaving them vulnerable to the physiological, psychological and psychosocial sequelae of unresolved pain. Lack of understanding of headache in children and adolescents with shunted hydrocephalus causes significant suffering and disability for the child and the adolescent with shunted hydrocephalus. In the general pediatric population, headache creates anxiety and disruption for children and families, and represents a substantial cost to both parents and the health care system (McGrath, 1990; Stanford, Chambers,
Within the general pediatric headache literature, specific risk factors have been defined with respect to headache experience (e.g., sex and age). However, these risk factors have not been defined within the pediatric shunted hydrocephalic patient population.

The neurosurgical health care team, consisting of expert practitioners for children and adolescents with shunted hydrocephalus, has a limited understanding of the headache experience from the child’s or adolescent’s perspective. Other than in relation to shunt function, the quality research addressing the headaches of children and adolescents with shunted hydrocephalus is limited. Current research does not address the headache experience of these children and adolescents from their perspective. This lack of understanding impedes effective management of headache education for children and families. Our present understanding of the child’s and adolescent’s headache is based on clinical experience, which presents a possible disconnect between the practitioner’s perspective of headache and the child’s headache experience.

There is a definite need to address the issue of headache in the child and the adolescent with shunted hydrocephalus. Treatment and management of headaches can be greatly enhanced for these children and adolescents once headache is further defined clinically and understood from the child’s or adolescent’s point of view.

**Purpose of the Study**

The purpose of the study was to determine the prevalence of headache in the child and the adolescent with shunted hydrocephalus outside of shunt malfunctioning and to provide a description of child’s and adolescent’s headache experience in relation to their school, social and family functioning. Due to the nature of the research questions, a mixed methods design was used to comprehensively explore the headache experience of children and adolescents with shunted hydrocephalus. Quantitative methodology was used to address the research questions
relating to the prevalence, nature and frequency of headache, and to address potential child factors related to headache. Qualitative methodology was used to provide an avenue for the children and adolescents to describe their headache experiences related to their school, social and family functioning. Exploring these experiences will fill gaps in our understanding of headache in these children.
Chapter 2

Literature Review

Within this chapter, the pediatric neurosurgical headache literature is reviewed. The literature review is divided into sections on (a) acute headache and the child with shunted hydrocephalus, (b) recurrent/chronic headache and the child with shunted hydrocephalus, (c) recurrent headaches and pain events in the spina bifida population and (d) headache within the general pediatric patient population. A summary of the literature is presented. In depth review of the qualitative literature was deferred to the qualitative results and discussion chapters.

Acute Headache and the Child with Shunted Hydrocephalus

Children with shunted hydrocephalus frequently reported headache (Barnes et al., 2002; Stellman-Ward, Bannister, & Lewis, 1997). Headache could be accompanied by nausea, vomiting, and lethargy, which could be indicative of shunt malfunction (Barnes et al.). Headache for the pediatric neurosurgical population has been predominantly viewed as a symptom associated with fluctuations in ICP and shunt malfunction (delBigio, 2002; Kirkpatrick, Englemen, & Minns, 1989; Barnes et al.; Lee, Uribe, Ragheb, Morrison, & Jagid, 1999; Sainte-Rose, Piatt, & Renier, 1991; Epstein, Marlin, & Wald, 1978). This symptom is usually interpreted as an underlying pathology within the central nervous system; as something to be captured in imaging and resolved with a surgical procedure. Chronic headache fluctuating or continuous in intensity has been attributed to slit ventricle syndrome and migraine headaches (del Bigio; Baskin, Manwaring, & Rekate, 1998; Lee et al., 1999; Dhalerup et al., 1985). However, outside of shunt malfunction, the headache experience for these children is ill-defined and poorly understood.
Kirkpatrick et al. (1989) performed a retrospective analysis of the clinical features of 107 children presenting with hydrocephalus and increased ICP from medical documentation. Fifty-one of the children were infants, 22 were between the ages of 1 and 4 years, and 34 were over the age of 5 years. The most common symptoms of shunt malfunction were vomiting, behavioural changes, and headache. Headache was more common in the group over 5 years of age, which may be indicative of their ability to report their experience. However, from the data presented, it was unclear how many children in the older group had headache and what the characteristics of their headache were. There was also no correlation between any clinical symptom and ICP.

In a retrospective study, Barnes et al. (2002) evaluated 53 pediatric patients to determine the predictive value of symptoms, signs and radiographic findings accompanying presumed VP shunt malfunction. Data were collected on the referral pattern, presenting signs and symptoms, results of CT imaging, operative findings, and clinical outcomes on patients who were referred to a pediatric neurosurgeon for assessment of shunt function. The sample was subdivided into two groups. One was defined as having a proven shunt block as evidenced by surgical findings and the other as having a presumed functional shunt. Symptoms, CT scan findings and clinical course were then compared. Of the 53 enrolled patients, 37 underwent surgery because of CT findings indicative of ventriculomegaly (increased size of ventricles on CT imaging).

Postoperatively, 34 of the 53 patients had resolution of their presenting symptom. The common presenting symptoms were headache, drowsiness and vomiting. Although it was unclear as to which symptoms resolved postoperatively, the main indication of resolution was attributed to decreased ventricle size on postoperative imaging.

The authors reported on 34 children. However, there were three children for whom results were not indicated, and there was no explanation as to why they were lost to follow up.
Of the 16 cases that were presumed to have a functional shunt, the headaches in three were attributed to viral illness, three to CSF over drainage, and 10 had no identifiable diagnosis. Of the 10 undiagnosed children, four had shunt block, were taken to surgery, and had symptom resolution. Symptom resolution for this subset of patients was documented as improved Glasgow Coma Scale (GCS) and CT findings. An odds ratio of 2.5 with 95% confidence levels was reported for these 10 participants with headaches in the absence of shunt malfunction. Confidence parameters were not indicated. An odds ratio also was calculated incorporating all study participants comparing headache presentation in both the shunt malfunction and the functional shunt group and was found to be 1.5 with a 95% confidence level of 0.3 and 10.9.

Children presenting with headache as a primary symptom had a 1.5 times greater chance of having a shunt block. From the study population, 82% of patients presenting with headache, vomiting, and drowsiness had a shunt block. Other recently reported symptoms associated with confirmed shunt malfunction are (a) headache in 47.0-55.0% of cases, (b) vomiting in 40.0-90.0% of cases, and (c) drowsiness in 30.0-60.0% of cases (Lee et al., 1999). Barnes et al. (2002) concluded that headache as a single symptom of shunt malfunction was less predictive than multiple symptoms of acute shunt block. In the absence of other symptoms, he recommended that (a) practitioners should adopt a low threshold for seeking neurosurgical opinion; and (b) a careful search for an alternate diagnosis is warranted.

Conversely, Dhalerup et al. (1985), in a prospective study cohort study following 4 pediatric patients in the outpatient setting, found repeated and severe attacks of bi-temporal and bi-frontal headache as the only symptom of severe shunt dysfunction without ventricular dilation on CT scan. All 4 patients had ICP monitoring, and ICP was found to be high. Although this study was a case report of only 4 patients with no statistical analyses, severe headache as the
only symptom of increased ICP caused by shunt dysfunction in children who have normal or even small ventricles was introduced.

Foltz and Banks (1988) indicated that headache was a symptom of low ICP secondary to over drainage. He retrospectively reviewed the clinical presentation and treatment of 14 pediatric patients to characterize headaches. Foltz and Banks used descriptive statistics to conclude that headache was the most common symptom preoperatively. Headache occurred when the child was in the upright position and during activity, and the child was relieved when lying down. Six of the 14 children, when supine, showed immediate improvement, five showed modest improvements (not clearly defined) and, in three children, the symptoms resolved within 30 minutes. Preoperative evaluation involved CT imaging. The CTs were reported to be nearly normal, and the shunts were in good positions. ICP monitoring showed ICP below the normal range. All patients underwent surgical intervention and their ICP measurements returned to normal range following surgery. There was no comment on headache resolution postoperatively.

**Recurrent/Chronic Headache and the Child with Shunted Hydrocephalus**

Although headache within the shunted population has generally revolved around the acute presentation of headache and shunt malfunction in relation to ICP changes, recurrent and chronic headaches have been identified in the neurosurgical literature. Epstein et al. (1978) commented that chronic or recurring headaches are a persistent complaint in a small but significant number of children with shunted hydrocephalus. Although intermittent shunt malfunction may be the underlying problem, it is evident that the symptom is complex, and may occur despite a functional shunt. Epstein et al. were the first to highlight the complexity of the headaches in this population. They stated that headache may be functional, related to idiopathic fluctuation of ICP as a result of altered intracranial dynamics. Furthermore, they commented that inconclusive radiographic findings can further obscure the diagnosis. In their review of
nine cases, they developed an algorithm for treatment highlighting the need for headache subgroups to be recognized to effectively treat according to etiology. Epstein et al. did not report on the possibility of other factors outside of shunt malfunction attributing to headache within this population. They did, however, include in the algorithm that, if imaging is normal, the patient should have a psychiatric consult. The algorithm highlighted that the headache pathology may not necessarily be related primarily to shunt malfunction and ICP. The suggestion of a psychiatric consult alluded to the complexity of the child’s headache experience and the possibility of the etiology being multifactorial.

Abbott, Epstein and Wisoff (1991) addressed the therapeutic dilemma of patients presenting with the complaint of chronic headache either fluctuating or continuous in intensity as the only symptom of possible shunt malfunction. Their goal was to develop a method to therapeutically and appropriately respond to the headache experience. They reviewed charts of 12 patients between the ages of 8 and 42 years who presented with nonprogressive headaches. All 12 patients had a shunt series (i.e., X-rays of the skull, chest, and abdomen) to ensure continuity of the shunt, and had nuclear medicine testing of the shunt done to ensure its patency. There were no abnormal findings. ICP monitoring was done on all patients, and three had headaches associated with increased ICP, two had negative pressures while having headache and, in seven patients, there was no relationship between headache and ICP pressures. They recommended the use of ICP monitoring as part of the treatment modality for patients presenting with recurrent headache and normal preliminary evaluation.

Nowak and James (1989) introduced the diagnostic dilemma of migraine in the child with hydrocephalus. Migraine can manifest with or without aura and may affect some portion of cerebral circulation more than others. Nowak and James’ goal was to describe the association between migraine in children and adolescents with hydrocephalus. They reviewed five children
aged 1, 4, 5, 8, and 11 years. All patients had normal CT imaging and had headaches persisting after shunt revisions. Headache characteristics in the younger age group (5 years and under) were attributed to vomiting, lethargy, and loss of appetite. After 6 years of age, the children were able to describe headache with greater precision. Four of the five patients had a family history of migraines. All patients were treated with propranolol, and the headaches episodes resolved. This study had involved retrospective case reviews, so the information presented about the cases was dependent on the documentation in the chart. Furthermore, it is not clear as to how these cases were selected, so the results could have been biased.

Nowak and James (1991) studied migraine in the hydrocephalic pediatric patient population. Headache, vomiting and altered sensorium was seen in patients with migraine, as well as those with shunt malfunction (Nowak & James, 1989). They retrospectively reviewed 10 patients with shunted hydrocephalus presenting with severe headache, episodic vomiting, and impairment of consciousness. Of the 10 patients, eight had undergone repeated procedures for suspected shunt malfunction before the diagnosis of migraine was made. Migraine therapy (defined as treatment with propranolol) was started, and 8 out of the 10 patients showed improvement of the symptoms, although what constituted improvement was not clear. Limitations that could have biased the study results included sample size, sample selection, and undefined criteria used to classify the migraines. From the limited study results, the author concluded that children should be assessed to see if the clinical and family history, in light of normal imaging, could be indicative of a migraine headache.

Stellman et al. (1997) were the first to formally study chronic recurrent headache in the pediatric hydrocephalic patient population. A two-part study was undertaken to describe the child headache experience. First, a retrospective chart review was undertaken to investigate the incidence of chronic headache documented in the medical notes. Second, a questionnaire was
sent to patients who were reported to have chronic headache to further investigate the incidence and nature of their headaches. Specifically, the goal was to clarify the headaches as migraine- or stress-related, and to investigate the sorts of stresses children and their families identified.

Children 7 years of age and older with congenital or acquired hydrocephalus were included. Patients whose etiology entailed space occupying lesions were excluded. Of the 150 charts reviewed, 20 were not included due to incomplete documentation. Data collected included demographics, diagnosis, shunt history, history of epilepsy, history of chronic headache, history of investigations, specific diagnosis of migraine, and history of treatment. Questionnaires were sent to 130 parents and children who were each asked to complete separate questionnaires concerning the child’s experience of headache. Questions were asked about the incidence, frequency, duration of unexplained chronic headache, site of headache, symptom experience, family history of headache, factors thought to trigger and relieve headache, schooling history, possible stress factors, and a pictorial depiction of the quality of the headache.

Cases from Stellman et al.’s (1997) initial review were categorized as to whether chronic headache in the absence of obvious shunt malfunction was documented in the notes. Of the 130 patient charts reviewed, 53 included the diagnosis of chronic headache (40.8%). Although the criteria used to define chronic headache and consistency regarding documentation were unclear, 42 of the 53 patients identified as having chronic headache had multiple complaints of headache, which were reported over a period of months or years. Thirty-five cases of children presenting with headache were investigated, and 14 of the 35 were taken for surgery. However, it is unclear whether the 35 were from the 53 patients with documented headache in the charts, or were part of the 130 patients enrolled in the study. It is interesting to note that of the 14 patients who underwent surgical shunt revision, 12 continued to have headache postoperatively. However, the length and characteristics of the postoperative headache were not documented. Eighty-one of the
130 children had had one or more shunt revisions. Of the 81 children undergoing shunt revision, 20 (24.6%) continued to complain of headache post revision.

Of the 130 questionnaires, 57 were completed and returned (43.0% response rate). The information supplied by the parent and child within the questionnaire was identical in all but one case, raising the question as to who filled out the questionnaires. However, in reviewing the questionnaire data, a further 22 children were identified as having recurrent headaches. Therefore, with the combined chart review and the questionnaire, 75/130 patients reviewed had headache (57.7%). Of these 75 patients, 11 were diagnosed with migraine. The incidence of migraine headache was 8.5% in the medical notes, with the incidence rising to 21.5% using self-report. This rate was substantially higher than the 4.0% incidence of migraine in the general pediatric population (McGrath & Hillier, 2001). However, the criterion used to make the diagnosis was unclear. The authors further concluded that, of the 75 patients having headache, 17 reported symptoms consistent with migraine headaches, 20 reported symptoms consistent with non-migraine headache and 28 had unexplained headache documented, which was not thoroughly described or classified. Overall, the classification system used to categorize the headaches was unclear. There was no statistically supported difference in sex, age, and etiology of the hydrocephalus. However, there was no indication of stratification, nor whether the study had sufficient power and sample size to substantiate the findings (Stellman et al., 1997).

Additional information from the questionnaire revealed that 25 of the 130 children had a history of being sexually abused or having behavioural psychosocial problems. Of these 25, 15 were identified as suffering from chronic headache. School placement was documented in 59 of the 130 charts, and 21 children attended special needs schools, 18 attended mainstream schools with help in the classrooms, and 20 children were in the mainstream school system. Using chi-square analysis, headache was related to school placement. Children attending mainstream
school without any supports were more likely to report headache than those children in schools with supports ($X^2 = 4.2, p < 0.05$) (Stellman et al., 1997).

Although Stellman et al. (1997) characterized headache within this patient population, there were many limitations. First, the data extrapolated retrospectively from the clinic notes may not have been representative of the patient’s headache experience. Headaches may not have been consistently documented within the clinic notes, and data collected were dependent on the individual doctor's examination and history taking. It is unclear from the study whether the data collected were from one particular surgeon or multiple clinicians. Second, because the sample was derived from a clinic database, it may have represented a subset of the population resulting in a selection bias. Clinics often see patients who are unwell, which could potentially inflate the proportion of chronic headache. The referral pattern for this clinic was unclear. Ultimately, the results were not generalizable or truly representative of the shunted pediatric hydrocephalic patient population.

In a second study, Stellman-Ward and Hewson (2002) investigated the psychological factors associated with headaches in children with shunted hydrocephalus. A retrospective chart review was undertaken to establish who had documentation of recurrent headache; 130 patients were identified. This study population was the same one used in their previous study. All families were contacted and were asked to complete questionnaires concerning child psychopathology using the Rutter parent questionnaire revised (Goodman, 1994), to manifest child anxiety utilizing the Fear Survey Schedule for Children revised (Ollendick & Cerny, 1981), and to complete a questionnaire regarding family coping (McCubbin, Olson, & Larson, 1991). Of the 130 questionnaires, 67 were completed. Fifty-eight percent of the children scored greater than 11 on the mean Rutter parent questionnaire (Goodman), which is the cutoff for clinical psychopathology. The authors indicated that children with headache scored higher than children
without headaches on the Rutter Parent scale (Goodman) \((p = 0.03)\) and the Manifest Child Anxiety Scale (Ollendick & Cerny) \((p = 0.004)\). However, no statistical analysis was presented.

Gupta et al. (2007) looked at the long-term outcomes for children with treated hydrocephalus. A self-report patient survey was used, and the data collected included demographic characteristics, familial factors, co morbidities, quality of life issues, and treatment complications. Standardized measures for quality of life were not used. The only inclusion criterion for the study was that the patient and/or guardian needed to be aware of a diagnosis of hydrocephalus. Patients were recruited through the Hydrocephalus Association patient registry, and 1459 patients were enrolled in the study. To assess long-term functional and social outcomes, a subgroup analysis was done on those participants who, at the time of the survey, were greater than 20 years of age (403 of the 1459 respondents). This cohort was then divided into three groups based on age of diagnosis (birth to 18 months; 19 months to 12 years; 13 years to 19 years). Part of the functional assessment included whether the participant was having headaches. Of the 403 participants, 203 (51.0\%) reported having headaches, although the headaches were not characterized. It is interesting to note that when headache experience was further divided groups based on age of diagnosis, 158 of the 203 positive responders were diagnosed with hydrocephalus at less than 18 months of age, 27 of the 203 at 19 months to 12 years of age, and 18 of the 203 at 13 years to 19 years of age. Furthermore, 273 of the 403 participants had a history of depression, and of those, 213 (71.0\%) were diagnosed with hydrocephalus at less than 18 months of age.

Recently, Rekate and Kranz (2009) looked at lifetime incidence of headache in patients with shunted hydrocephalus aged 19 months to 45 years. Patient data were obtained through the Hydrocephalus Association Database, a self-reporting database with information from individuals treated for hydrocephalus and their families. Rekate and Kranz focused on a small
part of the database related to the question, “Do you or your family members suffer from (does your child complain of) frequent or chronic headache”? A total of 1233 participants were recruited from the database and were subcategorized to the groupings of child (19 months to 12 years), adolescent (13-19 years), and adult (20-45 years). Among the 1233 study participants, 634 (51.0%) were children, 213 (17.0%) were adolescents, and 386 (32.0%) were adults.

Responses for the child age group were primarily reported by the parents or caregiver. Twenty-nine percent of children, 42.0% of the adolescents, and 44.0% of adults reported frequent and disabling headache. The nature and classification of the headaches were not described. The incidence of headache was not significantly different in adolescents and adults. However, the rates of incidence of headache between children and adolescents and between children and adults were significantly different ($p < 0.05$). The authors also indicated that headache had a significant impact on the quality of life of the study participants. From the study findings, Rekate and Kranz developed an algorithm for headache management in patients with a presumed functional shunt. The algorithm entailed ruling out increased intracranial pressure and antimigraine management, and advocated for a shunt removal protocol. The proposed algorithm did not address or evaluate psychosocial factors that could potentially contribute to headache. Although there are many methodological limitations inherent in Rekate et al.’s and Gupta et al.’s (2007) studies related to selection bias, proxy reporting, and the use of valid measurement tools that impact the generalizability of the findings, the studies highlighted the reality of headache for this patient population, and the need for incorporation of the physiological, psychosocial, and psychological aspects of pain in patient management.

Kulkarni and Shams (2007) addressed the quality of life in children with hydrocephalus and predictors of long-term outcome. Quality of life was measured using a reliable and validated outcome measure: the hydrocephalus outcome questionnaire (HOQ) (Kulkarni, Rabin, & Drake,
Of the 346 study participants between the ages of 5 and 18 years, the mean HOQ score was 0.68 (0 = worst quality of life and 1.0 = best quality of life). The multivariable analysis showed that (a) increased seizure frequency, (b) increased length of stay in hospital for initial treatment of hydrocephalus, (c) increased length of stay for treatment of shunt infection and shunt overdrainage, (d) increased number of proximal shunt catheters in situ, and (e) distance from family residence to health care facility were all related to decreased quality of life. The study findings have begun to address factors impacting the quality of life in children with shunted hydrocephalus using a validated outcome measure; however, current research has yet to address headache pain as a factor impacting quality of life.

**Pain and Headache in the Spina Bifida Population**

Clancy, McGrath and Oddson (2005) studied pain in children and adolescents with spina bifida. In a two-phased study, 68 children with spina bifida between 8 and 19 years of age were investigated in terms of the frequency, intensity, location, and duration of pain experienced, and in terms of the relationship between parent report and child self-report. Medical charts were reviewed for documentation of pain, and parent-child dyads completed the Pediatric Pain Questionnaire (Varni, Thompson, & Hanson, 1987) to examine parent proxy report and self-report of pain. Fifty-six percent of children reported experiencing pain once a week or more often. Pain occurred most frequently in the head, back, abdomen, neck, shoulder, legs, and hands. Of the 68 children, 49 (72.0%) had shunted hydrocephalus and 43 (88.0%) reported having headaches. This study highlighted headache as an unrecognized pain event for spina bifida patients with shunted hydrocephalus that is frequently untreated. The findings of this study were statistically significant. There was adequate power and sample size to perform the statistical analysis, and the measures used were valid and reliable.
Chronic headaches have been studied in adult patients with spina bifida and hydrocephalus. Edwards et al. (2001) evaluated the presentation and etiology of chronic headache in adult patients with spina bifida and hydrocephalus. Secondary aims were to assess the usefulness of ICP monitoring and to evaluate outcomes in patients with chronic headache. Chronic headache was defined as headache of at least one month in duration. It could have been continuous or intermittent but had to occur on most days. Patients presenting with hard signs of raised ICP (defined as decreased level of consciousness and papilloedema) were excluded from the study. The study was a retrospective case review of all patients over a 10-year period with hydrocephalus and spina bifida who were investigated within an Edinburgh hospital. The patients were identified from a patient database. Data from 42 cases were reviewed in terms of patient demographics, neurosurgical procedures and individual headache episode. Data on the headache episode entailed the presenting character of the headache, the symptom duration, the associated symptoms, the investigation undertaken, the determined etiology of the presenting headache, and the outcome and resolution of the headache. Of the 42 patients reviewed, 23 had undergone investigation for chronic headache in adult life and collectively had 51 documented headache episodes. Headache episodes per patient ranged from one to seven, and the mean duration of headache prior to investigation was 7.5 months. Of the 51 documented episodes, 35.0% were of unknown etiology, 2.0% were related to shunt overdrainage, 25.0% to shunt block, 4.0% to endoscopic third ventriculostomy (ETV) failure, 2.0% to CPC failure, 10.0% to arrested hydrocephalus, 8.0% to chiari malformation, 4.0% to tension headache, 4.0% to migraine headaches, and 6.0% to scar neuralgia. Previous etiology of headache was not predictive of subsequent etiologies. Chronic headaches were unrelated to either the level of the spina bifida, the coexistence of epilepsy, previous foramen magnum decompressions, the total number of shunt revisions, the number of shunt revisions in the first ten years of life, or the
number of proximal shunt revisions. Univariate and multivariate analysis confirmed that older age and absence of any previous choroid plexus coagulation were both associated with chronic headache. Of the 51 headache episodes, 17 were associated with increased ICP due to shunt malfunction or third ventriculostomy failure, 44 episodes were described as intermittent, and 30 were described as being generalized. The timing of headache (e.g., in the early morning) and location of the headaches were poor predictors of the presence of raised ICP. Of the 42 patients with chronic headache, 18 had no underlying cause of the headaches and were managed expectantly with close clinical observation. Overall, 82.0% of headache episodes resolved with treatment or observation alone. Of the 42 patients, four had intractable headaches with no increased ICP and were referred to a multidisciplinary team for control of their symptoms. The interventions employed by the multidisciplinary team and the factors affecting headache experience were not described. However, the authors noted that the use of the multidisciplinary team had decreased symptom intensity and frequency but did not completely alleviate symptoms. Thirty-five percent of patients had unknown etiology of their headache, and the etiology of headache was presumed to be multifactorial. Those patients who referred to a specialist to help with pain management experienced a decreased intensity of their symptoms. However, there was no indication as to how the symptom changes were measured. The statistical findings are suspect as there was no comment on sample size justification nor on power of the study.

**Headache within the General Pediatric Population**

Headache within the general pediatric population has been reported to be between 12.2% to 68.0% (Seshia, 2004; Dooley, Gordon, & Wood, 2003; Carlsson, Larsson, & Mark, 1996; Egermark-Eriksson, 1982; Passchier & Orlebeke, 1985; Antilla, Mestahonkala, Aromaa, Sourander, & Helenius, 2002; Lipton, 1997; McGrath et al., 2001; Ozge et al., 2003; Laurell et al., 2004; Zwart et al., 2004, Abu-Arfeh, Razak, Sivaraman, & Graham, 2010). The variability
in the reporting of the prevalence of recurrent headache can be attributed to differences in sampling methods used, the age and the sex of the study population, the diagnostic criteria used, and how the data were analyzed. Factors associated with increased episodes of recurrent headache that are well-substantiated in the literature are sex and age. Increased prevalence of headache has been associated with females and with the adolescent age range (12 years of age and older) (Laurell et al.; Zwart et al.; Ayatollahi et al., 2002; Lewis, 2004; McGrath et al.; LeResche et al., 2005; Slater et al., 2009).

A recent systematic review of population-based studies which looked at the prevalence of headache in children and adolescents reported that the overall prevalence of headache at any point in time in a population of 80,876 children was 58.4% with 95% CI (58.1-58.8) (Abu-Arafeh et al., 2010). In their systematic review, the authors searched the literature between January 1990 and December 2007 addressing the prevalence of headache and migraine in children and adolescents. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher, Liberati, Tetzlaff, & Altman, 2009) was used for the data collection, analysis, and reporting of the study. Inclusion criteria for the study were (a) population based studies with randomly selected participants, (b) children and adolescents under 20 years of age, (c) availability of descriptive data and ease of reproducibility, (d) migraine diagnosis based on IHS criteria, (e) clear description of the method of data collection, and (f) appropriate statistical analysis. Their searches in Pubmed, Google Scholar, Cochrane databases, and Embase revealed 258 articles of which 50 met the study criteria.

Within the general pediatric population, headache results range from minor disruption of children’s activities to complete incapacitation from social and physical activities (McGrath, 1990; Solomon, Skobieranda, & Gragg, 1994; Powers & Andrasik, 2005). Massey, Garnefski, Gebhardt and van der Leeden (2009) reported that daily frustration, potentially related to the
inability to partake in daily activities, was related to a higher incidence of experiencing more than one headache on the same day. In a Canadian survey looking at children’s pain experience, 40.0% of children and adolescents reported that recurrent headache was a major cause of suffering and disability (Gordon, Dooley & Wood, 2004). Langeveld and colleagues (1997) examined quality of life for adolescents with headache and reported that adolescents with recurrent headache have less satisfaction with life and health. Connelly (2003) reported that children inflicted with recurrent pediatric headache demonstrated marked impairment in mental health, interpersonal function, and general quality of life during and between attacks. Carlsson et al. (1996) performed a prospective study that compared the psychosocial functioning of children with and without headache. Children were first categorized as either having chronic headache or not using International Headache Society (IHS) criteria. Those who had headaches were then individually matched for school, class, and sex with headache-free controls. The children with headache experienced more somatic complaints, stress, psychological symptoms, absenteeism from school due to illness, and reported fewer caring persons as compared to the headache-free controls. Further research has shown adolescent headache to be highly correlated ($r = 0.48$) with depression, and recurrent headaches were twice more common in adolescents who are depressed than those who were not (Carlsson et al.).

In a longitudinal study looking at the epidemiological characteristics of headache and the impact of headache on child health, children with headaches were reported to have experienced other somatic symptoms, feelings of increased anxiety, functional limitations, and quality of life impairments (Nyame et al., 2010). The study was a prospective cohort design that was school-based and carried out within the community setting. Study participants were between 8 and 13 years of age. A research assistant administered a survey initially asking if they had experienced headaches, chest pain, stomach pain, or limb pain within the last week, and were asked to rate
their pain using a five point scale from 0 (not at all) to 4 (a whole lot). All study participants completed the State-Trait Anxiety Inventory for children (STAIC) (Speilberg, Reheiser, Ritterband, Sydemen & Unger, 1995), the Pediatric Functional Disability Inventory (PFDI) (Varni, Seid & Rode, 1999) and the Pediatric Quality of Life Inventory (PEDSQL) (Claar & Walker, 2006). Eighty-nine percent of children reported headache over the 6 month period, and the weekly prevalence of headache was 38.2%. Pain scores were reported between 0 to 4, and the mean was 0.6 (SD = 0.73). There was statistically significant correlation between headache pain scores and the number of somatic symptoms (r = 0.44, 95% CI: 0.31-0.54), and there was a strong correlation between pain score and total number of headaches reported (r = 0.80). There was a strong association reported in T-anxiety related to headache (anxiety consistent over time) (p < 0.05 and r = 0.45). There was also moderate correlation between headache pain scores and functional disability (r = 0.53, 95% CI: 0.42-0.63), and quality of life (r = 0.48, 95% CI: 0.36-0.59) that was independent of sex. The study findings highlighted the implications of headache pain and the association of headache to somatic complaints, feelings of anxiety, functional limitations, and decreased quality of life.

In a critical review of the literature measuring the impact of headache in children, Kernick, Reinhold and Campbell (2009) reported that there was a substantial headache-related morbidity—specifically related to school attendance and participation—for children with headaches. Their review focused on literature that reported on the impact of headache on quality of life in children. The authors reviewed 33 papers, and although the majority of studies had methodological limitations related to inadequate description of the study's design, methodology, data analysis, and criteria used to define headache, they concluded that children were most notably affected while in the school environment. From the review, the authors also concluded that affect of headache was directly related to headache frequency and severity.
Summary of Literature Review

Within the pediatric neurosurgical research, the headache experience of the patient with hydrocephalus has been generally characterized as an acute pain episode associated with shunt malfunction. The majority of neurosurgical headache research has been focused on physiological causes of headache in relation to ICP dynamics, clinical symptoms, and treatment modalities. Headaches affecting this population have been acknowledged, but the research has been predominantly comprised of multiple case reports of complex headache scenarios with respect to the child with shunted hydrocephalus. The case reports have been retrospective, descriptive in nature, and extremely limited with regards to the number of subjects studied. The small study sample sizes and the practice of recruiting participants retrospectively from outpatient databases have affected the generalizability of the results. Due to the retrospective nature of the chart reviews, the data collected have been dependent on the thoroughness of the documentation within the medical record. The studies addressing headache in the pediatric hydrocephalic patient population have been primarily focused on finding a diagnosis or underlying pathology for headache, as compared to describing or qualifying the headache experience and the factors that influence it. Ultimately, the headache experience for these children remains poorly researched.
Chapter 3

Conceptual Framework

Pain, is a complex entity incorporating sensory, physiological, subjective, and personal components. To address the headache pain experience of children and adolescents with shunted hydrocephalus, two conceptualizations of pain—the gate control theory (GCT) (Melzack, 1965) and the neuromatrix theory (Melzack, 1996)—and the International Headache Society’s (IHS) headache classification system were used to explore the child's and the adolescent's headache experience. The reason for the multimodal approach is that presently there is no singular theory or model that comprehensively addresses headache pain in the child and the adolescent with shunted hydrocephalus. Therefore, in this chapter, Melzack’s theories and the IHS criteria will be discussed as the conceptual framework for this study.

Theoretical Perspectives on Pain

**Gate control theory of pain.** The GCT (Melzack, 1965) has evolved while recognizing the complexity and multifactorial etiologies of pain. It has been built on the strengths and weaknesses of previous theories of pain, including the specificity theory of pain. The specificity theory, according to Descartes (1664), ascribed pain events as occurring through unidirectional, channels. Within Specificity theory, a specific pain system carries pain messages from pain receptors in the skin to specific pain centres in the brain. Therefore, a specific pain impetus was thought to have a predictable pain response by stimulating the skin receptors and initiating a specific physiological response. Von Frey (Melzack & Wall, 1983) further adapted specificity theory stating that there were pain-specific fibres that were thought to have straightforward transmissions paths to specific receptors in the brain. Therefore, pain response was thought to be directly related to a specific pain stimulus. According to Von Frey, the pain system was made up
of pain specific fibres originally termed A-delta-fibres, C-fibres, touch fibres and cold fibres; each fibre was thought to have a straight-through transmission path to a specific brain centre (Melzack & Wall). Pain was viewed as predictable, reproducible, and only attributable to a single cause. Inherent within this theory was the belief that there is a direct relationship between pain intensity and the degree of physiological damage. This understanding of pain gave rise to the expectation that a given therapy for a pain event should work to resolve pain. However, our present understanding of headache and pain has acknowledged that pain is not simply a function of tissue damage alone. Rather, the etiology of pain episodes can be multifactorial, and influenced by attention, anxiety, and other psychological variables such as age, sex, experience with pain, and perception of pain (McGrath & Hillier, 2001; Andrasik, Flor, & Turk, 2005; McGrath, 1990). The limitations in understanding pain from the perspective of the specificity theory have been that it (a) has failed to address pain that continues in the absence of identifiable pathology; (b) has not explained the absence of pain with identifiable pathology; (c) has not addressed the varied individual responses to pain and treatment; and (d) has not addressed the strong relationship between pain, impairment and disability (Andrasik et al.).

The GCT (Melzack, 1965) has informed our present understanding of pain. It is in opposition to and goes beyond the specificity theory (Descartes, 1664) by illustrating that the amount and quality of pain perceived is determined by many psychological variables in addition to physiological mechanisms (Melzack; Melzack & Wall, 1983, Melzack, 1996). The GCT highlights the concept of modulation in the dorsal horns of the spinal cord, and the excitatory and inhibitory influences of the brain within the pain process. Within this theory, the dorsal horns are no longer viewed as passive transmission stations but sites where inhibition, excitation and modulation occur (Melzack). Modulation includes both inhibition and facilitation, and incorporates both negative and positive feedback loops that are triggered by ascending spinal
pathways within different sensory and psychological contexts (Sufka & Price, 2002). As a result, nocioceptive information is subject to regulatory mechanisms located in the dorsal horns of the spinal cord causing hyperalgesic or hypoalgesic states. The gating component of this theory is carried out by the interneurons of the substantia gelatinosa, which can modulate input to the dorsal horns through either presynaptic inhibition or facilitation of afferent fibres (Sufka & Price).

Most importantly, GCT highlights the relationship between pain experience and higher brain functioning. The brain is seen as an active system that filters, selects and modulates inputs. Therefore, psychological factors, previously dismissed as reactions (i.e., stress, worry, fear, and anxiety) to pain, are now seen as an integral part of the pain process. Understanding the brain’s involvement in relation to the pain experience helps to explain individual differences in pain response and highlights pain's multidimensional aspect. Presently, within the neurosurgical context, headache pain has been predominantly associated with intracranial pressure changes and shunt functioning. However, drawing on the tenets of the gate control theory (Melzack, 1965), there are multiple child factors and experiential factors outside of shunt functioning that could potentially precipitate headache pain.

**Neuromatrix theory of pain.** The GCT highlights the central nervous system as an essential component in the pain process. The neuromatrix theory of pain addresses brain function in the pain experience highlighting that the qualities of a pain experience can originate from neural networks within the brain. From Melzack’s work on phantom limb pain, pain is produced by sensory stimulation modulated and processed within the brain, which can generate sensations and qualities of the experience (Melzack, 1999, Melzack, 2001). This theory is in sharp contrast to the specificity theory of pain (DesCartes, 1664) emphasizing that pain is not necessarily related to injury, but can also originate centrally in the absence of sensory input.
Melzack’s work indicated that: (a) the body is subserved by neural processes in the brain that are normally activated and modulated by inputs from the body, but can act in the absence of inputs; (b) the qualities we normally feel from the body, including pain, are also felt in the absence of inputs from the body; (c) the body is defined as a unity distinct from other people and the surrounding world; and (d) the brain processes that underlie the body-self incorporate genetic components that can be modified by experience (Melzack, 1996). Therefore, the brain generates the experience of the body, and sensory and cognitive inputs modulate the experience; they do not directly cause it (Melzack). This theory suggested that there are neural networks built into the brain impacting the pain experience. The neuromatrix theory of pain introduced four components to CNS involvement in pain including (a) the neuromatrix, (b) the neurosignature, (c) the sentient hub, and (d) the activation of patterned movements (Melzack).

The neuromatrix was defined as a widespread network of neurons that permit parallel processing and synthesis of brain and sensory input (Melzack, 1996). It is a widely distributed neural network including somatosensory, limbic, and thalamocortical components. The synaptic architecture of the neuromatrix is determined by genetic and sensory influences. Sensory influences include (a) input from somatic receptors, (b) visual and other sensory cognitive input (c) phasic/tonic cognitive and emotional input, (d) intrinsic inhibitory modulation, and (e) activity of the body’s stress regulating system. The neuromatrix processes information, generates patterns, and produces the pain that is experienced as a whole body. The neuromatrix can generate sensations of pain on its own or produce a neurosignature pattern of pain. The neurosignature for pain is generated by the cyclical processing and synthesis of input within the neuromatrix. The neurosignature is modulated by sensory inputs and by cognitive events such as psychological stress (Melzack). The output from the neurosignature is projected to areas of the
brain termed the sentient hub (Melzack) that then activates the spinal cord to produce muscle patterns and response to pain.

Within the neuromatrix theory of pain, Melzack also highlighted the role of stress within the pain process (Melzack, 1996). Stress is a bodily system that is activated by physical injury, infection—or any threat to biological homeostasis—as well as by psychological threat and insult of the body-self (Melzack, 2001). It disrupts the brain’s homeostatic regulation system thereby initiating complex hormonal and biological processes to reinstate homeostasis. The perception of injury begins a cascade of neuronal, behavioural and hormonal activity to reinstate homeostasis. Initially, cytokines and adrenalin are released, and the sympathetic system is activated. Subsequently, the hypothalamic–pituitary–adrenal (HPA) system is activated causing the release of ACTH and the activation of the adrenal cortex to release cortisol. Cortisol acts on the immune and endogenous opioid system (McCance & Huether, 2000). If output of cortisol is prolonged, it can produce conditions for chronic pain.

Headache pain can cause both psychological and physical stress, which can disrupt the brain’s homeostatic regulating system, and initiate the complex hormonal and biological processes to reinstate homeostasis. However, Melzack (1996) highlighted that, as a result of the body’s attempt to reinstate homeostasis and homeostasis regulation patterns that have failed, the neuromatrix can be altered. Damage to the neuromatrix in response to stress events can give rise to chronic pain (Melzack).

Ultimately, within the neuromatrix theory (Melzack, 1999), the neurosignature (the output pattern) for pain experience is determined by the synaptic architecture of the neuromatrix, which is produced by genetic and sensory influences. Most importantly, within the neuromatrix theory, genetic contributions, and neuronal and hormonal mechanisms of stress are seen as equally affecting the pain experience. Therefore, in contrast to the GCT theory of pain
(Melzack, 1965), the neuromatrix theory of pain (Melzack, 2001) highlighted the possibility that there may be factors inherent in the diagnosis of hydrocephalus itself, both genetic and biological, that could theoretically cause an increased headache experience specific to this patient population.

**International Headache Classification Criteria**

The criteria proposed by IHS (2004) also contributed to the conceptualization of pain in this proposal. The IHS criteria are considered the gold standard for classifying headaches, and were used to define the clinical symptoms manifested by the children and the adolescents with recurrent headache and shunted hydrocephalus. The 2004 edition of the IHS criteria has been revised and has been found to be more clinically suitable for use with children than the previous edition. The IHS classification system highlights clinical features that help in the assessment of headache disorders and subsequent management. Criteria within this classification system incorporate descriptors pertaining to headache duration, frequency, nature, and associated symptoms (i.e., photophobia, vomiting, nausea, and sensory or motor involvement) (Appendix A). The IHS criteria provided a means of both defining the nature and the clinical manifestations of the child's and adolescent’s headache experience, and classifying the headaches in accordance with typologies used within the general pediatric headache population.

**Proposed Conceptual Framework for Recurrent Headache for the Child and the Adolescent with Shunted Hydrocephalus**

The conceptual framework for the headache experience for the child and the adolescent with shunted hydrocephalus incorporated the gate control theory of pain (Melzack, 1965), the neuromatrix theory (Melzack, 1999), and the IHS headache classification system (International Headache Society, 2004). There was no model that comprehensively addressed headache for the child and the adolescent with shunted hydrocephalus. The conceptual foundation of this study (a)
paid credence to the complexity of headache pain, (b) was used in the development of the research questions, (c) informed the instruments used for data collection, and (d) was used to classify the headaches.

Drawing on the existing theories and the headache criteria, a conceptual framework was introduced to describe the headache experience in children and adolescents with hydrocephalus in order to explore headache beyond the physiological and sensory components of the headache pain. The conceptual framework highlighted the complexity of pain and psychological, psychosocial, and possible genetic factors that could impact the child's and the adolescent's headache experience. However, despite the fact that the two pain theories have helped to broaden our understanding of headache pain beyond the physiological and sensory aspects of pain, neither of the theories thoroughly addressed the social context of pain, nor how the various factors interacted and ultimately affected the pain experience. Despite this limitation, the use of the two theories and the IHS criteria (International Headache Society, 2004) as the conceptual framework for the study was in accordance with the exploratory nature and the purpose of the study. The study’s conceptual framework provided opportunity to gain further insight into the headache experience of children and adolescents with shunted hydrocephalus.

The proposed conceptual framework initially drew on the GCT’s main proponents: the impact of modulation and higher brain functioning on the pain experience, and the multifactorial aspects of pain. The current understanding of headache for the child and the adolescent with shunted hydrocephalus was attributed to changes in ICP, which is predominantly a physiological correlation. Although ICP can activate pain receptors in the dura and initiate a sequence of neural events leading to a pain response, there are a multitude of other factors that can influence the pain experience. The physiological pain process can be modified through the process of modulation and higher brain functioning. Essentially the gate to the pain experience can be
opened or closed depending on various factors. For the child and the adolescent with shunted hydrocephalus, factors considered that could influence the pain experience were age, sex, etiology of hydrocephalus, number of shunt revisions, and the age at the time of initial shunt insertion. These factors, for the purpose of this study, have been termed “child factors” and were derived from the literature, clinical experience, and expert opinion. Expert opinion incorporated clinical factors observed by the primary researcher and study site staff neurosurgeons with 10 to 30 years of neurosurgical experience. The child factors may precipitate or influence a headache attack, increase pain, prolong disability, or maintain the cycle of repeated headaches. Increased age and being female have been reported in the literature as being positively related to headache experience (Laurell et al., 2004; Zwart et al., 2004; Ayatollahi et al., 2002; Lewis, 2004; McGrath & Hillier, 2001). Etiology of hydrocephalus, number of shunt revisions, and age of initial shunt insertion, based on clinical experience and expert opinion, have been common factors associated with hydrocephalus. On multiple levels, these factors could have impacted the headache experience both physiologically and cognitively. Previous experience and how the child and the adolescent with shunted hydrocephalus perceived and understood their headache in relation to their hydrocephalus shared a key etiological role in headache for children.

Furthermore, the GCT (Melzack, 1965) informed the interview guide used in the qualitative interviews. Probing questions were developed to ask the child about sensory, affective, and emotional components of their headache experience as outlined in gate control theory and to recognize how physiological, psychological, and psychosocial factors can affect the experience of pain as hypothesized in both the gate control and neuromatrix theories.

Children might also have a genetic predisposition for headache (McGrath & Hillier, 2001). The neuromatrix theory of pain illustrated the complexity of CNS involvement in the pain experience. Drawing on the GCT, the neuromatrix theory highlighted CNS involvement in
the pain experience, and how sensory inputs can modulate pain. However, it moved beyond the GCT to explain how the brain and neuromatrix can genetically impact pain. Therefore, based on this theory, the child and the adolescent with shunted hydrocephalus, a condition affecting the CNS, might inherently have a predisposition to headache related to genetic and physiological changes to the CNS.

The neuromatrix theory also highlighted how stress plays an important role in the pain experience. Stress, whether perceived or actual, initiates a cascade of neuronal and hormonal events to achieve homeostasis, which can ultimately alter the neuromatrix (Melzack, 1996). Headache for the child with shunted hydrocephalus can be seen as a potential stressor for the child, manifested in how they perceive their headache and how it impacts their everyday functioning as defined by their social, family, and school functioning. McGrath and colleagues (2001) highlighted that situation-specific stress has been the primary cause of headache for children, and that many potential sources of stress are associated with school, with social and leisure activities, and family relationships. Headache within a stress-coping paradigm can be seen as a stressor that requires a coping response. Therefore, the impact of headache on a child has been determined by their ability to cope with headache and function within their normal routines (Bandell-Hoekstra et al., 2002). Therefore, stress events manifested in the child's and the adolescent's understanding of headache, and the impact of their headaches on school, social, and family functioning can potentially alter the neuromatrix and predispose these children to pain events. The neuromatrix theory of pain (Melzack) was used to guide which child factors were to be investigated within this study, most notably with respect to etiology and the subcategories of etiology.

The IHS headache classification system (International Headache Society, 2004) has provided an opportunity to classify the headaches for these children and adolescents outside of
the shunt, and to thoroughly describe the nature and frequency of the child's and the adolescent's headache experience. The use of the IHS criteria has provided opportunity to formally address and incorporate the headache experience of the child and the adolescent with shunted hydrocephalus into the general pediatric headache literature. As part of the data collection, the IHS criteria were used to inform Interview #1 as a means of classifying and capturing the nature of the headaches. Interview #1 was developed specifically incorporating criteria used in the headache classification system pertaining to the location, pain intensity, quality, aggravating factors, occurrence of nausea, vomiting, photophobia and photophobia with headache.

The study’s conceptual framework is based on key concepts from the GCT (Melzack, 1965), the neuromatrix theory (Melzack, 1999), and the IHS headache criteria (International Headache Society, 2004). The two theories and the IHS criteria have provided the landscape to describe headache for the child and the adolescent with shunted hydrocephalus while incorporating the multifactorial aspects of headache pain.
Chapter 4

Methods

A mixed method study design was used to explore the clinical and experiential components of child and adolescent headache pain. Mixed methods research involves the collection, analysis, and mixing of both quantitative and qualitative data. Mixed methods research is based on the assumption that incorporating both types of data results in a better understanding of the research problem than one data type alone (Creswell & Plano-Clark, 2007). Because of the potential complexities associated with headache pain within this study population, a singular methodology was thought to be inadequate to explore the subject matter comprehensively. Therefore, a mixed methods design was used, drawing on the strengths of both qualitative and quantitative research design, with the intent to (a) provide a more complete picture by noting trends and generalizations as well as in depth knowledge of participants’ perspectives, (b) enhance quantitative and qualitative study findings, and (c) enrich and explain the quantitative results when the quantitative results are inadequate to provide explanations of outcomes (Creswell & Plano-Clark).

The ultimate goal was to provide understanding of headache for the child and the adolescent with shunted hydrocephalus. The specific research questions were as follows:

Research Questions

1. What is the prevalence, nature, and frequency of headache in children and adolescents with shunted hydrocephalus?

2. What ‘child factors’ including (a) age, (b) sex, (c) etiology of hydrocephalus, (d) number of shunt revisions, (e) age of initial shunt insertion, and (f) history of shunt infections are associated with headache children and adolescents with shunted hydrocephalus?
3. How do the child and the adolescent with shunted hydrocephalus describe (a) their headache experience, and (b) the impact of headache on their (i) social functioning, (ii) family relations and (iii) schooling?

Definitions

**Headache.** In this study, headache referred to primary headaches defined as headache occurrence without another underlying disorder (International Headache Society, 2004). The number of headaches was defined as the number of days the child and the adolescent reported having headache within a one month period. Although all children and adolescents enrolled in the study had an underlying neurosurgical diagnosis, as per the inclusion criteria on page 39, the headaches were assumed not to be attributed to their underlying diagnosis.

**Headache types.** All headache typologies were based on modified headache criteria of the IHS (2004). The modification excluded the temporal characteristics associated with the headaches. Headache classifications were (a) migraine-like headaches, (b) tension-like headaches, (c) mixed headaches, and (d) unclassifiable headaches. The headache classifications were defined as follows:

**Migraine-like headaches.** Headache which has at least two of the following characteristics (a) unilateral location, (b) pulsating quality, (c) moderate or severe pain intensity, or (d) aggravation by or causing avoidance of routine physical activity. During the headache, the child or adolescent experienced one of the following (a) nausea and/or vomiting or (b) photophobia and phonophobia.

**Tension-like headaches:** Headache with at least two of the following characteristics (a) bilateral location, (b) pressing or tightening (non-pulsating) quality, (c) mild or moderate intensity, or (d) not aggravated by routine physical activity such as walking or climbing stairs.
During the headache the child or adolescent experienced (a) no nausea or vomiting, or (b) one episode of photophobia or phonophobia.

*Mixed headaches*: Headaches with specific criteria related to both migrainelike and tensionlike headaches as defined above. All clinical manifestations for headache classification were met relating to location, intensity, aggravating factors, occurrence of nausea, vomiting, photophobia, and phonophobia with headache.

*Unclassifiable headaches*: Headaches that were missing data on which the children were not able to report, or headaches not meeting all clinical categories outlined in the IHS criteria required to classify headaches.

**Pain intensity.** Pain intensity is the amount of pain experienced during the headache event using the Numerical Rating Scale (von Baeyer, 2006). The operationalization of the scale is described on page 57. Pain intensity is one of the headache characteristics in the IHS headache classification (International Headache Society, 2004).

**Shunt.** A shunt is a small thin tube that is surgically inserted into the ventricle and tunneled underneath the skin to the peritoneal cavity to allow CSF to be reabsorbed within the body. Shunting is the primary treatment for hydrocephalus (Greenberg, 1997).

**Hydrocephalus.** Hydrocephalus is a condition specific to the central nervous system resulting from an imbalance between the production and absorption of cerebral spinal fluid within the ventricular system (Greenberg, 1997).

**Child.** An individual who, in this study, was 7 to 10 years of age.

**Adolescent.** An individual who, in this study, was 11 to 18 years of age.

**Prevalence.** Prevalence was the fraction of a group of people possessing a clinical condition or outcome at a given point in time (Fletcher, Fletcher, & Wagner, 1996). For the
purpose of the study, headache prevalence was the child's or adolescent's self-report of having experienced headache within the previous month.

**Nature of headaches.** The nature of headaches was defined according to the criteria used for primary headaches in the IHS headache classification criteria (2004) (Appendix A). It incorporated (a) location of the headache, (b) frequency of headache, (c) how the headache felt, (d) pain scores, (e) presence of phonophobia, (f) presence of light sensitivity, (g) presence of nausea and vomiting, and (h) impact of activity on the recurrent headache.

**Child factors.** Child factors included age (in years), sex (male or female), etiology of hydrocephalus, age at the time of the initial shunt insertion (in weeks), number of shunt revisions (numerical count), and history of shunt infections (yes or no).

**Sex.** Sex was defined as the biological designation of male and female as well as sex characteristics related to socialization. Although gender and sex are two separate entities when discussing social issues, gender, was not addressed within this study. Sex was purposely selected for both qualitative and quantitative data collection and analysis allowing for triangulation of the data. Due to the exploratory and descriptive focus of the present study and the nature and limitations of the mixed methods study design, further analysis of gender and socialization was beyond the scope of the study.

**Shunt infection.** Shunt infection was a documented positive CSF culture collected at the study institution.

**Etiology of hydrocephalus.** Etiology of hydrocephalus was categorized as (a) congenital with myelomeningocele, (b) congenital without myelomeningocele, (c) intraventricular haemorrhage, (d) meningitis, (e) tumour, (f) trauma, or (g) other. The classification scheme for etiology of hydrocephalus was based on the classification system in The Handbook of Neurosurgery (Greenberg, 1997).
Experience. The use of the word experience within qualitative research can be controversial (Allen & Cloyes, 2005). Experience, for the purpose of this study, was defined by the author as the child’s or adolescent’s self-reporting of their encounter with headache and its effect on their school, social and family functioning. Therefore, experience was derived from headache that had been personally encountered and lived through by the child and adolescent.

Nature. Nature, defined by the author, was the inherent characteristics associated with headache.

Inclusion/Exclusion Criteria

Children eligible for inclusion in the study were (a) diagnosed with shunted hydrocephalus, (b) English-speaking, (c) between 7 and 18 years of age, (d) at least 6 months post-shunt insertion, and (e) cognitively able to report their headache experiences. For the child’s and adolescent’s cognitive ability, the parents were asked if the child had been (a) identified (recognized as having cognitive issues but awaiting assessment), (b) in a special education program, or (c) in the mainstream school system. Children and adolescents who had been identified or who were in special education programs, and had an Identification Placement and Review Committee (IPRC) evaluation with a verbal IQ score greater than 70 were included in the study.

Children who (a) were nonverbal and (b) presented to clinic with headache requiring immediate neurosurgical intervention were excluded.

Assumptions

At the outset of the study, it was assumed that those children and adolescents who agreed to be study participants were willing to share and provide a valid account of their headache experience. For those participants involved in the qualitative component of the study, it was also assumed that the children and the adolescents were able to articulate and describe their headache
experiences. However, it became apparent throughout the interviews that it was the first opportunity for many of the participants to speak about headaches, and the first time they had been asked questions about their headache experience. Therefore, although the study participants provided answers and were able to talk about their headache experience, these facts raised questions as to whether the depth of the interview data could have been enhanced if the children and the adolescents had had an opportunity to reflect on their headache experience, and whether it was fair to make assumptions prior to the commencement of the study about the participants’ willingness and ability to share their headache experiences.

It was also assumed that the headache experience described by the child and the adolescent were not related to a shunt malfunction as they had been reviewed by a neurosurgeon. However, based on the nature of the diagnosis of hydrocephalus and its involvement with the central nervous system, it could not be assumed that the headaches described were independent of their underlying diagnosis, nor independent of possible unknown variations of their central nervous system that could propagate headaches. For the purpose of the study, it was assumed that the children and the adolescents describing their headaches had a functional shunt and that shunt function was independent of other factors within the CNS that could possibly influence headache pain.

Inherent in the study was the assumption of a power imbalance between the interviewer and interviewee while conducting interviews with the children and the adolescents (Benner, 1994, Elwood & Martin, 2000). Throughout the data collection and interview process, the researcher and research assistants were particularly attuned to minimizing the potential power imbalance inherent in interviewing children. Strategies used to equalize the potential power inequalities included (a) allowing the child to pick the setting of the interview and where they wanted to sit during the interview, (b) presenting the interview as an informal discussion engaging the child or
adolescent rather than a formal question and answer session, and (c) reassuring the child or adolescent that there were no right or wrong answers (Benner; Elwood et al.; Holstein & Gulbrim, 2003). Most important, at the outset of the interview, the interviewer emphasized that the child was the expert and was the best person to describe the headaches. Further techniques implemented in the study by the researcher during the interview process were (a) conveying a genuine interest in understanding the participant, and using natural and age-appropriate language, (b) actively listening with little interruption, (c) paraphrasing what the child had said, and (d) engaging in dialogue with the child and the adolescent for further clarification (Benner, 1994), and accepting answers without criticism (Docherty & Sandelowski, 1999).

**Philosophical assumptions.** Inherent in any research methodology are philosophical assumptions that provide a foundation for research. These philosophical assumptions, often called ”worldviews” or “paradigms”, influence all aspects of the study (e.g. design, data collection, analyses). All worldviews have common elements but take different stances on these elements. They differ in their views about the nature of reality (ontology), how we gain knowledge of what we know (epistemology), the role that values play in research (axiology), the process of research (methodology), and the language of research (rhetoric (Creswell, 2003) .

According to Creswell’s taxonomy of the major worldviews, there are four paradigms including postpositivism, constructivism, advocacy and participatory, and pragmatism (Creswell). Postpositivism is associated with quantitative approaches that make knowledge claims based on cause-and-effect thinking, reductionism, measurement of variables and theory verification. Constructivism is associated with qualitative research and makes knowledge claims based on the meaning and understanding of a phenomenon from the study's participants and their subjective views. Advocacy and participatory worldviews are influenced by political concerns and issues pertaining to empowerment and marginalization. This research can be either qualitative or
quantitative and is characteristically collaborative and change-oriented. Pragmatism as a worldview is focused on the consequence of research with the research question being of primary importance rather than methods. Therefore, the study design is not strictly defined by one truth or reality. Pragmatism incorporates multiple methods of data collection (both qualitative and quantitative) that inform the phenomenon under study. Characteristics associated with pragmatism are as follows: (a) pragmatism is not committed to any one system of philosophy or reality; (b) researchers are able to choose methods to optimally meet the research needs and study purpose; (c) researchers look to many approaches to collecting and analyzing data, integrating both qualitative and quantitative data to provide the best understanding of the research phenomenon; and (d) pragmatists, using a mixed methods design, have an established purpose for mixing the qualitative and quantitative research findings (Murphy, 1990).

Ultimately, pragmatism allows for the use of multiple methods, different worldviews and assumptions to address a research question.

Pragmatism is typically associated with mixed methods research and, for this study, was derived from the work of Peirce, James, Mead, and Dewey (Cherryholmes, 1992).

Fundamentally, pragmatism is not committed to any one system of philosophy or reality. Hence, knowledge claims arise out of actions, situations and consequences encountered by an individual having lived the phenomenon being studied (Creswell, 2003). For this study, the child’s and adolescent’s descriptions of how their headaches affected their daily activities provided knowledge pertaining to their perspectives on headache experience. Pragmatism, was used to gain further insight and understanding of the headache experience for these children and adolescents. The headache experience for these children and adolescents with shunted hydrocephalus has not been previously explored; therefore, in accordance with the exploratory nature of the study, the pragmatic paradigm provided a cursory description of headache and the
consequences of headache on the child and adolescents school, social and family functioning. As a philosophical underpinning for mixed method studies, the focus was on the research problem (e.g. headache pain) and the use of pluralistic approaches (e.g. quantitative and qualitative) to derive knowledge about the problem (Tashakkori & Teddie, 1998). Pragmatism has been criticized as being vague, ambiguous and simplistic (Hilldebrand, 2003). As the worldview associated with mixed method study, pragmatism has been critiqued in its ability to connect qualitative and quantitative assumptions (Creswell). However, for the purpose of this exploratory and descriptive study, the mixed methods design and the pragmatic worldview were ideal to begin to understand the clinical and experiential components of headache for these children and adolescents.

**Study Design**

Based on the exploratory and descriptive nature of the research questions, a mixed methods research design was used. This design supported the use of both qualitative and quantitative research methods in the same study offsetting the disadvantages of using only one and another method alone, and providing a diverse data set. Table 1 outlines the strengths and weaknesses of using qualitative and quantitative methodologies for the child and adolescent headache. A mixed method study incorporating both methodologies was used to gain clarity about headache; researching it from multiple vantage points (Streubert & Carpenter, 1999). Mixed methods designs are based on a pragmatic worldview, focusing on the consequence of research, the primary importance of the questions asked, and multiple methods of data collection (Creswell, 2003; Creswell & Plano-Clark, 2007; Tashakkori & Teddie, 2003).

Pain is a complex entity, incorporating sensory, psychosocial, and psychological components, so the use of a mixed methods design in this study reflected the multidimensional aspects of a pain experience and drew on tenets of both methodologies to broaden what is known
about headache pain, and the pain experience of children and adolescents with shunted hydrocephalus.

Consistent with the conceptualization of this study (Chapter 3), the etiology of headache was multifactorial. The quantitative component of the study addressed prevalence and potential child factors associated with headache occurrence. The qualitative component of the study allowed for the child to describe their headache experience from their perspective. Therefore, the use of a mixed methods design was appropriate, as it allowed for the development of a diverse set of data addressing multiple factors potentially contributing to the pain experience. This diverse data set allowed for a comprehensive characterization and description of the headache experience of these children from their own perspective. The concurrent mixed method of triangulation was used to interface the qualitative and quantitative data, and to answer the research questions relating to child and adolescent headache. Concurrent triangulation is intended to obtain different but complementary data to best understand a research problem.
Table 1

*Strengths and Weaknesses of Qualitative/Quantitative Methodologies for the Child and Adolescents’ Headache*

<table>
<thead>
<tr>
<th>Research method</th>
<th>Strengths</th>
<th>Weaknesses</th>
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<tbody>
<tr>
<td>Quantitative</td>
<td>Rapid data collection</td>
<td>Self report of headache</td>
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<tr>
<td></td>
<td>Clearly defined child factor</td>
<td>Bias in retrospective data collection of child factors</td>
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<tr>
<td></td>
<td>Study instruments contain</td>
<td>and assumptions</td>
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<tr>
<td></td>
<td>concise criteria to classify</td>
<td>made about which</td>
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<tr>
<td></td>
<td>headaches in accordance to IHS criteria</td>
<td>child factors to collect data on</td>
</tr>
<tr>
<td></td>
<td>Analysis of data using</td>
<td>Some respondents</td>
</tr>
<tr>
<td></td>
<td>descriptive and inferential statistics</td>
<td>may not be able to answer/respond to</td>
</tr>
<tr>
<td></td>
<td>Data results used for comparison</td>
<td>Interpretation not discussed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Focus is on preconceived issues and concepts</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Statistical significance not indicative of clinical significance</td>
</tr>
<tr>
<td>Qualitative</td>
<td>Descriptive interviews allow for participants to describe their headaches in their own words</td>
<td>Time consuming interview dynamics related to interviewing children</td>
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<tr>
<td>Questions in qualitative interview</td>
<td>provide framework for open ended inquiry into how headache affects school, social, and family environment</td>
<td>Children and adolescents’ ability to speak about headaches (i.e. may be first time speaking about them)</td>
</tr>
<tr>
<td>Able to analyze headache descriptions specific to age and sex</td>
<td>Clinical setting</td>
<td>Results based on interpretations of research/research team assumes children/adolescents are speaking about headache</td>
</tr>
</tbody>
</table>
(Creswell & Palno-Clark, 2007; Tashakkori & Teddie, 2003). Because pragmatism and mixed methods research value objective and subjective knowledge, it is inherent within this methodology that contradictory results will occur, which is reflective of the multiple views of knowing and valuing the social world (Creswell & Plano-Clarke). By considering rival explanations throughout the analysis, the researcher gains a more complete understanding (Streubert & Carpenter, 1999) of the phenomenon under study.

Historically, triangulation of data sources was initially seen as a way of seeking convergence across qualitative and quantitative methods (Jick, 1979). However, recognizing that inherently all methodologies have limitations and biases, triangulation is a means of neutralizing or cancelling the biases of other methods (Creswell, 2003, Fielding & Fielding, 1989). Therefore, triangulation of the results helps to confirm findings and conclusions, and to compare and contrast results as there is no expectation that the results will converge. Although the concurrent method of triangulation used in this study was appropriate for the exploratory and descriptive nature of the research questions, another triangulation methodology that could have been used was a data transformation model of triangulation (Creswell & Plano-Clarke, 2007).

The idea behind data transformation is to convert one form of data into the other so that it can be easily merged. For example, the qualitative data could be converged to quantitative data by counting the number of occurrences of codes or themes, and then the quantified results could be compared with variables in the quantitative analysis.

This methodology took place in two stages. In the first stage, qualitative and quantitative data were collected concurrently with the goal of elaborating, enhancing, and clarifying results from one method with the results from the other method (Greene, Caracelli, & Graham, 1989). During data collection, the priority between the two methods was equal (Tashakkori & Teddie, 2003). In the first stage, quantitative and qualitative data on the child’s and the adolescent’s
headache experience were collected, prepared, explored, and analyzed independently. During the second stage of the triangulation process, the two sets of data and results were merged and compared in relation to the research questions. Comparison of the data sets occurred through discussion and the use of matrices. Matrices were used for the child factors of age, sex, and etiology. However, the majority of the comparisons were made in the discussion section of the study. With this approach, a statistical result was reported and followed up with quotes or information about a theme that confirmed or disconfirmed a quantitative finding (Creswell & Plano-Clarke, 2007). Therefore, the integration of the results of the two methods occurred during the discussion phase of the study where the convergence of the findings and any discrepancies were explained (Creswell, 2003; Tashakkori & Teddie). This allowed for a comprehensive description of the child’s and the adolescent’s headache experience and was an appropriate method of triangulation, which was used to answer the study’s mixed method research questions.

Sample, Sampling Procedure and Sample Size

Both purposeful and convenience sampling methods were used during data collection. Convenience sampling was used to answer the first two research questions related to the prevalence, frequency, nature, and child factors associated with the headache experience. Children and adolescents with shunted hydrocephalus who met the inclusion criteria were recruited sequentially throughout the study period when they attended their outpatient follow up appointments. All eligible study participants, once consent was obtained, were asked a screening question, and demographic data relating to the child factors were collected. Those responding positively to the screening question proceeded to Part 2 of the study, and were asked questions relating to the nature of their headaches, based on the IHS criteria.
To answer the third research question, convenience, sequential, and purposeful sampling were used to recruit the children and adolescents for the descriptive qualitative interviews. Convenience and sequential sampling were used initially, as described above, for Part 1 and 2 of the research study. However, in the third part of the research study, children and adolescents who responded “yes” to having headache were then stratified sequentially to adolescent and child age groups. Stratification was used to ensure equal representation of both age categories within the qualitative interviews in anticipation of triangulating the qualitative and quantitative results. The age strata were based on the literature, which indicates the increased prevalence of headache with increasing age in the general paediatric headache population (Laurell et al., 2004; Zwart et al., 2004; Ayatollahi et al., 2002; Lewis, 2004; McGrath & Hillier, 2001). Figure 1 summarizes the recruitment and data collection strategies used in the study.

**Sample size.** A sample size of 250 participants was required to assure appropriate power and statistical significance to answer the first two research questions pertaining to the quantitative component of the study. The sample size was calculated based on the assumption that 60.0% of the children and the adolescents would have headache. The assumption was based both on expert neurosurgical opinion and on general paediatric headache research (Hershey et al., 2007; Galleli et al., 2005; Koening et al., 2002; Sillanpaa et al., 1996; Wang, Fuh, & Lu., 2009; Shivpuri, Rajesh, & Jain., 2003; Kroner-Herwig, Heinric, & Morris., 2007; and Bandell-Hoekstra et al., 2000). The primary goal of the study was to determine the prevalence of headache. Therefore a sample size of 250 was chosen as it would produce a 95% confidence intervals of +/- 6% (absolute) around a prevalence of 60.0% (Desu et al., 1990). Furthermore, to address the child factors related to headache, a sample size of 250 participants is sufficient to achieve 80.0% power to detect differences of at least 18.0% (absolute; representing an odds ratio of 2.0) between two groups of equal size; this assumes a two-sided alpha of 0.05 and beta at 0.20
(Desu et al.). To explore the adjusted contribution of child factors in relation to headache, a minimum of 80 participants with the event of interest (headache) were required to conduct a logistic regression with up to eight covariates based on Norman & Streiner (2008) recommendation of 10 participants per event in logistic regression. For the qualitative component of the study, a subsample of 20 children and adolescents was recruited and stratified equally to the predefined child and adolescent age groups. The sample size was relatively small, but appropriate for the research question (Guba & Lincoln, 1989). The final sample size was based on the study design, the descriptive nature of the study, the quality of the data, and the amount of useful information obtained from each participant (Sandelowski, 1995; Morse, 2000).

**Setting.** The study took place in a neurosurgical outpatient clinic setting within a paediatric university affiliated hospital in central Canada. The clinic provides family-centred care to children and adolescents regionally and internationally, and is comprised of a large multidisciplinary team specifically meeting the needs of this patient population. Within this neurosurgical setting, there were five staff neurosurgeons and outpatient neurosurgical clinics daily. The children and the adolescents attending this outpatient setting had repeat visits and routine follow-up appointments. However, each child and adolescent was only entered into the study once.

**Data Collection Procedures**

Following REB approval, study recruitment and data collection began in January 2009 for an 8-month period concluding in November 2009. Children and adolescents attending any of the five neurosurgical clinics for well visits who had met the inclusion criteria were approached to take part in the study by the research nurse.

**Data management.** Prior to data collection, the researcher coded the demographic variables and previously defined child factors numerically. For example, for the child factor sex,
male was coded as 0 and female was coded as 1. An Access database was developed for all the study data and the demographic and child variables were defined within the program, coded and ranges were defined (where applicable). Coding of the variables allowed for consistency among the research assistants who entered the data into the prepared database for analysis. Both research assistants were educated by the researcher regarding the coding scheme. The primary researcher reviewed the coding scheme with the research assistants. All coded data were reviewed by the second research assistant and the primary researcher at study completion to ensure accurate coding technique. The variable etiology was documented and coded by the research nurse and subsequently rechecked by the primary investigator to ensure accuracy of the data. All headache classification data were reviewed by the primary researcher and validated with an external reviewer.

Demographic data, data from the screening question, and from the second interview were double entered into the computer data management program Microsoft Office Excel program and Access for all study participants. Initially, all data were entered into the Access database by the research nurse. Upon completion of data collection, all data that had been entered into the Access database were reviewed by the researcher and research assistant and were reentered into an Excel database as part of a secondary review. The Microsoft Office Excel program database was exported to SAS (statistical analysis software) for the statistical analysis. Data were cleaned with the use of a computer program using logit and range checks. When there was a discrepancy related to the data entered by the research assistant and the researcher, the researcher located the primary document and determined the appropriate code for the data and the correction was made.

Anonymity and privacy. All participants were given a study number and coded identification number (ID). All data collected for each participant had the same number and ID code. Only the research assistants and the researcher were aware of the coding scheme. The
numbering of the participants commenced with 01 and was assigned sequentially. There were no personal identifiers on any of the data collection forms.

**Security.** Paper copies of demographic data were kept together in a locked filing cabinet, separate from the master data sheet and consents, and were only accessed by the primary researcher, research assistant, and doctoral supervisory committee. All individuals involved in the study had Research Ethics Board training consistent with the requirements of the institution. All data were stored in a double locked area to which only the researcher had access. Computer data were kept in a double locked area, and all computer documents were password protected and encrypted. The data were secured according to the institutional requirements for confidentiality in accordance with the CIHR Tri-Council Privacy Commission. One back-up copy of the data was stored on an encrypted USB key, which was stored in a locked drawer in the primary researcher’s office. Audio tapes of the interviews, once transcribed and reviewed by the researcher, were destroyed. Similarly, once the demographic data had been entered into the database and checked for accuracy, the paper copy of the demographic information was destroyed, as was consistent with the current institutional CREB practice and the current privacy legislation in Ontario. All data pertaining to the study will be kept for a 7-year period after the study completion date. At that time all documents will be erased from the computer databases.

**Missing data.** There were no incomplete demographic data or data pertaining to the child factors. The only data missing was from the interview questions relating to the IHS Headache Classification. This missing data was related to the location of the headache, the sensory headache descriptors, and the pain intensity. Four children were not able to state or show where their headaches occurred despite multiple attempts by the research assistant to help them answer the question. These children responded “I don’t know.” With respect to the sensory descriptors, due to the nature of the structured interview and that the interview was designed specifically
using the IHS criteria, if the descriptors within the survey were not applicable to the child's or adolescent's headache, no other sensory descriptors could be entered or used. Sixteen children did not respond to the question related to the headache descriptors. Children and adolescents in the qualitative interviews were able to describe their headaches using their own terminology. The children were asked to pick a predefined answer to classify the type of headache. If the specific descriptor did not pertain to the child’s headache experience, the descriptor was coded as 999. Essentially, data missing from the first interview were related to (a) the descriptors not being applicable to their headaches, (b) the child or adolescent did not experience the symptom, or (c) the terminology used from the IHS criteria may not have been terminology the child or adolescent was familiar with nor would use to describe their headaches. Therefore, no attempt was made to find the missing data. Data pertaining to the description of the headaches not collected using quantitative methods were addressed during the qualitative interviews.

Data Collection

Neurosurgical clinic lists were reviewed by the research nurse for routine follow-up appointments for children and adolescents with shunted hydrocephalus. Children meeting the study inclusion criteria were given an information sheet regarding the study from the research nurse when coming to clinic. After reviewing the information sheet, they were asked if they were interested in being involved in the study. Once the child and family agreed to participate in the study, consent was obtained by the researcher (Appendix B, H). The research nurse also kept a log of children and adolescents refusing to participate in the study and the reasons why (Appendix C).

Demographic data were obtained from the neurosurgery database, the chart review, and the parent report. The neurosurgery data base was developed in 1952, and contains all medical and demographic information specific to children and adolescents with the diagnosis of
hydrocephalus under the care of the specified neurosurgical service. It is continually updated by a research nurse hired to manage the database. Demographic data obtained included the age of the child, sex, etiology of hydrocephalus, number of shunt revisions, age at the time of initial shunt insertion, school placement, and history of shunt infection. These data were documented by the research nurse on the demographic data collection form (Appendix D).

Following collection of the demographic data, a combination of closed interviews and semi-structured interviews were undertaken to answer the qualitative and quantitative research questions relating to the prevalence, clinical presentation, and description of the child and the adolescent with shunted hydrocephalus headache experience.

The data collection session was made up of three parts. Parts 1 and 2 of the data collection were collected by a research nurse. Two research nurses were involved in the study. The first research nurse collected data from January 2009 until August 2009. The second research nurse collected data from August 2009 until November 2009. Both research nurses had a background in pediatric headaches and were trained in interviewing. Part 3 of the data collection, the qualitative interview, was performed by the doctoral candidate who had a background in pediatric headaches and was trained in interviewing children.

Part 1 of the data collection session was a screening question for headache in children (Appendix E). The question was general and not too restrictive to avoid selection bias. The screening question was used to answer Research Question #1 (pg. 35) pertaining to the prevalence of headache outside of shunt malfunction for the child and the adolescent with shunted hydrocephalus. Based on the child or adolescent’s response, they were either categorized as positive or negative for headaches. The child was categorized as positive if they answered “yes” to having headache in the last month. The child was categorized as negative if the child answered “no” to having headache in the last month. If the child was categorized as
negative to having headache, they did not proceed to Part 2 and 3 of the data collection interview. However, their demographic information was recorded for analysis pertaining to child factors and prevalence.

Part 2 of the data collection session involved a structured interview (Streubert & Carpenter, 1999). The structured interview incorporated questions relating to headache with predetermined answers (Appendix F). The structured interview was used to further characterize and classify the positive headache responders using the International Headache Society’s primary headache categorization (Appendix A). Children between 7 and 9 years of age had a primary caregiver present for Part 2 of the data collection to allow for accurate characterization of the headache. Prior to beginning the interviews, all children and adolescents were asked if they wanted to have a parent present.

Part 3 of the data collection session involved semi-structured descriptive interviews (Sandelowkski, 2000) to answer Research Question #3. The descriptive interview incorporated questions to capture the child's and the adolescent's perspective and the impact of headache in relation to family, social functioning and school (Appendix G). All interviews were conducted face-to-face with the child or adolescent using a standard interview protocol (Appendices E, F, and G). The interview guide was developed by the researcher based on pediatric headache research and clinical experience. The questionnaire was piloted on children of similar age groups for clarity and understanding. No changes were required.

The screening question and subsequent interviews were combined in one data collection session occurring either before or after the clinic visit. The screening question and first interview took place in a private clinic room. For those children and adolescents who participated in the qualitative descriptive interviews, the interviews took place in a private area close to the clinic area. the children and the adolescents chose the location of the interview. During the qualitative
interview process, the researcher compiled field notes and made reflective notes on any thoughts and ideas after each interview. Field notes are informal notes taken during the interview highlighting events relating to the interview site and environment, and the researcher’s feelings, reactions, insights, and interpretations (Miles & Huberman, 1994). The interview data were transcribed by the research assistants into a Microsoft Word document in preparation for analysis. The research assistants were trained in transcription and given a written template for transcribing the data, which provided standard rules for transcription. The research assistants also completed a course relating to Research Ethics Board policy and procedure for confidentiality specific to the study institution. The interviews were transcribed verbatim. The researcher reviewed the transcripts to ensure the accuracy of the content. Minor corrections were made, mostly related to spelling. Potential biases to the credibility of the qualitative data collected in the qualitative descriptive interview were addressed by using purposeful sampling, standardized interview protocols, data collection tools, and transcription templates (Creswell, 2003; Creswell & Plano-Clarke, 2007).

**Instrumentation.** Part 1 of the data collection was a single screening question for headache: “Have you had a headache in the last month?” The question was binary, and the child or adolescent either answered “yes” or “no” (Appendix E). Screening questions have been used in previous studies that attempted to define prevalence of headache in various pediatric and adult populations (Laurell et al., 2003; Torelli, Beghi, & Manzoni, 2005; Fendrich, 2007; Beghi, Monticelli, Amoruso, Zarrelli, & Italian General Practitioner Study, 2003; Shivpuri et al., 2003; Dent, 2004; Gervil, Ulrich, Olesen, & Russell, 1988; Dooley, 2005, 2003; Gallelli et al., 2005).

Part 2 of the data collection involved a closed ended interview used to classify the positive headache responders for primary headaches (Appendix F). The survey was used to characterize each of the headache types (migrainelike headaches, tensionlike headaches, mixed
headaches or undescrivable headaches). Therefore, if children had more than one type of headache, they completed more than one survey. The survey was developed by using the second edition of the IHS Classification (International Headache Society, 2004), specifically by focusing on the criteria pertaining to primary headaches (Appendix A). The classification system was first developed by a team of headache experts in 1988 (International Headache Society) to provide a general and accepted classification of headaches for research and management. The first edition was developed predominantly from a consensus of expert opinion. This first edition provided a solid framework for adult migraine but was clinically less sensitive to migraine in the pediatric population. The second iteration, published in 2004, (International Headache Society) incorporated developmentally sensitive changes to permit a broader applicability for children and adolescents while maintaining specificity and improving sensitivity. Although evidence-based research provides a better description of different headache disorders, it is not purely an evidenced based classification system. However, it is a classification system that is well-accepted in the literature and continues to be used as the gold standard clinically worldwide for headache classification, treatment, and management.

The Numerical Rating Scale (NRS) was used to capture the intensity of a pain experience (von Baeyer, 2006). The NRS was initially developed for acute post procedural pain. However, in the research literature this measure has been used for disease related pain, and has well-established reliability and validity (Stinson et al., 2006) as a self-report measure in this age group. Self-report is an appropriate measure of pain intensity in children who are old enough to understand and use self-report, are not distressed, do not have impaired cognition, and are verbally able to communicate (von Baeyer). Children meeting the study inclusion criteria also met the criteria to provide a self-report of pain. The numerical rating scale includes indicators from 0 to 10 with 0 being “no pain” and 10 being “the worst pain ever”. The child and the
adolescent were asked to provide a numerical rating of their pain intensity for each of their reported headache types. If the child stated they had two types of headache, they would report a pain intensity score for each headache. Children and adolescents were given instructions regarding the use of the research scale by the research assistant (Appendix I).

Part 3 of data collection included a semi-structured descriptive interview. This interview was composed of questions that were derived from the literature review and the conceptual framework, and conceived of in consultation with expert practitioners specializing in headache and neurosurgery. The interview questions were open-ended to allow the children and the adolescents to express their unique thoughts and experiences to further describe the headache experience for the child and the adolescent with shunted hydrocephalus and its impact on family, social and school functioning (Appendix G). Probes were also developed within the interview guide and were used to aid in the development of thick descriptive data.

All three parts of the data collection process were pre-tested for clarity, comprehensiveness and feasibility with children and adolescents within this particular population who were known to experience headaches. Four consecutive patients with shunted hydrocephalus attending one of the five neurosurgical clinics who met the study inclusion criteria were asked to review the questions for clarity and understanding. Two participants were between 11 and 18 years of age and two were between 7 and 10 years of age. No changes were required based on piloting of the measures. Although they met the study inclusion criteria, they were not enrolled in the study.

**Qualitative interview data.** The qualitative interview data were transcribed verbatim by the research assistant into a Microsoft Word document. The researcher reviewed the interview and transcription to ensure accuracy in the transcribing process. All interviews were labeled according to the participant number assigned. All audio tapings were downloaded onto
an Intel audio/video computer program and were erased from the handheld recorder immediately after the interview. They were coded with their corresponding study numbers and also coded according to age and sex. The interviews were kept in a password protected encrypted computer, locked in a drawer, and kept in a locked office.

The researcher also entered the field notes obtained during the interview into a Microsoft Word document. The handwritten notes were also kept in a securely locked filing cabinet in a locked office as part of the audit trail. From the initial transcripts, multiple Microsoft Word documents and files were developed from the interview data to help with the data analysis. The initial interview file contained the whole interview. Subsequently subclassification systems of files were developed. The subclassification system was developed based on the sensory, emotional and affective components of pain described in the Gate Control Theory (Melzack, 1965) with further subcategories relating to the school social and family environment. Sub-classification files were used to organize the qualitative data for components of the analysis. They incorporated data abstracted from the interview questions and answers. The subclassification files that were developed addressed (a) the child's and the adolescent's description of their headaches categorized under physical, emotional and affective components, (b) coping and management strategies, (c) the impact of headache on school, (d) the impact of headache on social functioning, and (e) the impact of recurrent headache on family functioning. Each subclassification was titled accordingly. Matrices (Creswell & Plano-Clarke, 2007) were developed incorporating the data from the daughter files. Matrices (Appendix J) were used to allow for comparison between the qualitative and quantitative data. Four matrices were made: two for the child and the adolescent age strata, and two for sex. The matrices were used to analyze and describe the interview findings specific to age and sex. Files were developed and
maintained throughout the data collection by the primary researcher. Decisions regarding data management were documented and kept as part of the audit trail.

**Data Analyses**

Concurrent data analysis was used and involved two stages. The analysis began with separate data analysis of the qualitative and quantitative data followed by the merging of the results. Consistent with the convergence model of data analysis, once analyzed, the findings were triangulated (pg. 129) and discussed in the discussion chapter (Creswell & Plano-Clarke, 2007).

**Quantitative analysis.** The goal of the quantitative analysis was to answer the first two study research questions:

What is the prevalence, nature and frequency of headache in children and adolescents with shunted hydrocephalus?

What child factors, including (a) age, (b) sex, (c) etiology of hydrocephalus, (d) number of shunt revisions, (e) age of initial shunt insertion, and (f) history of shunt infections, are associated with headache children and adolescents with shunted hydrocephalus?

**Statistical analysis.** Categorical factors are presented as frequencies and percentages. For example, point prevalence of headache was calculated as the proportion of the children and the adolescents who answered “yes” to the screening question with respect to whether they had headaches, divided by the total number screened, and was expressed as a percentage. Continuous factors (e.g., age) are presented using measures of central tendency and univariate descriptive analyses, such as means and standard deviations (for distributions that are approximately normal), and medians and range (for skewed distributions).

The demographic data, clinical manifestations, and frequency of headache were analyzed using measures of central tendency and univariate descriptive analyses. Categorical data were
described using frequency distributions and percentages. Continuous variables were described using measures of central tendency. The demographic data included the independent variables in Table 3. The independent variables on the clinical manifestations and the frequency of headache were based on the study questionnaire developed from the IHS criteria, and are listed in Table 5. Further to the descriptive analyses, headache was either classified as migraine-like headaches, tension-like headaches, mixed headaches, or unclassifiable.

Bivariate analyses were undertaken to determine which child factors were associated with the child’s and adolescent’s headache experience. Initially, bivariate analyses were performed on the all of the child factors defined in the study to investigate their relationship to the child's or adolescent's report of headache.

Bivariate analyses were initially conducted using Chi-square tests of association, but due to small cell sizes (i.e. less than five) for a number of comparisons and for parsimony, Fisher’s exact test was used for all comparisons involving categorical data. To compare continuous factors between children with headache and those without, Students t-tests were used when normality could be assumed, and non-parametric Mann-Whitney U tests were used when a violation of the normality assumptions was suspected.

A multiple logistic regression analysis was conducted to further delineate the child factors associated with the child’s or adolescent’s report of recurrent headache. Independent variables with reported p-values of less than or equal to 0.20 in the bivariate analysis (Hosmer & Lemeshow, 2000) were incorporated in the multiple regression modeling. The factors that were significant in the bivariate analysis were then entered into the multiple logistic model.

Odds-ratios and 95% confidence intervals were presented for all factors that were entered into the model. Finally adequacy of the logistic regression model was examined using the Hosmer-Lemeshow test for fit (Hosmer & Lemeshow, 2000). All analyses were conducted
using SAS version 9.2 (Cary, NC). The level of statistical significance was set at 0.05 for all analyses.

**Qualitative analysis.** Content analysis of the qualitative data was used to provide a descriptive summary of the child and adolescents headache answering the third research question:

How does the child and the adolescent with shunted hydrocephalus describe (a) their headache experience, and (b) the impact of headache on their (i) social functioning, (ii) family relations, and (iii) schooling?

The qualitative analysis occurred concurrently with the data collection. All interviews were transcribed and coded within a week of completion by the research assistants. Both research assistants were given typed instructions regarding the transcribing process. All transcriptions were reviewed by the primary researcher. The primary researcher reviewed the first three interviews focusing on the interview technique. Particular attention was made to ensure that questions were open-ended and that there was open discussion and appropriate follow-up conversation based on what the children and the adolescents had said. This was done to maximize and refine the interviewing technique. Reflections with respect to the initial interviewing technique were captured in the field notes.

The qualitative data were analyzed using both deductive and inductive analysis and content analysis. Deductive and inductive analysis techniques are both appropriate analysis strategies for the exploratory and descriptive nature of the study (Miles & Hubermann, 2005). Content analysis is the strategy of choice in qualitative descriptive studies when research on a phenomenon is limited (Hsieh & Shannon, 2005). It involves the generation of codes and categories to understand the manifest and latent content of the data (Sandelowski, 2000). Coding involves a process of organizing material (Creswell, 2003). Deductive analysis was used to
generally describe the child’s and adolescent’s experience of recurrent headache. In deductive analysis, the researcher first creates a list of key categories prior to the interviews (Miles & Hubermann; Hsieh & Shannon). Subsequently, directive content analysis was used to analyse the data. Directive content analysis involves line-by-line analysis of the interviews and placing direct quotes from the interview data into the predefined categories (Hsieh & Shannon). The data were then used to generally describe the predefined categories. The use of the deductive analysis technique also helps to organize and prepare the data for further inductive analysis. The deductive categories used in this analysis were (a) physical pain descriptors, (b) emotional aspects of headache, (c) affective aspects of headache, (d) coping and management strategies, and (e) social, school, and family functioning. These categories were developed from the conceptual model (Chapter 3 pg. 25).

An inductive analysis was also conducted with the goal of developing overarching themes from the data. The inductive approach to analysis incorporates a conventional approach to content analysis. The conventional approach to content analysis allows the researcher to be immersed in the data, allowing new insights to emerge and categories to be developed from the descriptive interviews (Hsieh & Shannon, 2005). One advantage to content analysis is that the study participants’ perspectives and thoughts directly inform the thematic development. Knowledge is generated based on the participant’s unique perspective and grounded in the actual data (Hsieh & Shannon).

A descriptive inductive open coding technique described by Strauss and Corbin (1990) was used in the inductive analysis and thematic development. Open coding is used in the developing of codes and categories (Creswell, 2003; Miles & Hubermann, 1994; Streubert & Carpenter, 1999). The process of open coding entails labeling the phenomenon, developing categories, and subsequently making connections between the categories (Strauss & Corbin).
Throughout the analytic process of developing codes, techniques, such as the use of questioning and making comparisons, were used to achieve analytical depth (Strauss & Corbin).

After the interviews had been transcribed verbatim into a Microsoft Word document, the transcripts were read through many times. The goal of the initial read was to develop a preliminary understanding of the subjective headache experience as a whole. Subsequently, the transcript was analyzed line by line, and preliminary codes were developed by the researcher. The researcher read each sentence and paragraph, highlighting text and producing labels throughout. Once this line-by-line analysis was completed, the researcher read the whole text in its entirety. Once all interviews were analyzed, all the codes were reviewed, defined and collapsed into the final coding scheme.

From the coding scheme, themes and subcategories were developed. The subcategories and themes were formed by grouping the concepts pertaining to the same phenomena (Strauss & Corbin, 1990). Definitions were applied to the codes (Hsieh & Shannon, 2005). A document was developed with the codes, their definitions, and examples supporting each code identified from the interview data. Finally, themes were developed from the inductive categories.

Throughout the qualitative research process, the researcher memoed impressions and thoughts related to the analyses. Memoing was used during the coding process and has been defined by Glaser (1978) as the write up of ideas about codes and their relationships. Memos are conceptual in intent and their purpose is to tie the data into a recognizable cluster developing categories. Memoing moves from empirical data to a more integrated understanding of the event. The memos in the study were dated, titled, and stored with the interview data. Through memoing, labels emerged to help in the coding scheme.

Various techniques were used during the data collection and analysis to enhance the credibility of the findings. First, participants with various experiences were included. The wide
range of experience contributed to a richer variation of the child’s and adolescent’s recurrent headache experience, and also increased the credibility within the study (Cavanagh, 1997).

Second, an audit trail was used to document decisions made pertaining to the collection and analysis of the data. This trail ensured that “rules” existed for coding thus ensuring accuracy in the process of coding and transcribing the data (Burnard, 1991; Cavanagh, 1997). Decisions relating to how meanings were derived and the unit of analysis were described within the audit trail. Definitions were also assigned to the categories used in the study. When presenting themes relating to the analysis, representative quotations were used from the transcribed text to highlight and support the thematic development.

Finally, an independent researcher trained in qualitative analytic methods reviewed the analysis of some of the interviews to ensure the data were labeled and sorted in a reliable manner (Sandelowski, 2000). The researcher also met periodically with the expert qualitative researcher on the committee and the supervisor on the research team to review the analysis strategies and the some of the transcripts. Constant comparative techniques and the use of negative cases were also used within the analysis (Creswell & Plano-Clarke, 2007).

Triangulation of the data from the quantitative and qualitative data analyses occurred in the qualitative results and had been previously described in the study design. In the discussion chapter, triangulation was used to directly compare and contrast the quantitative statistic results with the qualitative findings (Creswell & Plano-Clarke, 2007).

**Ethics**

Prior to the start of the study, the proposal was submitted for ethical review through an accredited clinical research ethics board (REB) at both the study site and the affiliated university research ethics board. All data were saved in accordance with the institutional policies of the study institution.
Children and families were informed that their participation was voluntary and, regardless of their participation in the study, their standard of care would remain the same. The study was explained in age appropriate terms and informed consent was obtained. The consent form was read to the child and parent in detail, and they were asked if they understood what the consent form had said and if they had any questions. The guiding principle for consent was the child’s capacity to give consent, guided by the Tri Council’s Policy regarding competency and consent (Canadian Institutes of Health Research, 2005). If the child was able to understand the information presented, the child was seen as capable to sign the consent. The researcher assessed the child’s capacity to give consent by asking the child to explain the study in which they agreed to participate. If the answer was consistent with the general purpose of study, the child was deemed capable for providing consent. Each child was assessed individually by the researcher, in discussion with the parent, to determine their child’s capacity to give consent. There were no study participants unable to give consent. All children and adolescents were given a $5 gift certificate to thank them for their time participating in the study. For the children participating in the Part 3 of the study, their parents were reimbursed for their parking, and they were given a movie pass to thank them for their participation. Participants were informed of the process and were ensured their confidentiality and anonymity would be maintained throughout the research process. The researcher reviewed this process at the time of obtaining consent. Although demographic data were collected, the child was identified by a study number during the demographic data collection, and subsequently, all interviews were labeled with this number. There was no record of any unique identifiers (e.g., the child’s name or hospital number) on any of the documentation. The information was stored in a locked filing cabinet, in a locked office only accessible by the doctoral researcher and her supervisor. The information gathered was for the primary purpose of this study. The research assistants were trained and informed of
procedures in place to maintain the confidentiality of the child and the adolescent, and both research assistants undertook and passed the REB training at the clinical setting. Participants were informed that confidentiality would only be breached if, at anytime during the interviews, there was any indication that the child or adolescent may be engaging in activities that are illegal or causing harm to themselves or others.

Once the audio tapes of the interviews were downloaded onto the computer program, and were transcribed and reviewed by the researcher, the original audio recordings were erased as per REB requirements.
Chapter 5
Quantitative Results

The purpose of this chapter is to present the quantitative findings of this mixed methods study. The results of this chapter are presented as follows (a) description of study sample and the sample characteristics, (b) the prevalence, frequency, and nature of headache, and (c) the relationship between child factors and headaches.

Sample and Sample characteristics

Sample. Two hundred and fifty children were recruited between January 2009 and November 2009. Two hundred and forty seven children were involved in the study analysis because, upon review of the database, 3 children had been double entered. The recruitment and data collection process is summarized in Figure 1. The main reasons for non-participation were due to (a) the child or adolescent not attending the scheduled clinic appointment (n = 12), and (b) a change in the scheduled clinic time related to clinic flow or delays related to imaging (Computerized Tomography and Magnetic Resonance Imaging) bookings (n = 4).

Sample characteristics. The average age of the study participants was 13.2 years (SD 3.2). The age range was 7 to 18 years, and the median age was 14 years. The average age of shunt insertion was 2 years (SD 3.6). The age range was from 1 week to 14 years, and the median age for shunt insertion was 13 weeks. This finding was consistent with clinical practice as the majority of children with hydrocephalus have been diagnosed and treated at less than 6 months of age (Greenberg, 1999). The sample consisted of 46.9% (116/247) males and 53.0% (131/247) females, which is representative of the pediatric hydrocephalus population as there is no sex predilection. All study participants that were enrolled in the study completed the study. None of the study participants experienced any emotional reactions during data collection.
Figure 1. Flow Diagram of Study Sample and Data Collection.
or required any supportive services from other members of the health care team. The demographic data and the data pertaining to the child factors are summarized in Table 2.

Prevalence, Frequency and Nature of Headache

**Prevalence.** Of the 247 children and adolescents in the study, 163 out of 247 (65.9%) reported that they had headache in the past month and 84 out of 247 (34.1%) reported that they did not (Table 3).

**Frequency.** For children who reported that they had headache (n = 163), the mean frequency of headache within the past 30 or 31 days (depending on the month in which they were asked) was 6.2 days (SD 8.0); the median was 3.0 days (range 1-31 days). The frequency of headache was highly positively skewed (mean > median). The skewness value for the data was +2.1. The majority of children (70.5%) reported that they had had headache for 1 to 5 days in the past month. Twenty nine point four percent reported having 1 headache day per month, 61.3% reported having headaches for 2 to 15 days per month, and 10.4% reported having headaches for 16 to 31 days per month. A breakdown of headache types relative to the reported frequency of headache days within the month is shown in Table 4. There was no relationship between the frequency of headache days and headache type. There was also no relationship between frequency of headache days with sex, age, or etiology (Table 5).

**Nature of headaches.** One hundred and sixty-three children reported that they had had headaches in the past month. Among them, 149 (91.4%) initially described one type of headache and 14 (8.6%) initially described more than one headache type. Overall, there were 177 headache descriptions from the 163 children reporting either one or more than one type of headache. Once the headaches were classified based on using the modified IHS criteria (pg 36 of the methodology chapter), three out of the 14 who reported having more than one type of headache within the last month actually had headaches classified as the same headache type.
Table 2
Demographic Data of Study Sample and Child factors (n = 247)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years: mean (Standard deviation); median (Intraquartile range)</td>
<td>13.2 (3.3); 14.0 (11.0, 16.0)</td>
</tr>
<tr>
<td>Age of Insertion in weeks: mean (standard deviation); median (intraquartile range)</td>
<td>1.9 (3.6); 0.3 (0.06, 1.23)</td>
</tr>
<tr>
<td>Sex: n (%)</td>
<td></td>
</tr>
<tr>
<td>- Female</td>
<td>116 (47.0)</td>
</tr>
<tr>
<td>- Male</td>
<td>131 (53.0)</td>
</tr>
<tr>
<td>Etiology: n (%)</td>
<td></td>
</tr>
<tr>
<td>- Congenital with myelomeningocele</td>
<td>54 (21.9)</td>
</tr>
<tr>
<td>- Congenital without myelomeningocele</td>
<td>94 (38.1)</td>
</tr>
<tr>
<td>- Meningitis</td>
<td>8 (3.2)</td>
</tr>
<tr>
<td>- Bleed</td>
<td>40 (16.2)</td>
</tr>
<tr>
<td>- Tumor</td>
<td>36 (14.6)</td>
</tr>
<tr>
<td>- Trauma</td>
<td>4 (1.6)</td>
</tr>
<tr>
<td>- Other</td>
<td>7 (4.5)</td>
</tr>
<tr>
<td></td>
<td>n (%)</td>
</tr>
<tr>
<td>--------------</td>
<td>-------</td>
</tr>
<tr>
<td>Infection</td>
<td></td>
</tr>
<tr>
<td>- Yes</td>
<td>44 (17.8)</td>
</tr>
<tr>
<td>- No</td>
<td>203 (82.2)</td>
</tr>
<tr>
<td>Number of Shunt Revisions</td>
<td></td>
</tr>
<tr>
<td>- 0</td>
<td>91 (36.8)</td>
</tr>
<tr>
<td>- 1</td>
<td>60 (24.3)</td>
</tr>
<tr>
<td>- 2</td>
<td>30 (12.2)</td>
</tr>
<tr>
<td>- 3</td>
<td>24 (9.7)</td>
</tr>
<tr>
<td>- 4</td>
<td>11 (4.5)</td>
</tr>
<tr>
<td>- 5 or more</td>
<td>31 (12.6)</td>
</tr>
</tbody>
</table>
Table 3

*Prevalence and Frequency of Headaches for all Study Participants (N=247)*

<table>
<thead>
<tr>
<th>Headache within past month:</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Yes: n (%)</td>
<td>163 (66.0)</td>
</tr>
<tr>
<td>- No: n (%)</td>
<td>84 (34.0)</td>
</tr>
<tr>
<td>Number of days of headaches in past month:</td>
<td>mean (Standard Deviation)</td>
</tr>
<tr>
<td>Number of days of headaches in past month:</td>
<td>median (minimum, maximum)</td>
</tr>
<tr>
<td>Frequency of days of headaches in past month: n (%)</td>
<td>- 1 day</td>
</tr>
<tr>
<td></td>
<td>- 2 to 15 days</td>
</tr>
<tr>
<td></td>
<td>- 16 to 31 days</td>
</tr>
</tbody>
</table>
Figure 2. Number of Headache Days Reported by 66% of Children and Adolescents who had Headache over the Last Month (N=163).
Table 4

*Frequency of Reported Headache Days in Past Month by Headache Classification (N= 163)*

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Migraine</th>
<th>Tension</th>
<th>Mixed</th>
<th>Unclassifiable</th>
<th>Multiple types</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>-1 only</td>
<td>17 (35.4)</td>
<td>9 (18.8)</td>
<td>13 (27.1)</td>
<td>6 (12.5)</td>
<td>3 (6.3)</td>
<td>0.273</td>
</tr>
<tr>
<td>-2 to 15</td>
<td>29 (29.0)</td>
<td>10 (10.0)</td>
<td>40 (40.0)</td>
<td>16 (16.0)</td>
<td>5 (5.0)</td>
<td></td>
</tr>
<tr>
<td>-16 to 31</td>
<td>5 (33.3)</td>
<td>1 (6.7)</td>
<td>6 (40.0)</td>
<td>0 (0.0)</td>
<td>3 (20.0)</td>
<td></td>
</tr>
<tr>
<td>Total N (%)</td>
<td>51 (31.3)</td>
<td>20 (12.3)</td>
<td>59 (36.2)</td>
<td>22 (13.5)</td>
<td>11 (6.7)</td>
<td></td>
</tr>
</tbody>
</table>

*Note. n=11 that reported multiple types of headaches (migraine and mixed: n=7; Migraine and Tension: n=1; Migraine and unclassifiable: n=1)*
Table 5

*Frequency of Reported Headache Days by Sex, Age and Etiology (N=163)*

<table>
<thead>
<tr>
<th>Factor</th>
<th>Headache Days</th>
<th>1 Only</th>
<th>2 to 15</th>
<th>16 to 31</th>
<th>p-value across groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age: mean (SD)</td>
<td></td>
<td>13.4 (3.3)</td>
<td>12.9 (3.2)</td>
<td>14.20 (3.1)</td>
<td>0.273</td>
</tr>
<tr>
<td>Age of insertion: mean (SD)</td>
<td></td>
<td>1.4 (3.0)</td>
<td>1.8 (3.5)</td>
<td>1.97 (3.6)</td>
<td>0.779</td>
</tr>
<tr>
<td>Gender: n (%)*</td>
<td></td>
<td>20 (24.1)</td>
<td>57 (68.7)</td>
<td>6 (7.2)</td>
<td>0.147</td>
</tr>
<tr>
<td>- Female</td>
<td></td>
<td>28 (35.0)</td>
<td>43 (53.8)</td>
<td>9 (11.3)</td>
<td></td>
</tr>
<tr>
<td>- Male</td>
<td></td>
<td>12 (27.3)</td>
<td>27 (61.4)</td>
<td>5 (11.4)</td>
<td>0.656</td>
</tr>
<tr>
<td>Etiology: n (%)*</td>
<td></td>
<td>22 (36.7)</td>
<td>33 (54.1)</td>
<td>6 (9.8)</td>
<td></td>
</tr>
<tr>
<td>- Congenital with myelomeningocele</td>
<td></td>
<td>12 (27.3)</td>
<td>27 (61.4)</td>
<td>5 (11.4)</td>
<td></td>
</tr>
<tr>
<td>- Congenital without myelomeningocele</td>
<td></td>
<td>9 (36.0)</td>
<td>15 (60.0)</td>
<td>1 (4.0)</td>
<td></td>
</tr>
<tr>
<td>- Infection</td>
<td></td>
<td>0 (0.0)</td>
<td>5 (93.3)</td>
<td>1 (16.7)</td>
<td></td>
</tr>
<tr>
<td>- Intraventricular hemorrhage</td>
<td></td>
<td>9 (36.0)</td>
<td>15 (60.0)</td>
<td>1 (4.0)</td>
<td></td>
</tr>
<tr>
<td>- Tumor</td>
<td></td>
<td>3 (17.7)</td>
<td>12 (70.6)</td>
<td>2 (11.8)</td>
<td></td>
</tr>
<tr>
<td>- Trauma</td>
<td></td>
<td>1 (50.0)</td>
<td>1 (50.0)</td>
<td>0 (0.0)</td>
<td></td>
</tr>
<tr>
<td>- Other</td>
<td></td>
<td>1 (12.5)</td>
<td>7 (87.5)</td>
<td>0 (0.0)</td>
<td></td>
</tr>
</tbody>
</table>

*Note.* Percentages are expressed as row percents (e.g. percent of individuals who had 1 to 5 headache days that had migraines); Fisher’s Exact Test was used.
Table 6

*Summary of Participant Headache Characteristics Reported by Children N=163*

<table>
<thead>
<tr>
<th>Headache characteristic</th>
<th>Of 177 headache events</th>
</tr>
</thead>
<tbody>
<tr>
<td>Noise worsens headache: n (%)</td>
<td></td>
</tr>
<tr>
<td>- Yes</td>
<td>126 (71.6)</td>
</tr>
<tr>
<td>- No</td>
<td>50 (28.4)</td>
</tr>
<tr>
<td>Photophobia: n (%)</td>
<td></td>
</tr>
<tr>
<td>- Yes</td>
<td>93 (52.5)</td>
</tr>
<tr>
<td>- No</td>
<td>84 (47.5)</td>
</tr>
<tr>
<td>Nausea and vomiting: n (%)</td>
<td></td>
</tr>
<tr>
<td>- Yes</td>
<td>64 (36.2)</td>
</tr>
<tr>
<td>- No</td>
<td>113 (63.8)</td>
</tr>
<tr>
<td>Headache description: n (%)</td>
<td></td>
</tr>
<tr>
<td>- “2”</td>
<td>76 (47.2)</td>
</tr>
<tr>
<td>- “1”</td>
<td>84 (52.2)</td>
</tr>
<tr>
<td>- “0”</td>
<td>1 (0.6)</td>
</tr>
<tr>
<td>Activity worsens headache: n (%)</td>
<td></td>
</tr>
<tr>
<td>- Yes</td>
<td>107 (60.5)</td>
</tr>
<tr>
<td>- No</td>
<td>70 (39.5)</td>
</tr>
</tbody>
</table>

Note. 1=pounding, 2=tightness, 0=not describe
Table 7

*Summary of Participant Headache Characteristics Reported by Children (N=163)*

<table>
<thead>
<tr>
<th>Headache characteristics</th>
<th>Of 177 reported headaches</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensory, visual, speech deficits with headache: n (%)</td>
<td></td>
</tr>
<tr>
<td>- Yes</td>
<td>46 (26.0)</td>
</tr>
<tr>
<td>- No</td>
<td>131 (74.0)</td>
</tr>
<tr>
<td>Breakdown of sensory, visual and speech deficits: n (%)</td>
<td></td>
</tr>
<tr>
<td>- Sensory</td>
<td>8 (17.4)</td>
</tr>
<tr>
<td>- Visual</td>
<td>19 (41.3)</td>
</tr>
<tr>
<td>- Speech</td>
<td>6 (13.0)</td>
</tr>
<tr>
<td>- Sensory and speech</td>
<td>3 (6.5)</td>
</tr>
<tr>
<td>- Sensory and visual</td>
<td>7 (15.2)</td>
</tr>
<tr>
<td>- Visual and speech</td>
<td>3 (6.5)</td>
</tr>
</tbody>
</table>
Therefore, 11 out of the 163 (6.7%) children had multiple classifiable headache types, and 152 (93.3%) children had single headache types. Of the 152 children with single headache types, 51 (33.5%) described migraine-like headaches, 20 (13.0%) described tension-like headache, 59 (38.8%) described mixed headache types, and 22 (13.2%) were unclassifiable headaches. Of the 11 children with classifiable multiple headaches, seven reported having mixed- and migraine-type headaches, one reported migraine and tension-type headaches, two reported migraine- and unclassifiable-type headaches, and one reported having mixed- and unclassifiable-type headaches. Headaches with missing data were defined as unclassifiable. The missing data (related to noise and the description of headache as tight or pounding) reflected the child’s uncertainty as to whether these sensory characteristics were related to their headaches, or whether the sensory descriptors specific to the IHS criteria were appropriate descriptors for this study population. Table 6 and 7 are a summary of the headache characteristics for all the headaches initially reported by the children and the adolescents. The headache characteristics in Table 6 and 7 reflect the 163 single headache types reported by the children and the adolescents, and the 14 children that initially reported having multiple headaches prior to being classified using the modified IHS criteria, for a total of 177 reported headaches.

**Relationship Between Child Factors and Headache**

Bivariate and multiple regression analyses were used to determine the relationship between child factors and headache. The child factors included in the analysis were (a) age, (b) sex, (c) etiology of hydrocephalus, (d) number of shunt revisions, (e) age of initial shunt insertion, and (f) history of shunt infections. The dependent variable for the logistic regression was the child’s or adolescent's self-report of headache categorized as either “yes” or “no” within the last month.
The results of the Fisher’s exact test analysis of the categorical independent child factor variables are summarized in Table 8. The results of the t-test bivariate analysis of the continuous child factor variables are summarized in Table 9. Etiology of hydrocephalus was statistically significant in the bivariate analysis (p = 0.037). Other than etiology, the only other independent factor that met the criterion for inclusion into the multiple regression model (p<0.200) was sex. Results of the multiple regression analysis including sex and etiology are summarized in Table 10. For the multiple regression analysis, the congenital with myelomeningocele subcategory of etiology was used as the comparison with other etiologies including (a) congenital without myelomeningocele, (b) intracranial hemorrhage (ICH), (c) infection, (d) tumour, (e) trauma and (f) other subcategories. When compared with congenital with myelomeningocele subcategory, the subcategory tumour OR=0.22 (95% CI {0.08, 0.56}, p = 0.002) and congenital without myelomeningocele OR=0.42 (95% CI {0.19, 0.94}, p = 0.04) were statistically significant. The model was a good fit for the data and was confirmed by the Hosmer-Lemeshow Test for fit. The test statistic was a Chi-Square (7df) = 1.45, P = 0.984).

**Summary of Quantitative Results**

The prevalence of headache for children and adolescents in this study was 65.9% (163/247). Frequency of reported headache ranged from one day per month to daily. The majority of children and adolescents reported one to five headaches per month with the mean number of headache days being six days per month and the median being three.

Of the 163 children and adolescents reporting headache, 14 self-reported two or more headache types; however, once classified using the IHS criteria, only 11 were classified as having multiple headache types. Therefore, 152 children and adolescents reported one headache type and 11 children reported multiple headaches that were individually classifiable. The majority of children and adolescents described migraine-like headaches (33.5%) or mixed
headache types (38.8%). Approximately 13% of headaches were unclassifiable. Of the child factors, only etiology was statistically significant. No statistically significant association was found between report of headache and age, sex, age of shunt insertion, infection or number of shunt revisions. In the multiple regression analysis, etiology maintained significance. When the subcategories of etiology were compared with the subcategory congenital with myelomeningocele, children with tumours and congenital hydrocephalus not related to myelomeningocele were less likely to report headache.
Table 8

*Bivariate Analysis of Categorical Variables Crossed with Presence or Absence of HA*

<table>
<thead>
<tr>
<th></th>
<th>Headache in past month (n=163)</th>
<th>No Headache in past month (n=84)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Etiology: n(%)</strong></td>
<td></td>
<td></td>
<td>0.037</td>
</tr>
<tr>
<td>- Congenital with</td>
<td>44 (81.5)</td>
<td>10 (18.5)</td>
<td></td>
</tr>
<tr>
<td>myelomeningocele</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Congenital without</td>
<td>61 (64.9)</td>
<td>33 (35.1)</td>
<td></td>
</tr>
<tr>
<td>myelomeningocele</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Infection</td>
<td>6 (75.0)</td>
<td>2 (25.0)</td>
<td></td>
</tr>
<tr>
<td>- Bleed</td>
<td>25 (62.5)</td>
<td>15 (37.5)</td>
<td></td>
</tr>
<tr>
<td>- Tumor</td>
<td>17 (47.2)</td>
<td>19 (52.8)</td>
<td></td>
</tr>
<tr>
<td>- Trauma</td>
<td>2 (50.0)</td>
<td>2 (50.0)</td>
<td></td>
</tr>
<tr>
<td>- Other</td>
<td>8 (72.7)</td>
<td>3 (27.3)</td>
<td></td>
</tr>
<tr>
<td><strong>Infection: n(%)</strong></td>
<td></td>
<td></td>
<td>0.599</td>
</tr>
<tr>
<td>- Yes</td>
<td>31 (70.5)</td>
<td>13 (29.6)</td>
<td></td>
</tr>
<tr>
<td>- No</td>
<td>132 (65.0)</td>
<td>71 (35.0)</td>
<td></td>
</tr>
<tr>
<td><strong>Sex: n(%)</strong></td>
<td></td>
<td></td>
<td>0.106</td>
</tr>
<tr>
<td>- Female</td>
<td>83 (71.6)</td>
<td>33 (28.5)</td>
<td></td>
</tr>
<tr>
<td>- Male</td>
<td>80 (61.1)</td>
<td>51 (38.9)</td>
<td></td>
</tr>
</tbody>
</table>

*Note:* Percents are expressed as row percents (e.g. percent of males that experienced a headache); Fisher’s Exact Test was used for all comparisons.
Table 9

*Bivariate Analyses of Continuous Child Factors Crossed with Presence or Absence of Headache*

<table>
<thead>
<tr>
<th>Child Factors</th>
<th>Headache in past month (n=163)</th>
<th>No headache in past month (n=84)</th>
<th>Test Statistic</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Median</td>
<td>IQR</td>
</tr>
<tr>
<td>Age (yrs)</td>
<td>13.2</td>
<td>3.2</td>
<td>14.0</td>
<td>10.0, 16.0</td>
</tr>
<tr>
<td>Age at Insertion(yrs)</td>
<td>1.7</td>
<td>3.4</td>
<td>0.3</td>
<td>0.0, 2.3</td>
</tr>
<tr>
<td>Number of Shunt revisions</td>
<td>1.6</td>
<td>1.8</td>
<td>1.0</td>
<td>0.0, 1.5</td>
</tr>
<tr>
<td></td>
<td>3.0</td>
<td></td>
<td>2.0</td>
<td></td>
</tr>
</tbody>
</table>

*Note.* *T*-test, **Mann-Whitney U non-parametric test used (z-value)
Table 10

*Multivariable Regression Analysis of Etiologies and Sex*

<table>
<thead>
<tr>
<th>Variable</th>
<th>OR (95% CI)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Etiology</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Congenital with myelomeningocele</td>
<td>1.00</td>
<td>Reference</td>
</tr>
<tr>
<td>- Congenital without myelomeningocele</td>
<td>0.42 (0.19, 0.94)</td>
<td>0.036</td>
</tr>
<tr>
<td>- Infection</td>
<td>0.69 (0.12, 3.96)</td>
<td>0.678</td>
</tr>
<tr>
<td>- Intraventricular hemorrhage</td>
<td>0.40 (0.16, 1.03)</td>
<td>0.058</td>
</tr>
<tr>
<td>- Tumor</td>
<td>0.22 (0.08, 0.56)</td>
<td>0.002</td>
</tr>
<tr>
<td>- Trauma</td>
<td>0.23 (0.03, 1.84)</td>
<td>0.165</td>
</tr>
<tr>
<td>- Other</td>
<td>0.65 (0.14, 2.91)</td>
<td>0.571</td>
</tr>
<tr>
<td>Sex: n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Female</td>
<td>1.50 (0.86, 2.61)</td>
<td>0.151</td>
</tr>
<tr>
<td>- Male</td>
<td>1.00</td>
<td>Reference</td>
</tr>
</tbody>
</table>


Chapter 6
Qualitative Results

The goal of the qualitative analysis was to describe, from the child’s and adolescent’s perspective, the headache experience and the effect of this experience on school, social, and family functioning. This chapter includes (a) a description of the sample and interview characteristics, (b) a description of the child’s and adolescent’s headaches, (c) the effect of age and sex on the child's and adolescent’s headaches, (d) a thematic analysis of the three major themes: invisibility, control, and normalcy, (e) a description of the challenges related to the headaches and the impact of headaches on the child's and adolescent’s school, social and family functioning, and (f) triangulation of the qualitative and quantitative results. Throughout the presentation of the qualitative results, there was some initial interpretation of the findings that was followed up in the discussion chapter. This initial interpretation was done at this stage as part of the analytical process. Based on the nature of qualitative data, it was difficult to objectively present the results without beginning to think about the findings and questions the results based on clinical experience and what was reviewed in the literature. However, within this study, the majority of the interpretation took place in the discussion chapter. The quotes presented in this chapter were identified according to ID study number, age and sex.

Description of Sample and Interview Characteristics

Children and adolescents were recruited for interviews between January 2009 and November 2009. In total, 23 out of 24 children who met the eligibility criteria and agreed to participated were interviewed for the qualitative component of the study. Nine of the interview participants were male and 14 were female. Of the female participants, three were between 7 and 10 years of age, and of the male participants, five were between 7 and 10 years of age.
Table 11 summarizes the demographic data for the children and adolescents taking part in the qualitative interviews.
Table 11

Summary of Child Factors for Qualitative Sample by Age and Sex

<table>
<thead>
<tr>
<th>Child Factor</th>
<th>Males n = 9</th>
<th></th>
<th>Females n = 14</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>7-10 yrs n = 2</td>
<td>11-18 yrs n = 7</td>
<td>7-10 yrs n = 5</td>
<td>11-18 yrs n = 9</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7-10 yrs</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>11-18 yrs</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Etiology:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>congenital with myelomeningocele</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Congenital without myelomeningocele</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Tumor</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Hemorrhage</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Trauma</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Infection:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
<td>6</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Shunt revisions:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>1-4</td>
<td>1</td>
<td>5</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5-10</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>&gt;11</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Age of shunt insertion in weeks (average, range)</td>
<td>15.5 wks 113 wks 92.8 wks 202.3 wks</td>
<td>202.3 wks 8-13 wks 2-676 wks 2-364 wks 1-720 wks</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The frequency of headache ranged from one to 30 days. The majority of the children interviewed (21/23) reported headache less than five days a month. One child reported having headaches 15 days per month and another child reported having daily headaches. The one child who refused to be interviewed needed to leave immediately after their clinic appointment due to childcare issues. Individual interviews lasted between 18 and 43 minutes. The children and the adolescents were asked (a) to choose the location for the interview and (b) if they wanted a parent present. Of the 23 interviews (a) 19 took place on a bench in a quiet location outside the clinic area, (b) one took place in a private clinic room, (c) two took place in the clinic waiting room at the end of clinic, and (d) one took place in a lounge on the oncology unit. For the interviews which took place on the bench, there were a few instances where the interview flow was disrupted by noise from the atrium or clinic traffic. Of the 23 children interviewed, only one requested to have their parent present. During this interview, the parent needed to be repeatedly reminded not to interject nor correct comments made by the child. The parent was reminded that the questions being posed were to understand the headaches from the child’s perspective, and that there were no right or wrong answers. After reminding the parent of the intent of the study, the comments subsided. The child did not seem distracted by the parent’s comments and appeared comfortable answering questions with his parent present. Although it was difficult to ascertain how the parent’s presence impinged on the quality of the interview, the child’s responses were detailed, and his mother’s comments did not appear to influence his answers. When a disruption occurred, he stopped and then carried on with the response he had initiated. The child did not address the parent’s comments. Hence, this interview was analyzed in the same manner as all other interviews and incorporated in the findings.
**Description of Headaches**

When first asked to describe their headaches, the children’s and adolescents’ initial descriptions were always focused on the sensory aspect of pain and referred primarily to the physical nature of headache pain, mainly the location and the intensity. The physical nature of pain was predominantly described using sensory descriptors that were consistent with terminology used in the IHS headache criteria (International Headache Society, 2004), the McGill pain questionnaire (Melzack, 1975), and terminology frequently used in the clinical setting. Examples of the sensory descriptors used were: “My headaches, well everytime I get headaches, it feels like throbbing” (#84, 17-year-old male); “beating …pounding … hurting” (#127, 14-year-old male). Words used to describe the sensory aspects of headache pain in the IHS criteria are pounding, pressing and tightening (International Headache Society).

The McGill pain questionnaire (Melzack, 1975) is a measure developed to capture the subjective pain experience of an individual that focuses on language commonly used as a means of measuring or describing pain. It consists of 4 classes of word descriptors: sensory, affective, evaluative, and miscellaneous. Sensory descriptors encompass temporal-, spatial-, pressure-, and thermal-related words (e.g., sharp, pulsing); affective qualities describe tension, fear, and autonomic properties that are part of the pain experience (e.g., tiring, exhausting); and evaluative words describe the subjective overall intensity of the pain experience (e.g., annoying) (Melzack). Examples of sensory descriptors that children in this study used were “beating,” “thumping,” “pulsating,” “tightness,” and “pounding” when describing the nature, location and intensity of pain. The majority of the children and the adolescents also incorporated language that made reference to the shunt and shunt functioning: “It is like a pulsing or a pressure in my forehead. I feel really bad. I get stomach aches and that is only ever if my shunt breaks down...”(#52, 17-year- old female); “They are right where my shunt is, on my shunt side”(#32, 16-year-old...
male); and “Technically right by the shunt”“(85, 10-year-old female). When headaches were described relative to the shunt, they were predominantly spoken about as an “other” type of headache. These other headaches were described as an entity outside of themselves, and the children and the adolescents were very factual, straightforward, and pragmatic describing them physically in relation to symptoms of shunt function. Overall, when initially asked to describe their headaches children and adolescents predominantly (a) focused on the sensory aspects of the pain, (b) used familiar clinical terminology, and (c) focused their descriptions relative to the shunt and its functioning.

The way the children and the adolescents initially described their headaches and used language was age and developmentally appropriate. The nature of their descriptions was reflective of their clinical diagnosis and of a language familiar to the clinical and medical environment. The reason for this type of description could have been two-fold:

First, their responses could have simply been reflective of when, where and with whom the interviews had taken place. All of the interviews had taken place either before or after a clinic visit, in the hospital setting, and by a member of the health care team.

Second, their initial descriptions could be reflective of how children and adolescents with shunted hydrocephalus have been socialized and have been taught to speak about headache. Socialization within the neurosurgical clinical environment, from the time of shunt insertion, includes children and parents being taught about the importance of headache as a symptom of shunt functioning. This teaching is also reinforced in subsequent clinic visits. Therefore, within the neurosurgical context, there is a common language, a learned way of speaking, used by health care providers, the parents, and the children and the adolescents with respect to headaches.

The child's and the adolescent's social network with regards to headache education incorporated the parents and the health care team. The child's and the adolescent's social
network relating to headache has been further explored in the discussion chapter. The dialogue about headaches focused around a “typical” headache related to intracranial pressure changes associated with shunt functioning. The language used to assess shunt functioning related to headache incorporated specific language related to the onset of the headache, the time of day, the location, and the associated symptoms. The language used kept the headache in context, and ensured a mutual understanding of the headaches to ensure shunt functioning.

Children and adolescents were very confident describing their headaches in association with their shunt. They spoke in a way that put them at ease and convinced others that the shunt was functional and not a problem. There was a sense of safety in conforming and in speaking about the headaches using shunt-related terminology. Perhaps speaking of headaches in this manner ensured reciprocal understanding. For the child, clearly articulating headaches in relation to shunt function may evade hospitalizations, tests and investigation, and secure their normalcy. Furthermore, the comfort in describing the headaches in sensory terms and in association with the shunt, may be indicative of (a) the clinical environment and how headaches have been talked about in this context, (b) the child’s coping and management strategy (describing headaches in relation to the shunt and physical descriptors makes the headache something tangible and possibly fixable), (c) an attempt to keep the headache as a separate entity associated with the shunt, thereby maintaining their normalcy, (d) how children and adolescents with shunted hydrocephalus associate headaches with shunt functioning (which is reflective of their understanding of their diagnosis and headache), or (e) the possibility that children and adolescents with shunted hydrocephalus do not think about headache outside of shunt functioning and hydrocephalus (it is simply a part of who they are). The lack of attention paid to headache outside of shunt functioning may be expected if the shunt was inserted at a young age;
the shunt or headache may be considered normal for them, and may be incorporated into who they are.

In general, the majority of children and adolescents spoke concretely about the physical headache pain with a lack of affect. Their responses could be a reflection of how these children have been socialized with respect to headaches, or of a coping mechanism used by the children and the adolescents as an attempt to maintain normalcy. A few female adolescents showed some emotion when speaking about the physical headache pain, but in general the children and the adolescents seemed unaffected and lacked emotion. However, the lack of affect could possibly have been (a) sex related, (b) because they have become accustomed to living with unresolved pain in the presence of a functional shunt, (c) the acceptance of unresolved headache as a part of who they are, or (d) a coping mechanism.

When asked to describe their headaches beyond their sensory pain experience, many children experienced difficulty. They were not forthcoming with their responses, and they required probe questions to address the emotional and affective components of their pain. The probing required to get the children and the adolescents to describe the affective and emotional components of their headaches was in direct contrast to the children's and the adolescents' description of the sensory components of their headache pain. Children and adolescents involved in the interviews did not require probing to describe the sensory components of their headache pain. This could possibly be related to how the children and the adolescents are initially educated about headaches with respect to shunt functioning, and the sensory components of headache pain. Furthermore, perhaps speaking about headache outside of the physical pain descriptors, and outside of shunt malfunction, would bring to the surface an unknown set of circumstances that could be resolved with a neurosurgical intervention. Typically, headaches are discussed within the context of shunt functioning and are subsequently evaluated with a CT scan.
The CT Scan is one way of legitimizing headache in relation to shunt function. A CT Scan is a diagnostic imaging test done that shows changes in ventricle size indicative of intracranial pressure changes. Alternatively, the learned patterns of speaking and interaction within the clinic and hospital setting is familiar and may not be permissive to exploring headache outside of shunt functioning.

When describing headache beyond the sensory aspect, children and adolescents described their headaches as all encompassing and laden with emotions. Many of the descriptors portrayed that children and adolescents were victims of their headaches and were silently being overpowered by their headaches. One 11 year old male (#54) described when she had headache that she ‘just wanted to give up’. When speaking about the emotional and affective components of their headaches, they described feeling worried, sad, afraid, and angry. They worried about what the headache could mean. They were afraid of the pain. They were angry about how headaches compromised their ability to partake in their daily activities, and the fact that there were often no answers for their headaches. Finally, they were sad about missing out on the things that they wanted to be doing.

Consequences of the headache took on many attributes for the children and the adolescents. For some, headache pain meant tests, hospitalizations and surgeries. For others, it meant missing out or not taking part in activities. For adolescents, it meant the reality of living with unresolved pain that was not understood. Emotions expressed by the younger age group were primarily related to the shunt (e.g., needing surgery and it being broken) and to missing out on things they wanted to be doing. Conversely, the emotional responses of the older age group were less about the headaches in relation to shunt functioning and were more about the effect of the headaches on their daily activities. They tended to use descriptors such as (a) inconvenient, (b) resentful, (c) angry, and (d) “pissed off”; all of which had negative undertones when they
were speaking about the influence headaches had on their school, social, and family functioning. From the children’s and adolescents' descriptors, if the headaches were personified in the children's and the adolescents' descriptions, they were seen as “a rain cloud” or “a bully constantly hovering over their everything,” as described in the overpowering nature of the headaches (Pg. 112), and the metaphors used to describe the headaches (Pg. 95).

One female adolescent (#57) with congenital hydrocephalus, who was shunted in early infancy, described her headache as “inconvenient”. When asked why she described her headache in this way, she explained: “Just like when I have them, I feel bad, like, I don’t know . . . and lots of situations when you really don’t want to have a headache are the ones that trigger headaches. So, like, if you are going shopping or you have something to do, or if you, like, when there is something you really need to be doing is when they come” (#32, 14-year-old female).

Another 10-year-old female (#52) with congenital hydrocephalus related to spina bifida began with a metaphorical description of the physical headache pain, and immediately moved on to describe the resentment she had towards her headaches: “It’s like someone kicking me in the head every day, it was terrible.” She then went on to describe her headaches as evil. “[Headache] It’s an evil word …It’s an evil word I hate having headaches; I have had it all my life.” Her headache experience included multiple shunt revisions and multiple hospitalizations to investigate her headaches. The responses may have been a function of sex, age, developmental stage, or a prolonged headache experience. Further descriptions of emotions have been described on Page 101.

The affective descriptors often entailed words and phrases incorporating the overpowering nature of the headaches and a sense of defeat: “It makes me feel uh, it makes me feel not wanting to do anything, just sitting down, laying down (#58, 16-year-old female),” and “[I feel] weak, really heavy sometimes” (#84, 12-year-old female).
These descriptions highlighted that the child’s and adolescent’s headache pain extends beyond the physical component and incorporated both emotional and affective components. According to the gate control theory of pain (Melzack, 1965) and the neuromatrix theory of pain (Melzack, 1999), physical components of pain, along with emotional and affective components, can modify the pain experience. The emotional and affective descriptors used by the children and the adolescents raised questions as to (a) how the emotional and affective components of pain effect their headaches, and (b) whether etiology, age, past experience, and sex influence the emotional and affective response to their headache experience.

Some children spoke metaphorically about their headache pain. The metaphorical descriptors were predominantly used by the younger age group, and may have been reflective of their developmental stage with respect to language development. Younger children tended to speak more figuratively and used terminology that they were comfortable with and to which they were able to relate. The metaphors were cartoonlike in nature which could be reflective of the media and social environment in which children are acculturated. The use of metaphors may also have been a way for the younger children to describe something for which they were unable to find words. Furthermore, the metaphorical descriptors may have been reflective of (a) the overpowering nature of the headaches experienced by the children beyond shunt malfunction, (b) the child’s feelings of being victimized by their headaches, or (c) the language used developmentally by children in this age group.

Headaches were described using metaphors such as “a repulsive hammering”(#58, 7- year-old- female); “like being kicked in the teeth”(#64, 12- year- old- female); “like being kicked in the head”(#32, 7- year- old- male); “like being kicked in the stomach”(#32, 7- year- old- male); “like a hand reaching inside your brain”(#56, 16- year- old -male); “kinda like beating teeth out” (#53, 8- year- old- male); “a smashing in my brain”(#82, 17- year -old -male); “like a
painful heartbeat” (#84, 17-year-old female); “like a boulder on the top of my head” (#82, 17-year-old male); and “like a karate chop in the neck” (#84, 17-year-old female). The thought of being kicked in the teeth or stomach denotes a feeling of being winded, knocked down, or made defenseless. The children’s descriptors could be interpreted to portray headache pain that is out of control, overpowering, lurking in the darkness, or dominating all aspects of their beings. The metaphors may hold greater meaning, indicative of the children being victimized and bullied by their headaches.

**Age and sex-specific findings.**

**Age.** There was variability in the interview responses related to age and sex. The younger age group (7- to 10-year-old children) spoke in very concrete terms about their headaches, focusing predominantly on the sensory aspect of pain and headache in association with the shunt, referring to its location and functioning (e.g., “it hurts where my shunt is”). The younger age group tended to speak more in age-related metaphors when describing their headaches.

The younger children’s descriptions were predominantly present-focused, reflective of immediate concerns and issues, and were not anticipatory in nature (e.g., “can’t play with my friends, sometimes can’t get my schoolwork done”). When speaking about the emotions associated with their headaches, the younger age group mainly spoke of worry, sadness, and fear. The worry and fear expressed by the younger age group were primarily related to the shunt (e.g., needing surgery and the shunt being broken), and the sadness was primarily related to missing out on things that they wanted to be doing.

In comparison, the older age group (11- to 18-year-old children and adolescents) was generally more articulate in describing their headaches. They predominantly used sensory descriptors consistent with the IHS criteria and initially spoke about their headaches in a “matter-of-fact” way. They were less inclined to speak about headaches in relation to shunt function and
were more inclined to incorporate descriptors such as inconvenient, resentful, angry, and “pissed off,” (#100, 16- year-old female) all of which had negative undertones that expanded on the pain experience. Examples of the older age groups descriptors were, “You just get tired of it . . .they just get to me and [I] get really upset about it” (#85, 11 –year- old female) and “they are frustrating. I resent them” (#100, 16- year-old female). The variation in the description across the age groups may have been (a) a reflection of their stage of language development, (b) due to a realization that the headache was not simply about the shunt, or (c) reflective of a longer headache experience. The older children may have had a longer headache experience involving multiple investigations, and may have continued to have headaches despite a functional shunt. Conversely, younger children with respect to the frequency of headaches may not have experienced multiple unresolved headaches despite a functional shunt. The younger children also predominantly described their headaches concretely, relating to sensory pain.

**Sex.** The male participants of all ages were very pragmatic in their responses, present-focused, and matter-of-fact when speaking about their headaches and the bearing the headaches had on their school, social, and family functioning. For the majority of the male participants, headache pain was concretely described. One 14-year-old male (#34) described headache as a “pain in the head; that is why they are called headaches.” Another 17-year-old male (#33) stated, “Sometimes it is just painful, and sometimes I can just forget about it if I am doing something else.” When speaking about their headaches, males spoke concretely, predominantly in sensory and clinical terms and with minimal affect. They did not dwell on the emotional and affective aspects but were very matter-of-fact in their descriptions. The male study participants generally did not expand on their emotional and affective pain experience, even with probing. In some respects, they were more accepting of their headaches and described a keep-going attitude, and
continued to partake in many of their school, social, and family activities. This acceptance may have been a coping strategy or a way to be in control of their headache, and maintain normalcy.

Conversely, the female participants were more descriptive and open when speaking about their headaches. “[Headaches], I don’t want to get one… they hurt… like, I don’t want to be around anyone, or I will get really like… very sad and feel like I want to cry, but sometimes I don’t”(#82, 11-year-old female). They were more inclined to speak of headaches outside of sensory and clinical terms, and expanded the physical pain beyond the head, incorporating the whole body: “Like, my whole energy goes down; I just kind of give up”(#64, 12 year old female). Female adolescents were more articulate and expressive when speaking about their headaches and spoke more of the headaches' overpowering nature. The descriptors used by the female participants portrayed them as being subordinate to their headaches, and as being overcome and victimized by their headache pain. Examples of descriptors were: “Pain so bad just want to scream…”(#64, 12- year -old female); “Interact with my daily living because sometimes I can’t do anything”(#52, 17- year- old female). Females 11 to 18 years of age were also more articulate about the emotional and affective aspects of pain related to their headache experience. Throughout the interviews, there was a sense that the females were experiencing more of a struggle with the headaches and there was a sense of resentment towards the headaches: “They are painful, and some people don’t wish that they have them at that moment, and when I get them I wish I didn’t have them” (#52, 17- year -old female). The descriptors used by the female participants portrayed them as being helpless and subordinate to their headaches. They were overcome by headache pain and victimized by the pain. There was a sense of vulnerability when the female adolescents spoke of their headaches. Their comments were both present-focused and also anticipatory. Because the female participants were more articulate and detailed about the emotional impact of their headaches, the interviewer
experienced a sense of empathy with them with respect to their struggle and emotions. This sense of empathy was not felt by the interviewer when interviewing the males. The difference may have been a consequence of (a) sex differences of the participants when speaking about pain and the language used, (b) the female participants having been more comfortable speaking with a female interviewer, who possibly shared similar values and was emotionally compatible, (c) the male participants having been interviewed by a female interviewer, changing the dynamic of the interview in that they may not have wanted to appear weak by showing emotion, (d) being a male adolescent (developmentally, this is how males interact, and they may have been trying to uphold an image), or (e) sex differences in coping strategies.

Both male and female participants of all ages expressed worry, anger and sadness relating to their headache experience. Overall, the females’ concerns extended beyond the concrete and the present, and were more anticipatory in nature. The anticipatory concerns expressed by the female participants potentially could be indicative of a vulnerability they experience related to their headaches. One child described her concern about the unrelenting pain: “It would get worse and worse, like the pain would get stronger and stronger, and then it would get worse and worse and never stop” (82, 11-year-old female). Females tended to be more passionate when describing the effects of their headaches and were very articulate in portraying their anger and resentment. They also spoke about feeling guilty about complaining about their headaches, and feeling badly about telling family members about their headaches because they did not want to worry or burden others. “My family worries… I don’t want to put my family through that again (57, 12-year-old female).” The guilt may have been related to sex as none of the male participants expressed feeling guilty. The guilt could have potentially been compromising their ability to manage and control their headaches, because they purposefully may have been keeping their headaches hidden to not burden others.
The younger age group spoke very concretely about the consequence of their headaches on their school, social, and family functioning, and on present concerns that were affecting their daily interactions. The majority of 7 to 10-year-olds spoke about their difficulties concentrating, doing homework, and their daily struggles in the classroom. With respect to social interactions, the younger children spoke about missing out on playing with friends, the disappointment of changing a play date, or the headaches interfering with what they were doing (e.g., having to put their head down and sit quietly). Some children were developing an awareness of plans changing in the family because of their headaches, and of family members’ concerns and worry about their headaches.

When asked about how headaches impinged on their school, social, and family functioning, the older age group responded that they did not miss out on school or social activities. Their responses may reflect their developmental stage, the important role peers play in the adolescent period, or a coping mechanism for the adolescent living with unresolved headaches. However, upon further discussion about the effect of headaches on their school and social functioning, the adolescents clearly articulated that they encountered difficulty studying and concentrating in school. They missed tests, and had concerns about their grades and about losing their school year. Some described fears of being unable to attend university with their friends. In comparison to the younger age group, adolescents (particularly males) spoke more about persevering and not cancelling events with their friends. However, in comparison to the younger age group, the adolescents were also preemptive in choosing activities in which they would participate as a means of circumventing a headache event. This management strategy may be a function of age and experience, and has been addressed in the discussion.
Major Themes

Three themes emerged that described the headache experience of children and adolescents with shunted hydrocephalus; (a) invisibility, (b) normalcy, and (c) control. The themes and their subcategories are presented in Table 12.

**Invisibility.** Headache by nature is an invisible condition. Invisibility, in the context of the present study, refers to a hidden condition that is veiled with secrecy and includes visible absence in the school, social, and family environments. For the children and the adolescents with shunted hydrocephalus, headache only became visible when they spoke about it or, for a few, became recognizable by behaviours associated with their headache and how they physically managed them. Examples of invisible behaviours entailed putting their head down on their desk when experiencing a headache in school, or removing themselves from play with their friends to sit quietly by themselves. For many, their management strategies entailed not taking part in activities. Once spoken about, headache became salient and potentially manageable; until that time, the headache was hidden. The children and the adolescents did not readily speak of their headache experience. The sensory, emotional and affective components of their headaches, prior to being described, were invisible. The emotional and affective components of their pain experience were more hidden and secret than their sensory pain experience. The children and the adolescents required probing to describe their headaches beyond the sensory aspect. One 14-year-old-male (#34) stated very bluntly, “Headache is pain in the head.” After making that statement, he seemed very perplexed that it could be anything more than that. As a result of their headaches, children and adolescents described how they became invisible as social beings in the school, social, and family environments. The social invisibility has been described further on Page 116.
Table 12

Qualitative Themes and Subcategories

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Control/out of control | Management strategies |
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The invisibility of the child’s and adolescent’s headache experience was manifested in their description of (a) their hidden emotions, (b) the overpowering nature of the headache, (c) the gatekeeping associated with the headaches, (d) their headache management strategies, and (e) the missing out experienced in the school, social, and family environments, which in turn affected their ability to be visible as social beings. These subthemes have been explored below.

**Hidden Emotions.** In accordance with the gate control theory (Melzack, 1965), it is imperative to look beyond the physiological indicators of pain. Once prompted beyond the sensory descriptors, it became apparent that the children and the adolescents with shunted hydrocephalus experienced a myriad of emotions in relation to their headaches, all of which were invisible to the exterior and not readily discussed. Emotions included worry, fear, anger, sadness, and guilt. These emotions often occurred in combination, were not mutually exclusive, and stemmed from multiple meanings of headache pain. Melzack (1965) suggested that it is important to explore the emotional component of pain as it plays an important role in the pain experience. The GCT (Melzack) highlighted the relationship between the physiological and psychological factors in relation to a pain event and the multitude of factors inherent in the experience which modulate pain. Higher central nervous system processes, such as emotions, meaning, and past experience exerted a powerful influence on the pain experience. The emotions described by the children adolescents were that of fear, anger, sadness worry and guilt.

**Fear.** Both children and adolescents stated that they were “scared” or “afraid” of their headaches. They were afraid of (a) the physical aspects of the pain, (b) the inability to manage the headache pain, (c) the uncertainty associated with the headaches, (d) the potential meaning of headaches, and (e) the implications of having the headache. The following was an excerpt from an interview with a 12-year-old female (#64) (I=Interviewer; R=Respondent):

I: “Do you ever worry about your headaches?”
R: “Yeah.”
I: “What do you worry about?”
R: “That they are going to get worse and I can’t stop them.”
I: “And then what would happen?”
R: “I am scared to go there.”
I: “Why? What are you scared of?”
R: “I can’t get rid of it. I have been in pain all my life, that is what I am scared of.”
I: “And what do you think is wrong?”
R: “My head, I think something is wrong, my shunt... the cyst is growing back, everything, I am scared, I am scared every day.”

In the interview, the female began by describing the worry she experienced in relation to her headache pain. Initially, she was worried that the headaches would get worse and the pain would become unmanageable; her worry then escalated to fear. She was afraid of living with unresolved pain and the reality that the headache could be indicative of progression or changes to her underlying disease. This example illustrates how females were more articulate regarding the emotional impact of their headache. The fear she expressed was invisible; a hidden emotion that only became known once she spoke about it. Headache meant hidden worry, that something was wrong with the cyst, that she may need surgery, and that she may be in pain all her life. The above example also raised questions as to whether she was afraid that the headaches were being missed, or that she was being left to deal with the headaches alone.

For many of the children, headaches brought up fears of being in hospital, having surgeries, and having headaches investigated without resolution. One 11-year-old female (#84) stated:
“I worry that it has to do something with the shunt, I worry that something might be wrong and I’ll have to go and get something done at a hospital or something… It just gets me scared for it. I’m like, of yeah is this gonna happen… is this gonna happen… is this gonna happen but then I try think like it won’t happen I’m fine… I’m scared about that I’ll have to go and get it fixed like something’s… like, when I get it before, I’ve had to have it revised before and I got really sick from it and then I knew something was wrong…”

This quote highlighted the fear she experienced in relation to her headaches. Her fears were based on past experience, incorporating previous hospitalizations and surgeries. Fear related to previous hospitalizations and surgeries was a common finding in children and adolescents who had required previous shunt surgeries. For children and adolescents who did not have previous experiences or hospitalizations, fears stemmed from the uncertainty of not knowing what it meant, or what could potentially happen. This quote also illustrated the emotion, uncertainty and past experiences that, in accordance to the gate control theory, influence the pain experience. Past experience modulates how children perceive pain, and sculpts their pain experience.

**Anger.** Children and adolescents described feeling angry about and resentful of their headaches. Their anger and resentment predominantly stemmed from the realization of how their day-to-day activities were hindered by their headaches. One 16-year-old female (#57) stated, “[Headaches], like I said they can be really painful or just sort of, but whatever it is I feel sort of like everything is elevated, you’re more anxious, more stressed, you’re more likely to get upset about things…” In this description, everyday stressors and occurrences were compounded by the headaches. The exponential tendencies of the headaches were cumbersome and burdensome for some of the children and the adolescents. “They are like a kind of a nuisance, ‘cause you get them and then they are always there and, like, if they come more frequently
you’re like, oh, another headache great. And just, and just get tired of it and you just don’t want them there obviously, and then when they are there you are, like, okay well how am I going to deal with it this time, just like every other time,” (#64, 16-year-old female). This quote is illustrative of how children and adolescents with shunted hydrocephalus were constantly dealing with the stress of managing their headaches, and with the potential of headache during their daily activities. Headaches were seen as a source of stress, potentially affecting their ability to cope.

A few of the children and the adolescents expressed feelings of anger and frustration about not having answers for their headaches, and for the lack of resolution of their headaches. One 17-year-old female (#100) stated, “Headaches are frustrating... ‘cause it really, really hurts and it just won’t go away. They don’t go away and no one can tell me what’s wrong with me.” Her description was reflective of a longing to be fixed and normal, which overshadowed and dominated her existence. The uncertainty and lack of resolution were predominantly experienced by the adolescents, and were common sources of anger and resentment. The anger and resentment may be indicative of (a) the lack of control they had over their headaches, (b) the realization that there may not be an answer for their headaches, (c) the overpowering nature experienced with respect to their headaches and how it affected their everyday activities, and (d) a longing for normalcy.

**Sadness.** More children than adolescents expressed feelings of sadness in relation to the headache pain. One 7-year-old male (#53) stated, “[The headaches] make me want to cry because they are hurtful.” The children's sadness, similar to their anger and resentment, was related to missing out on events and activities because of the headaches, and to despair related to the lack of resolution of the headaches. Sadness was an emotion described by both children and adolescents, and was invisible until the children acknowledged their sadness, and how it
influenced their everyday activities. The consequence of their headaches has been discussed further on Page 115.

Children and adolescents were very articulate about the activities in which they were not able to partake while experiencing headache, and about the sadness experienced related to the missing out. One 11-year-old female (#32), when asked how headaches made her feel, answered, “Very sad… and I feel like I want to cry sometimes but don’t…[the headaches] are painful, and some people don’t wish that they have them at that moment. I still wish and when I get them I wish I didn’t because it doesn’t happen that often—every couple of months, it’s not that bad…[they make me sad] because there are other things you could be doing at that moment or something, like say dancing: you can’t dance when you have a headache.” This quote illustrated the invisible emotions of sadness and resentment experienced by the female related to her inability to participate in dance. It also was indicative of a social absence, of the fact she was physically unable to take part in an activity she enjoyed, and of the control the headache pain exerted on her daily activities.

As a result of not being able to take part in the dancing, the female experienced invisibility as a social being. She was unable to be physically present and take part in her dance class, so she was visibly invisible. As a social being, her absence was noted by her inability to attend dance class because of headache. Invisibility was illustrated on multiple levels from her (a) inability to take part in activities she enjoyed, (b) missing out on opportunities related to her social and leisure activities, (c) headaches invisibly dictating what she was able to do and not do, and (d) invisibility as a social being. She was missing out because of her headache, but nobody really knew or saw the impact of the headache. Her missing out refers to the invisibility of the headache outside of shunt functioning.
A 10-year-old female (#82) spoke about how she enjoyed writing and commented on how the headaches affected her writing ability. She stated that she enjoyed spending her time writing at the kitchen table. However, when she had a headache, she would only think about the things she was not able to do. She stated, “[Writing], I do like to do it, sometimes. It makes me feel better, but sometimes makes me feel worse because if you think about anything you would rather be doing, you’d also think about what you’re not doing and that makes you very sad.”

A 16-year-old female (#57) stated, “Headaches are throbbing, painful… and sometimes very annoying 'cause like sometimes you are with your friends and you will get one and you’ll just get there and get it. And like well you will be playing a game or you will be doing something and it just changes your mood and you get annoyed cause you just got to your friend’s and that kind of thing.”

These examples highlighted the twofold aspect of invisibility experienced by children and adolescents with headache: the hidden emotions and the missing out. They also exemplified how females were more articulate when describing emotional and affective components of headache pain, and more apt to feel victimized by their headache pain.

**Worry.** Both children and adolescents worried about their headaches. The worry they experienced was multifaceted. They worried about shunt functioning, about the underlying etiology related to their hydrocephalus, and about what the headaches could mean. The following quotes are examples of the worry described by children and adolescents regarding their headache pain: “I think about where the tumour is coming from, the brain tumour, the shunt, or is it just like a cold or a flu?”(#33, 12 –year- old -male); “Umm once or twice I get a really bad headache… basically I am thinking that my brain tumour is growing”(#85, 10- year- old- male); “I worry about going back into the hospital. I know it is gonna happen eventually. I have a brain
tumour, like how long are you going to stay out of hospital when you have a brain tumour?
Like, really that is what I think (#88, 12-year-old male)

Worry associated with headache appeared to be related to the underlying etiology of their hydrocephalus. Children with brain tumours predominantly spoke of tumour recurrence, and children with other etiologies of hydrocephalus predominantly worried about a “broken” shunt. Worry experienced by the children and the adolescents with headaches and shunted hydrocephalus appeared to be related to their underlying pathology. It raised questions as to whether, when first asked to speak about their headaches, children and adolescents were not as forthcoming with their responses because of the association with disease recurrence or having to deal with the unknown. Perhaps the tendency to describe their headaches in a physical manner was a coping mechanism used to deal with the uncertainty and fear related to their underlying pathology. Secondly, they worried about possible hospitalizations, surgeries and being in hospital for extended periods of time. The following quotes are examples of this worry: “I worry about them sometimes 'cause they can get really bad sometimes and I just, like, uh oh what to do. 'Cause they, cause sometimes when I need to go to like the doctor they’re pretty bad…and I need to get shots” (#33, 12-year-old male); “Most of my headaches, I would be worried if my shunt was broken again… and I would, well, be having an operation to fix it… I get mad and 'cause I have another operation and I don’t like that… it worries me a lot... I just worry that it’s, it could possibly not go right and I have to have another one cause it has happened before…”(#52, 17-year-old female) The descriptions of the children and the adolescents who had previous shunt revisions were based on their past experience. In contrast, the worry of those who had not experienced a shunt revision was based on how they imagined it might be. As highlighted in the gate control theory (Melzack, 1965), the meaning of headache or headache pain influences the pain experience. The meaning of the pain could have also influenced how children and
adolescents spoke about their headaches. The meaning may have had bearing on the child’s or adolescent’s ability to make pain visible.

For the female adolescents, worry was predominantly described as anticipatory and oriented towards an unforeseen future, as described in the following quotes. Their worry also exposed their vulnerability to headache pain and the control manifested by the headache pain: “Don’t worry about much, just how long it will last..” (#127, 7-year-old female); “Worry about it getting worse, can’t do something about it and it causes problems…” (#100, 16-year-old female); “Generally don’t worry… worry if I gets really bad… worry about what to do” (#52, 17-year-old female); “worry that something is actually wrong and no one understands…” (#78, 16-year-old female). As one adolescent stated, “What if the headaches don’t go away?” (#57, 12-year-old female). The differences regarding the type of worry expressed raised the question of whether age and/or sex affect the worry about headache and the underlying pain.

Anticipatory worry was predominantly experienced by adolescent females. Their worry may be reflective of (a) past experiences, (b) the realization that their headaches had persisted despite a functional shunt, (c) how pain is described specific to sex, and (d) a perceived vulnerability and lack of control. As females were more in tune with the emotional psychological components of pain, they were potentially more likely to have increased headache frequency or exaggerated pain intensity. The increased emotional awareness could potentially be a factor modulating the pain experience of the female adolescent (Melzack, 1965).

**Guilt.** Some children and adolescents experienced guilt in relation to their headache experience. A few described how they felt guilty about disrupting others’ schedules and plans. One child (#78, 11-year-old female), when speaking about telling her family about her headache, stated, “Um, well they’re supportive and, like, they understand that if I am complaining about it, it’s gonna be bad, but, like, I feel bad telling them because it impacts their day too.” Another
child (#82, 10-year-old female) stated, “I had to take my father away from the party, I felt so bad, nobody ever says anything, I just feel bad.” The guilt experienced was invisible, yet the guilt also inhibited the headache pain from becoming visible. The children and the adolescents also felt guilty that they were not getting their school work done, and, when they had headaches, they were unable to do their best work. One 14-year-old female stated, “I am a good student in school, like I do really well, but when I have a headache, basically I do a tenth of what I could normally do.”

Guilt was also manifested in children who had other family members with health problems; they felt guilty talking about their headaches when other family members were also dealing with health issues. A 14-year-old female (#63), whose sister was diabetic, commented on how she felt about mentioning her headache in the context of her sister’s health condition: “My sister is diabetic so I feel guilty complaining about it, but like, 'cause, but still it is just I wish, I really, really wish I didn’t have it sometimes.”

In the above examples, guilt, similar to all the other emotions described, was an invisible component of the headache experience; it only became visible from speaking about it. Furthermore, guilt was associated with making the headaches visible. In declaring they had a headache, children and adolescents were aware of the effect of making their headaches visible to others through their verbal descriptions. They described being invisibly burdened with the struggle of whom they should tell should not tell.

Children and adolescents worried about others’ reactions to their headaches and how it affected others. The worry also incorporated a component of guilt: “My family worries… I don’t want to put my family through that again” (#57, 12-year old male). With respect to telling their siblings, the same child stated, “My sister thought I was dead, I will never do that again, I won’t tell them about [my] headache” (#64, 12-year-old female). Another child (#53, 12-year-
old male) stated, “It affects my brothers and sisters and I feel responsible.” Yet another child (#32, 11-year-old female) stated, “My dad gets angry because I am supposed to be doing something or chores, and gets angry because I can’t do it because of my headaches.” As a result of this invisible guilt, children and adolescents did not share every headache experience with their family, friends, and teachers. The telling about headaches has been further explored under gatekeeping on page 113.

**Overpowering Nature of Headaches.** The majority of children and adolescents described the overpowering nature of headaches. The overpowering nature of the headaches was defined as all-encompassing and taking over their entire being. The affective nature of the headache pain was predominantly described as being overpowering. When children had headaches, the headaches became their central focus. They described feeling “weak” and “heavy”, that they could not walk or move their body, and that they just wanted to lie down. One 14-year-old male (#81) described that, when having a headache, the headache was “the only thing I think about”, and that headaches just made him want to “crash”. Another child (#56, 16-year-old female), when asked what happens when he had a headache, stated, “I crash kind of… like my whole energy just goes down. I just kind of give up, I want a, I hate fighting with it, I just stop fighting with it.” When they were having the headache, they “think only about the pain, and not what you are supposed to be doing.” (#85, 14-year-old female) and “focus only on the headache and can’t get [their] mind off of them” (#33, 14-year-old male). The overpowering nature of the headaches was also described as limiting: “Limits my ability to put my best foot forward,” (#63, 14-year-old female) and “Makes me want to stop what I am doing” (#52, 11-year-old female). The overpowering nature of the headaches contributed to the invisibility of the headache experience. Many of the metaphors used in the description of the headaches were illustrative of the overpowering nature of the headaches.
Gatekeeping. Another aspect of the invisibility of their headaches was gatekeeping. Although the majority of children told someone about their headaches, there were quite a few who selectively chose which headaches to tell about and which they would not make known. One 17-year-old male (#56), when asked if he would tell his teacher about their headaches at school, stated, “Well, sometimes I used to but I don’t want it to seem… like um… be some sort of excuse not to do work.” Another 16-year-old female (#81), when asked if she told her parents about all of their headaches, stated, “No, I don’t want them to panic.” The gatekeeping may have been related to the invisible worry and guilt experienced by the children and the adolescents in relation to how others perceived their report of headache. Furthermore, the gatekeeping could have been a coping strategy or an attempt to control the headache by keeping it hidden and maintaining a perceived normalcy. As soon as the headache was mentioned, it was made visible to others, and the children and the adolescents were very sensitive to how others reacted and responded to them.

Although the majority of children and adolescents could not tell the difference between a shunt-related headache and a non-shunt-related headache, some children stated they could tell the difference. Therefore, they knew which ones to tell about and which ones to keep hidden. For example, one 14-year-old male (#33) described the difference between a shunt headache, tumour headache, and flu headache: “Um sometimes with the brain tumour one it’s like a pulsing one, with the shunt it’s on-and-off one, and when it is just the flu it’s a straight one, like it doesn’t go on and off or it doesn’t just pulse (child making a 'do do do' noise for the pulse).” It is interesting to note that the children and the adolescents who could not tell the difference between shunt-related headaches and non-shunt-related headaches also did not share all their headache experiences with others. Although not formally discussed in the interview, it appeared that the children and the adolescents independently assessed their headaches, and knew which to make
visible and which to keep invisible. Children and the adolescents assessed and controlled what information they would share, and to whom they would make their headaches visible. They were very protective of their headaches, gatekeeping exposure, and incorporating this gatekeeping as a part of their coping and management strategy.

**Management Strategies.** The invisibility of the headaches was further described in how the children and the adolescents with shunted hydrocephalus micromanged their headaches in their daily activities. In general, children and adolescents with shunted hydrocephalus used a multimodal approach to management of their headaches, and did not rely solely on one management strategy. Their management strategies incorporated a mix of pharmacological, physiological and psychological strategies. These strategies have been further described under the theme “control”. The invisibility of their headache management strategies have been explored below.

The children and the adolescents expressed a great deal of insight, self-awareness and responsibility in regards to managing their headaches. In general, the majority of children and adolescents independently made decisions regarding their headache management. It became evident that before physically managing their headaches, children and adolescents assessed their headaches and devised a management strategy.

The independence of and the majority of the decision making described by the children and adolescents in relation to their headaches were invisible to their parents, health care team, friends and teachers. The management strategies only became visible once they implemented the management strategy. The older age group had very reliable coping and management strategies, as described on page 124. They also accepted unresolved headaches as being part of who they were and “just ignored them” and, as one 17-year-old male (#56) adolescent stated, “You just keep moving.” The younger age group, in contrast to the older age group, were not as
independent with respect to their headache management, although the younger age group had begun to take responsibility and manage their headaches independently. Once deciding on a management approach, their strategies predominantly involved taking medication, sitting quietly while dealing with the acute pain, and contacting a parent, predominantly their mother. The older age group, when asked about headache management, rarely called their parents when having headache. They were very independent in managing and attempting to control their headaches.

Many of the management strategies made visible their “invisibility” because of their physical absence in school, social, and family situations. Children described sitting in the classroom and putting their head down, removing themselves from play with friends, and leaving the family room where they had been engaged in activities such as reading or watching a movie with their family. As social beings, the children and the adolescents became physically invisible and were unable to participate fully in their daily activities. As a result of the headache pain and some of the management strategies described, the children and the adolescents experienced “missing out” and multiple “hidden challenges” with respect to their functioning in the school, social, and family environments.

**Missing Out.** Missing out was defined as children and adolescents being unable to participate in activities as a result of their headaches. The majority of children described missing out on many activities related to school, social, and family functioning. The missing out described, in regards to their physical absence, contributed to their invisibility as social beings. As one 16-year-old female (#32) stated, she missed out “on all the things [she] want[s] to do.” Another child (#52, a 15-year-old female) commented that her headaches “sucked.” When asked why, she responded, “Cause they make me sick sometimes and I can’t do what I want.” With respect to the social isolation she experienced, she went on to say, “When I have my headaches, I
don’t like them; I don’t like it at all. I wish I had never had them because I can’t do the stuff that I want to do normally; I want to be left alone.” Throughout the interviews, children and adolescents described examples of how, as social beings, they were visibly invisible in the school, social and family environment. The consequence of headaches on school, family, and social functioning, outside of the invisibility, has been discussed below.

**School Functioning.** Although the majority of children and adolescents claimed they weren't miss school, some children spoke about how much school they were missing. One 14-year-old female (#77) stated that she had missed 6 weeks of school in a school year. Another 16-year-old female (#100) stated, “[I] missed so much school this semester, like half, that I won’t be able to do exams.” The children's and adolescents’ physical absence from school, as described by the children and the adolescents, affected their ability to (a) keep up with academic demands, (b) advance through the education system with their peers, and (c) take part in many school activities.

**Social Invisibility.** The children's and the adolescents' ability to socialize with friends and to participate fully in extracurricular activities were also affected by headaches. One 17-year-old male (#56) described what happened when he got a headache while with his friends: “Well um, with my friends when I get a headache, and my friends are around me acting, talking loud and stuff, I just move away.”

In general, the children and the adolescents predominantly spoke about cancelling or leaving the activity when experiencing headache, further contributing to their invisibility, “I try playing, it’s like if I can’t play properly I am not having fun… [I] don’t like playing with friends with headache. I go home and rest” (#32, 11-year-old female); “If playing with my friends I just go sit by a tree” (#53, 7-year-old male). The invisibility was further exemplified in their family functioning.
**Family Invisibility.** Children and adolescents frequently described how they missed out on family functions and, because of their headaches, how they were visibly invisible: “Well if I am not really feeling well, and they were going out for dinner, like, they would still go and bring me something back, (#56, 17-year-old male)”; “Well just like, if we were planning to go somewhere, like to relatives or something, I don’t get to see my family, or I’ll have to go upstairs” (#57, 14-year-old female); “Sitting down to have dinner or sitting down to watch a movie, sometimes I can’t do that because I have too bad of a headache” (#58, 16-year-old female). The children and the adolescents were aware of plans changing after stating that they had a headache. It also became apparent that the majority of the children, when suffering from a headache, were excluded from plans, were not able to participate fully as a family member, and missed out on family time. Some children spoke complacently about missing out on family activities and about their ability to participate fully at home, whereas others expressed sadness and resentment in not being able to partake in family activities.

**Hidden challenges: Impact on school, social and family functioning.** With headache physically present, the children and the adolescents described that they experienced multiple hidden challenges as a result of their headaches when partaking in activities within the school, social, and family environments. The greatest effect of the headaches was within the school environment. Those children and adolescents who attended school with headaches spoke predominantly about the difficulty concentrating/focusing and completing homework and assignments. They spoke of their hidden challenges and the stress they endured when trying to keep up even though they were physically present in school: “Well like it is a little bit harder ’cause I have the whole class talking, and then I just have to deal with my headache so, it’s just a little bit harder” (#81, 14-year-old male). One 13-year-old male (#33) stated, “Like sometimes I am trying to listen to somebody and then I have a headache and so then I can’t really listen to
them because of the head—because my head is really annoying me, hard on the mind.” When asked to further explain “hard on the mind”, he said, “Like, if I’m in school and trying to think like for a question on a test I can’t really think about that ‘cause it is like the headache is a big wall blocking my thoughts from coming in.”

A 12-year-old male (#75) stated, “Um, ’cause sometimes [the headaches] get really bad like I said I can’t concentrate and just focus on how bad my headache is. So I can’t really concentrate on, like, all my school work cause of my headache… I’m not getting all, all my school work done and I have to stay in for recess.”

With regards to homework and assignments, one 14-year-old male (#33) stated, “Um, they don’t really help at all because with homework. I am really stressed out about it. I can’t concentrate and it just hurts, it doesn’t help at all.” Another 14-year-old female (#57) stated, “I am a good student but when having headaches, I do a tenth of what I could do normally; productivity goes way down, so much harder to concentrate, a lot harder to focus.”

The inability to concentrate and focus at school as a result of their headaches was seen as a stressor for many of the children and the adolescents. When they had headaches, they were stressed about (a) not being able to perform as well academically as they knew they were able, (b) not getting work done, (c) having to play catch-up, and (d) the impact of their performance on their future progress. Their inability to focus and concentrate affected their ability to write tests, complete assignments, and do homework. When experiencing headaches at school, the only thing they were able to focus on was their headache.

Furthermore, children and adolescents often experienced an abundance of hidden pressures to keep up when experiencing headache. The adolescents were more astute when speaking about their headaches and the influence they had on their productivity. However, it
was apparent that, despite the headaches, the majority of the children and the adolescents felt pressure to continue to produce as though they did not have a headache.

Children and adolescents also described missing out on school activities because of their headaches, “[I] miss out on assemblies and guest speakers.”; “If assemblies are loud, like music and drums, they give me a headache; I go the office and stay there.” (#58, 10-year-old female); “[I] can’t take part in recess, can’t walk around, just have to sit and take it easy” (#127, 11-year-old female). Another child stated, “[I] don’t participate in gym class… it is okay as long as I’m not active” (#33, 14-year-old male). The impact of the headaches within the school environment further perpetuated their invisibility as social beings and the missing out they experienced from their everyday activities.

When physically missing school, the older age group described how their lack of attendance affected their ability to keep up with academic demands and further advance their education. When speaking about the effect of missed days of school on her schooling, one 16-year-old female (#100) stated, “[The headaches] are affecting it a lot ’cause I won’t be able to go to university ’cause I don’t have enough credits… I won’t be able to go to university with my friends.”

Headache within the social realm was described as an annoyance and as an obstacle to being able to take part in many social situations. One 16-year-old female (#100) described her headaches as an annoyance when she was with her friends. She further described the annoyance, “Cause like sometimes you are with your friends and you will get one and you’ll just get it. And like, well, you will be playing a game or you will be doing something and it just changes your mood and you get annoyed ’cause you just got to your friend’s and that kind of thing or just started.” Overall, when speaking about taking part in extracurricular activities and activities that they enjoyed, they described being frustrated and saddened by not being able to take part in
them. As one child stated, “I am losing the ability to do the things that I love” (#32, 14-year-old female). The missing out experienced in the social realm perpetuated social isolation, unwanted alone time, and feelings of frustration and sadness.

The consequence of the children's and adolescents’ headaches on family functioning resulted in their exclusion from plans, missing out on family time, and a disruption from their role in the family (e.g., not being able to complete chores expected of them). The influence of the headaches has been described in qualitative results under family invisibility on page 117.

The descriptions provided by the children and the adolescents relating to the invisibility and the effect of their headache experience portrayed them as being victimized by their headaches. The victimization was characterized by the overpowering nature of the headaches (page 109), the multiple hidden components of the headache pain experience (page 101), and the metaphors used to describe the headaches (page 96). Headaches were constantly overshadowing the children's and the adolescents' everyday activities and, for the majority of children and adolescents, the headaches were overpowering their ability to function in the social, school, and family environments. As victims, they were silenced, and not did not speak openly about their headache outside of the sensory experience. In general, the children and the adolescents were attempting to control the headaches, yet were being controlled by their headaches but were valiantly trying to uphold a sense of perceived normalcy.

**Normalcy**

There was a perceived ideal of normalcy to which the children and the adolescents appeared to cling. Normalcy, for the purpose of this analysis, referred to the ability to perform or take part in any activity, and to not being limited by an underlying impairment (Susman, 1994). The sense of normalcy was perceived in the interviews by how the children and the adolescents (a) responded when first asked about their headaches, (b) described their headache, and (c)
described being affected by their headaches. When initially speaking about headaches, the children and the adolescents would not outwardly acknowledge that they were being affected by their headaches. There appeared to be a “disconnect” in how the children described the consequence of headache on their school, social, and family functioning versus how they outwardly acknowledged the limitations. One 16-year-old male (#53) stated, “Um when I get a headache at school, um to be honest, it might be difficult to do my work… I would never miss school.” This quote highlighted that the priority for the adolescent, despite stating that his headache affected his ability to do his school work, was to attend school and maintain a perceived normalcy.

**Disconnect.** At the outset, the children and the adolescents described their headaches in reference to the shunt, as described on page 86 of the qualitative results. There was a sense of disconnect between the headache and the individual child and/or adolescent. They spoke about headache in relation to the shunt and as a separate entity outside of themselves. This disconnect could have been a means of protecting their normalcy and an attempt for the child not to be seen as different because of their shunted hydrocephalus. The headache was not about them, nor did it define who they were. The headaches were described as a symptom of shunt functioning.

This sense of normalcy was further reinforced in the responses, predominantly by the adolescents, when describing the association between their headaches and their ability to function. When speaking about the influence of headache on their school and social functioning, the majority of adolescents, in comparison to the younger age group, spoke about continuing to take part in activities while managing their headaches. There was a tendency for the children and the adolescents to downplay their headaches and the effect they had on their school, social, and family functioning. One 17-year-old male (#56) stated, “They aren’t a problem, they just come and go, but with school and stuff I can manage them.” Another 16-year-old male (#81),
with respect to school functioning, answered “no” when asked if he missed school because of headaches, and also responded “no” when asked if he was able to participate fully in school. He went on to say, “Well if I have an assignment I might not get to finish it on… I do some of it or none of it at all.” The interviews often required probing and further clarification in these domains. The initial response for the majority of the children and the adolescents was that they were not affected by their headaches.

When first asked about the effect their headaches had on their school, social, and family function, children and adolescents responded that headaches did not affect their functioning in these realms. The majority stated that they did not miss school because of headaches, and that they went to school despite a headache. The contradiction between what the child had initially reported and subsequently described was also apparent when they described the effect the headaches had on their social and family environments. Although initially responding that their headaches did not impact their ability to take part in familial and leisure activities, throughout the interviews, it was apparent that there was a dissociation between the children's initial responses with respect to headaches influencing their school, social, and family function, and how they subsequently described their influence. It is interesting to note that, when initially asked if the headaches affected their school, social, and family functioning, their response was predominantly “no”. When responding, the adolescents were particularly emphatic in their response. There was also a sense that their initial response of “no” to each of the questions was held like a badge of honour—something they strived for and took pride in. An example of this disconnect was from a 14-year-old female (#52) who, when asked if headaches affected her schooling, stated, “No... not really”. Then, upon further questioning about the effect of headache on her schooling stated, “I have missed so much this semester, like half… I can’t focus very well at first… and I can’t do my exams this semester.”
This contradiction was invisible to the children and the adolescents speaking about their headache experiences, as it appeared they were unaware of the contradiction. The disconnect was evident to the interviewer who listened to the children's and adolescents’ responses. These children and adolescents missed out on a myriad of activities, yet they denied the fact when asked. Throughout the interviews, the children and the adolescents described situations that indicated they were aware of the consequences of their headaches on school functioning, social interaction, and family functioning, exemplified in the Hidden Challenges on page 117. They described their decreased productivity in school, their awareness as to how others responded to their headaches, and how their headaches hindered their ability to take part in extracurricular and social activities. It appeared as though children and adolescents with headache, despite a functional shunt, exerted a great deal of energy to maintain and protect a perceived normalcy, presenting themselves as the same as other children and adolescents. This disconnect raised many questions and could be hypothesized to have been (a) a product of their reality, (b) a result of having unresolved headaches despite a functional shunt, (c) a coping strategy used to perpetuate the invisibility of their headaches, thereby promoting their normalcy, or (d) representative of the children's and the adolescents' attempt to present themselves as normal during the interview yet unable to maintain this representation throughout the interview.

**Control/Out of Control**

Children and adolescents were very adept at describing the management strategies they used to manage and control the symptoms associated with their headaches. However, when speaking about the consequences of their headaches, the children and the adolescents also described how they were being controlled by their headaches despite the management strategies used to control the sensory components of their pain. Headache control was twofold: firstly, in the child's and the adolescent's description of their management strategies, and secondly in their
descriptions of the effect headaches had on their ability to participate in school, social, and family functions.

**Management strategies.** All of the children and the adolescents with shunted hydrocephalus tended to use a multimodal approach in the management of their headaches and did not rely solely on one management strategy. Their management strategies incorporated a mix of pharmacological, physiological, and psychological strategies. One child (#82, 9-year-old female) called how she dealt with her headaches her “headache system,” describing a stepwise approach to managing her headaches. She would begin by taking medicine, putting her head down, removing herself from what she was doing, and if that did not suffice, she would then call her mother. Her headache system incorporated pharmacological and physical management strategies in a stepwise manner.

**Pharmacological management.** The majority of children and adolescents described how they initially took acetaminophen or nonsteroidal anti-inflammatories (NSAIDS) for their headaches to get some relief. One 14-year-old female stated, “Um, well if it is not too bad, I usually um take Motrin (NSAID) and usually that will fix it, if it’s like, if I was going to rate it on a pain scale if it is like a 5 or, well, not 5, but if it is like 7 or above, then generally I have to like, try and go quiet area for at least 10 or 15 minutes. And then I can go back, but sometimes if it is really bad I will have to like remove myself from the situation and lie down.” A 12-year-old female stated (#52), “[I] take Tylenol (acetaminophen) and if that doesn’t work, ‘cause that usually does, if it is really bad, and that doesn’t work then I lay down for as long as it takes to go away.”

Although most of the children took medication when they had the headache, some were preemptive in their management and would premedicate themselves when partaking in activities that they knew would precipitate a headache. One 9-year-old-female (#82) spoke of taking her
“headache pills” before attending school and always having her medication in her pocket: “Well when I have pockets like these I would usually, you know um, just take them whenever I needed them at school but if, um, I didn’t have pockets like a sweater kind of thing without pockets I would just take them before school… Yeah… I would take them a lot of times, I’m afraid… I just take them it’s because like my…it’s always loud at my school, it’s always loud.”

Premedicating was not a strategy described consistently by the children and the adolescents when asked to describe their management strategies.

Pharmacological management, whether preemptive or for symptom relief, was the first-line management strategy described by the children and the adolescents to control their headaches, incorporating the use of acetaminophen and NSAIDS.

**Physical management.** The majority of the children also spoke about physical strategies they used to help manage their headaches. They described putting their head down, splashing water on their face, and removing themselves from situations when a headache arose: “When I used to get [headaches] at school, um, I’d tell my educational assistant and she’d give me a cold cloth, it would help a bit, then I either would sit on the front hall bench, or walked around the school… uh… if I was walking around I’d normally sit down and that would get it away” (#32, 12-year-old male); “I lay uh, usually in the corner or usually talk to my mom or my dad or I just lay in bed and take a nap.” (#53, 7-year-old male); “I usually just try to keep my sisters quiet and just go to my room and turn off the light and just try to make it go away” (#66, 12-year-old male); “I just try to distract myself by doing something else like watching TV or something and usually it helps and I will keep pretty quiet and usually that helps” (#78, 9-year-old female).

Children also tended to avoid situations when they had a headache. They were adept at self-selecting activities and situations that may have precipitated a headache. As one 16-year-old
female (#57) commented, “There are things you don’t do because of headaches; you don’t go to certain places and don’t take part in certain activities.”

**Psychological management.** A few children described using pleasant thoughts and a “keep-going attitude” as a means of managing their headaches. One 17-year-old male (#56) stated, “Well when I get a headache, sometimes I think about things that can make it better. I, like, try to picture myself somewhere where there are lots of flowers, like somewhere naturistic.” The keep-going attitude came into play when the headaches persisted despite a functional shunt and management strategies failing. This keep-going attitude entailed trying to ignore the headache, forgetting about them, and just moving on. The keep going attitude may be a form of denial or distraction and will be explored in the discussion. Another 17-year-old male (#54) stated, “I try, like, if I have a headache I try to just keep doing what I like, if I have work to do I just keep trying to do it, I try not to let it make me like stop what I am doing and go and relax with it. I just try to keep doing what I am doing.” A 14-year-old male (#81) was asked, “And if that doesn’t help?” and responded by describing his headache management approach and then stated, “I just live with it.”

Throughout the interviews, the children and the adolescents described multiple management strategies used to manage their headaches. However, it was apparent that despite the strategies used to control their headaches, the children and the adolescents were being controlled by their headaches. Management strategies described by the children and the adolescents controlled or managed only the sensory aspect of the headache pain. However, the strategies failed to control the overpowering and emotional component of the headache experience which remained out of control as described by the hidden emotions and overpowering nature of the headaches (pages 103 and 112). As a result, the headaches were controlling the children's and adolescents’ ability to partake in activities related to their school, social, and
family functioning. Furthermore, the strategies described did not address the hidden challenges or the missing out previously described by the majority of the children and the adolescents. Therefore, the headaches, despite managing the sensory aspects of their headache pain, were out of control and affecting the child's and the adolescent's ability to function in their daily activities. The headaches, essentially controlled the child's and the adolescent's ability to function in the school, social, and family environments. The out-of-control aspect of the headaches have been explored below.

**Out of control.** Children and adolescents described how headaches hindered their normal activities. When the children and the adolescents experienced headaches, they did not take part in daily activities, isolated or removed themselves from their activities, and preferred to be by themselves. As one 14-year-old female (#78) stated, “…Headaches make me feel like not wanting to do anything, just sitting down, laying down.” Another 13-year-old female (#52) stated, “When I have a headache I can’t do stuff I wanna do, I wanna be left alone.” Another child (#53, 7-year-old male) stated that when he was having headaches, “I sit by a tree.” When experiencing headaches, the children's and adolescents’ decisions relating to their daily activities were being dictated by their headaches, despite attempts to contain them.

Normalcy and control/out-of-control were intertwined constructs in the descriptions of headache. The child’s and adolescent’s ability to control the physical pain, and the hidden challenges they experienced as a result of the headaches, affected their ability to take part in normal activities and maintain a perceived normalcy. It seemed that the children and the adolescents attempted to maintain a balance between controlling the visible and invisible aspects of their headaches, and perceived normalcy. However, some were unable to achieve this balance, and therefore needed to sacrifice either normalcy or control of their headache. For
some, it became a question of controlling the headaches or being controlled by the headaches; presenting themselves as being normal or becoming socially invisible.

Decisions related to normalcy and control were made either consciously or unconsciously. For the younger children, there did not seem to be a conscious trade-off. They had headache which prevented them from doing things. One 7-year-old male (#53) stated very concretely, when asked how headaches affected the things he liked to do, stated, “I just really don’t do them anymore… I lay down on my couch”. When asked when he would go back to doing what he was doing he replied, “When they go away… half a movie maybe…” Another 9-year-old female (#127) described how she managed having a headache when she was supposed to have a play date: “I would just call them and say I can’t go. Maybe tomorrow and maybe they would be free so I’d just do it then.” Their descriptions did not support putting a lot of effort in either maintaining normalcy or controlling the headache. Headache was predominantly seen as a sensory symptom. Therefore, their control of the headache symptoms affected their ability to take part in normal activities. There was not a great deal of emphasis placed on their perceived normalcy. Instead, they described, in a concrete manner, what they were missing out on because of the headache pain.

In contrast to the younger age group, the adolescents appeared to make a conscious decision pertaining to control and perceived normalcy. Adolescents spoke predominantly about maintaining normalcy despite headache control, as exemplified in the presenting normalcy theme. They would continue to partake in activities despite headache pain. This may be reflective of their stage of development, and the importance placed on peer relations.

The male adolescents were the most proficient at maintaining their normalcy and at being in control of their headaches. They spoke about their headaches in a concrete manner, dealt with the sensory headache pain, moved beyond unresolved emotions, and focused on maintaining
normal activities. The following quote is an example of the aforementioned management strategy, as described by a 16-year-old male (#56): “[Headaches], it comes and goes, like it isn’t something I worry about… Well um, with my friends, when I get a headache, and my friends are around me acting, talking loud and stuff, I just move away. Well, a lot of times we play basketball and soccer.” When asked if headaches would keep him from playing, he responded “no”. From their interviews and the description of their headaches, predominantly focusing on the sensory aspect of headache pain, the children and the adolescents appeared as though they had made a conscious decision to focus on their normalcy as opposed to the uncontrolled aspects of their headaches.

In contrast to their male counterparts, females appeared to sacrifice aspects of their normalcy while attempting to manage the physical components of their headaches. The females focused on the uncontrolled aspects of their pain, including the affective and emotional components of their headaches, and what they were unable to do. While they tried to uphold a perceived normalcy, there was an invisible struggle as they continued to struggle with the emotional and affective components of their headache pain, as well as other perceptions of their headache described previously in relation to anticipatory worry and guilt on pages 108 and 110. For this group, the headache seemed to dictate and control their reality; there was a sense of ambivalence and defeat with respect to the headache as described in the overpowering nature of the headaches. The sense of defeat is illustrated in the following quote by a female adolescent (#57) describing what she thought about when she would get a headache: “If it is gonna get worse, if it’s gonna mean I can’t do something, if it is gonna cause me a lot of problems, if it’s gonna put me in a bad mood…” She went on to say that, “[headaches] can be really painful or just sort of, but whatever it is I feel like it’s everything is more elevated; you’re more anxious, more stressed, you’re more likely to get upset… Socially, if I have a headache I just have to
cancel because it won’t be enjoyable.” With respect to her extracurricular activities she commented: “Well, I figure skate, so like, that can be a problem, because obviously I get dizzy, too, along with the headaches, so obviously I can’t skate. I’m in a band, which really isn’t the best situation for a person with headaches, um, I’m in a lot of concerts, I take piano and figure skate and am in a bunch of clubs, so sometimes I won’t be able to go to them because of headaches, and that can be very frustrating, because I really do love them, especially figure skating.” The above quote exemplified how the female adolescent attempted to partake in many extracurricular activities, yet was unable to participate fully, and was emotionally affected by her lack of involvement.

Female adolescents tended to succumb to a substandard sense of normalcy by sacrificing their headache control. It appeared as though their normalcy was superficial and inconsistent with their reality. Although articulate in describing the emotional and affective components of their headaches, they lacked the ability and the desire to change or move beyond the unresolved emotions. Consequently, the lack of control related to their unresolved emotions affected their ability to maintain a perceived normalcy. Female adolescents were very aware and articulate about what they were not able to do in relation to their peers.

**Summary of Qualitative Results**

Children and adolescents were very adept at describing the sensory aspect of pain related to their headache experience. The description of the headache was initially in association with the shunt. However, once moving beyond the physical descriptors, children and adolescents expressed emotions of sadness, anger, worry and guilt in association with their headaches. They described the headaches as overpowering and as to how they affected their ability to function in the school, social, and family environment. The effect of the headaches was dominated by the overarching themes of invisibility, normalcy and control. Invisibility incorporated
emotions: fear, worry, anger, guilt and sadness, (b) the overpowering nature of headache pain, (c) gatekeeping, (d) management strategies: pharmacological, psychological and psychosocial, (e) missing out, (f) social invisibility, (g) school invisibility and (h) family invisibility. The impact on school, social, and family functioning incorporated multiple hidden challenges, which affected the visibility of the child and the adolescent as a social being. Control incorporated pharmacological, physiological, and psychological management strategies, and being out of control. Normalcy incorporated the subtheme of disconnect.

**Triangulation of Qualitative and Quantitative Results**

At the outset of the study, it was initially hypothesized from the general pediatric literature review, and anecdotally from experienced pediatric neurosurgical clinicians, that age and sex would have been individual child factors that would have shaped the headache experience of children and adolescents with shunted hydrocephalus. From the quantitative analysis, neither sex nor age were statistically significant. However, from the descriptions in the qualitative interviews, it became apparent that the headache experience was described very differently by males versus females, and very differently by younger versus older age groups of children and adolescents. Females, in contrast to their male counterparts, seemed to attach more importance to their unresolved headache pain. The difference between males' and females' description of their headache experience was highlighted on numerous occasions in the interviews. Females were more expressive about the emotional components of their unresolved headache pain. They spoke more frequently about the implications of their unresolved headache pain for themselves and others, and many described an anticipatory worry related to their headaches. Males, as described on page 97, tended to use very concrete terms, and dealt predominantly with the sensory components of headache when communicating about their pain.
experiences. Males, in contrast to females, focused less on the affective and emotional aspects of their headache experience.

From the qualitative interviews, the frequency of headaches appeared to affect the headache description and interview content. Children and adolescents with an increased frequency of headaches expressed more emotion and anxiety related to their headache experience. Furthermore, there appeared to be an interaction between frequency of headache, headache descriptors, the female sex, and the older age group. Of the children and the adolescents taking part in the qualitative interviews 14 were female, nine were male. Of the females, five were 7-10 years of age and of the males, three were 7-10 years of age. Although not substantiated in the quantitative findings, within the qualitative sample, the female participants more thoroughly described, and expressed greater concern about the impact of their unresolved headache experience on their school, social, and family environments compared to their male counterparts. Females spoke more about the emotional and affective components of unresolved pain (page 98), and the worry related to the lack of resolution. Females were more likely to identify vulnerability to the untoward effects of unresolved pain, and the influence it had on their school, social, and family functioning.

From the quantitative analysis, etiology was the only child factor that was statistically significant. The possible reasons as to why etiology was related to headache in this patient population have been described in the discussion chapter. However, upon review of the qualitative interviews in association with various etiologies, children and adolescents with myelomeningocele appeared to be more descriptive and forthcoming about their headaches compared to the other children interviewed. They also described being more affected by their headache experience, and spoke more passionately about their headache experience (e.g., “I hate [the headaches], I wish I never had them”).
There was a distinct difference in the manner in which they spoke about their headaches. In comparison to other children and adolescents that were interviewed, the 4 children and adolescents with myelomeningocele spoke more frequently of unresolved headache episodes and expressed more anger and resentment related to headaches than children interviewed with other diagnoses. From the interviews, children with myelomeningocele appeared most negatively affected by their headaches. Perhaps the report of pain, and increased emotion, may have been reflective of headache frequency, concurrent pain events in other areas of the body, or other issues relating to their physical disabilities. For the child with hydrocephalus and myelomeningocele, their pain experience may have been heightened due to other physical, psychological and psychosocial factors inherent in hydrocephalus related to myelomeningocele. This concept has been further developed in the discussion.

Conversely, from the quantitative analysis, children with tumours had a decreased propensity to report headache. Children with tumours spoke pragmatically about their headaches, and focused less on the emotional and affective nature of the headaches. They tended to focus primarily on the sensory components of the headache pain. The reason for the pragmatic description of the headache pain, and the decreased reporting of headache pain compared to children with MMC, may be attributed to (a) the majority of children interviewed with tumours were male, (b) the temporality associated with the onset of symptoms and treatment, (c) lack of other physical disabilities associated with their diagnosis, and (d) the decreased frequency of unresolved headache.

The present study only begins to uncover the complex and multifactorial nature of the headache experience of children and adolescents with shunted hydrocephalus. The qualitative and quantitative components both provide insight into the complexity of headache for this patient population. From the quantitative component, the prevalence of headache within this patient
population exceeded that reported in the general pediatric headache research. Anecdotally, and based on expert neurosurgical opinion, eight child factors, incorporating demographic, physiological, and shunt-related variables were explored for their association with the child and adolescents headache experience. Of the variables investigated, etiology was the only variable that showed statistical significance. The fact that many of the child factors related to demographic, physiological, and shunt variables failed to show significance, and the prevalence exceeded that reported in the general pediatric research, has illustrated the complexity of headache pain for the study population. Conversely, in the qualitative component of the study, the children and the adolescents described multiple psychological, psychosocial and emotional experiences that could also help to explain the increased prevalence of headache for children and adolescents with shunted hydrocephalus.

However, neither the qualitative nor quantitative results could solely account for the increased prevalence of headache in the study population. With triangulation of the data, age and sex were factors that, despite being statistically insignificant in the quantitative analysis, showed distinct differences in the report and description of headaches in the qualitative component of the study that could have potentially impacted the prevalence of headache. The difference between age and sex in the qualitative and quantitative findings is an example of how the use of a mixed method study offsets the limitations in either study design, and provides broader insight into the intricacies of the child's and the adolescent's headache experience.
Chapter 7
Discussion

In this chapter, the findings from the research are discussed. The qualitative and quantitative findings are integrated highlighting components of the key themes of invisibility, control, and normalcy from the qualitative analysis with the quantitative statistics. Current research, practice and theory are used to provide plausible explanations for the study results. The discussion focuses on (a) the prevalence, frequency, and nature of headache in children and adolescents with shunted hydrocephalus, (b) the child factors associated with headache in children and adolescents with shunted hydrocephalus, (c) how children and adolescents with shunted hydrocephalus described their headache experience, and (d) how children and adolescents with shunted hydrocephalus described the impact of headache on school, social, and family functioning.

Prevalence, Frequency and Nature of Headache

Prevalence. Prevalence of headache in this study was 66.0%. This prevalence exceeded the prevalence that had been reported previously for children and adolescents with headache and shunted hydrocephalus (Rekate & Kranz, 2009; Gupta et al., 2007). The difference in the reporting of prevalence could be related to the study methodology and the criteria used to report headache.

Within the general pediatric headache research, headache prevalence has been reported between 14.0% and 87.0% (Hershey, 2005; Galleli et al., 2005; Koening et al., 2002; Sillanpaa & Antilla, 1996; Wang, Fuh, & Lu, 2009; Shivpuri et al., 2003; Kroner-Herwig et al., 2007; Bandell-Hoekstra et al., 2001; Abu-Arafeh, I. et al., 2010) for healthy children and adolescents between 7 and 18 years of age. A recent systematic review by Abu-Arafeh et al. indicated that
headache prevalence for healthy children was 58.4%. The timeframe for when headache occurred varied between a 3-month period to lifetime. Although the present study findings were similar to the prevalence of headache reported in this systematic review, the timeframe was significantly different. In general, the variability in reporting based on a review of headache prevalence research, was dependent on multiple factors including (a) the timeframe for the headache occurrence, (b) the method of data collection, (c) the demographics (specifically age and sex), and (d) the criteria used to define headaches.

For the majority of the epidemiological studies on headache prevalence, headache occurrence was determined by asking whether the child or adolescent had ever experienced headache. In the present study, the child or adolescent was specifically asked to retrospectively report on whether they had had any headaches (yes or no) within the previous month. Kroner-Herwig and colleagues (2007) assessed the distribution and characteristics of headache in children aged 7 to 14 years at various time points and reported headache prevalence as 67.0% when the child was asked to recall whether they had had headaches within the past 6-month period, 20.0% when asked if they had had headaches within the last month, 28.0% when asked if they had had headaches within the last 2 to 3 weeks, and 16.0% when asked if they had had experienced headaches within the last week. Zwart et al. (2004) reported that 76.0% of 13- to 18-year-olds reported having had headache in the past year and only 14% reported monthly headache. Paediatric headache prevalence within a 1 month timeframe for healthy children and adolescents between 7 and 18 years of age was between 13.0% and 20.0% (Kroner-Herwig et al.; Zwart et al.; Kernick et al., 2009). The prevalence of headache decreased as the timeframes became shorter in duration (Kroner-Herwig et al., Zwart et al., Kernick et al.).

In comparison, in the present study, the reported monthly headache prevalence was 3 times greater for children and adolescents with shunted hydrocephalus than in research headache
prevalence in healthy children and adolescents within a 1-month period (Kroner-Herwig et al., 2007; Zwart et al., 2004; Kernick et al., 2009). Based on the qualitative and quantitative findings, the increased prevalence of headache (informed by clinical experience, theoretical constructs pertaining to the study, and aspects of the literature review) could be attributed to (a) diagnosis of hydrocephalus (Melzack, 1996), (b) the importance placed on headache within the neurosurgical context in relation to shunt functioning, (c) the increased number of psychosocial challenges and emotions described by the children and the adolescents (Stanford et al., 2008), and (d) the children’s and adolescents’ predisposition to stress and stressful events (Meldrum, 2009). These hypotheses are explored by integrating theoretical constructs from (a) the neuromatrix theory of pain (Melzack, 1996), (b) the gate control theory of pain (Melzack, 1965), (c) the headache classification system (International Headache Society, 2004), and (d) the qualitative and quantitative findings.

**Diagnosis of hydrocephalus.** Children and adolescents who are diagnosed with hydrocephalus may be predisposed to headache because of a possible genetic or biological predisposition altering the pain processing pathways (Melzack, 1996). The neuromatrix theory of pain (Melzack) stipulates that neural processes can be activated and modulated in the absence of sensory input. Essentially, the brain can initiate a pain response without an external physiological trigger. According to this theory, brain processes are built-in by genetic specification and produce characteristic nerve impulses for the body. Hydrocephalus, within the context of the neuromatrix theory of pain, may potentially affect the brain’s neural networks and genetic substrate; thereby affecting the child’s and adolescent’s susceptibility to pain and increasing report of headache. Therefore, the increased prevalence of headache raises the question as to whether a child with hydrocephalus has a genetic or biological predisposition for headaches.
The significance of etiology as the only factor influencing headache has raised multiple questions including: (a) Is there a genetic predisposition to headache pain for children diagnosed with hydrocephalus? (b) Does hydrocephalus affect the composition of the pain pathways and increase the susceptibility to headache? and (c) Do these children potentially experience an alteration of the pain processing pathways related to multiple surgical interventions and unresolved headache episodes? Although hydrocephalus has not been studied specifically, other neurological and health conditions have been studied with respect to genetic predisposition to headache. For example, rolandic epilepsy, the most common benign epilepsy syndrome in children (Clarke, Baskurt, Strug, & Pal, 2009; Yankovsky, Andermann, & Bernasconi, 2005) was found to be genetically associated with migraine headaches (Clarke et al., 2009). Researchers have also explored acquired cerebral toxoplasmosis (Prandota, 2007), sickle-cell disease (Niebanck et al., 2007), solid organ transplantation (Shenoy & Webb, 2009), glutamate receptors in children with chronic posttraumatic headache (Goryunova et al., 2007), systemic lupus erythematosus (Lessa et al., 2006), and inherited prothrombotic risk factors in children with stroke (Herak et al., 2009). Other than a genetic link to migraine and epilepsy, there were no other links between headache prevalence and diagnosis. To date, researchers have not specifically addressed a genetic predisposition to headache in children with hydrocephalus. Investigating a potential genetic predisposition would provide a greater understanding of headache prevalence in this patient population.

In terms of a biological predisposition, the multiple surgical interventions and increased recurrent headaches associated with hydrocephalus, could potentially change the excitability of the central neurons that generate pain hypersensitivity (Porter et al., 1999). Theoretically, hydrocephalus, may predispose the individual to altered pain pathways that could hypothetically change the excitability of the central neurons in the spinal cord, thereby generating pain
hypothesis (Porter et al.; Woolf, 1983) and resulting in increased headache and report of headache pain. This phenomenon is known as central sensitization (Woolf). Central sensitization manifests at the single cell level as a change in receptive field properties, reducing the pain threshold, increasing the responsiveness, spatial extent, and recruitment of novel inputs (Woolf, 1996). Central sensitization refers to a cellular process within the central nervous system whereby the stimulus needed to generate a response decreases over time while the amplitude of the response increases. This theory has been applied to migraine and altered processing of sensory input in the brainstem, principally the trigeminal nucleus caudalis, which is thought to account for many of the temporal and symptomatic features of migraine (Dodick & Silberstein, 2006). Buchgreitz and colleagues (2006) examined the role of central sensitization in primary headaches in the general adult population. These researchers described a close relationship between altered pain perception and headache which could likely be explained by central sensitization.

Furthermore, hydrocephalus as a chronic health condition may predispose children and adolescents to an increased reporting of pain. The prevalence of headache pain reported by children and adolescents with shunted hydrocephalus was similar to headache pain reported by children with other chronic health conditions. Schnanberg and colleagues (2005) reported that 76.0% of children with polyarticular juvenile arthritis reported that they experienced pain on greater than 60.0% of the days in a two month period (Schnanberg et al.). In comparison to other chronic health conditions, children with hydrocephalus and rheumatoid arthritis have had a greater tendency to report increased pain relative to healthy children. The increased prevalence of pain in children with chronic health conditions raises questions about the psychosocial contributions to the pain experience. Schanberg and colleagues (2003) also studied pain, stress, and mood in children with rheumatoid arthritis and found that stress and mood were predictive of
increased pain in children aged 8 to 18 years (Schnanberg et al.). In accordance with the GCT (Melzack, 1965), psychosocial challenges and emotions affect the reporting of pain. Within the present study, children and adolescents described multiple psychosocial challenges associated with their headaches. Furthermore, in the multivariate analysis, in the etiology of congenital without myelomeningocele (MMC), fewer headaches were reported by children with MMC. The difference in the reporting of headache within the congenital with and without myelomeningocele groups may be related to other physical disabilities associated with having myelomeningocele and to the psychosocial issues inherent in having a physical disability. These findings, along with the qualitative accounts of the psychosocial components of the child's and the adolescent's headache experience, exemplify the potential contribution that hydrocephalus as a chronic health condition has on the headache experience.

**Importance placed on headache within the neurosurgical context.** The importance placed on headache for the child and the adolescent with shunted hydrocephalus begins at the time of shunt insertion. Due to the morbidity associated with shunt malfunction, children and adolescents with shunted hydrocephalus are educated that headache is a symptom of shunt malfunction. Therefore, the child’s and adolescent’s increased headache prevalence may be explained by the importance placed on headaches by physicians and nurses within the neurosurgical health care team, and potentially parents, in relation to shunt functioning. Hypothetically, children and adolescents with shunted hydrocephalus may develop an increased psychological sensitivity to headache and, consequently, may report headache more frequently. Kroner-Herwig et al. (2007) developed a profile of risk factors predictive of pediatric headache occurrence. Anxiety and anxiety sensitivity (defined as the extent of feeling threatened by a bodily response (Kroner-Herwig et al.) were predictive of headache occurrence as reported by the child. In accordance with Kroner-Herwig et al.’s findings, children and adolescents with
shunted hydrocephalus may have an increased propensity to report headache because of the neurosurgical context of headache, the concern of shunt malfunction, or the potential repercussions associated with their headaches as evidenced by the worry described by the children and the adolescents during the qualitative interviews. As described on page 87, when experiencing headache, children worried about what the headache meant, possible surgeries and hospitalizations, and the implications of living with unresolved pain. However, these children may also feel threatened by the headaches, as described by their hidden worry (page 106), and by the impact on their everyday activities; described in this study as “the missing out” (page 113) and “hidden challenges” (page 115).

**Psychosocial challenges and emotional factors.** Melzack, (1965) theorized that pain was modulated by multiple psychological, emotional and physiological factors. The increased prevalence of headache in this study could potentially be related to the psychosocial challenges and emotions described and experienced by the children and the adolescents with shunted hydrocephalus. In the qualitative interviews, the children and the adolescents expressed multiple emotions related to their headache experience (Page 101). For the child and the adolescent with shunted hydrocephalus and headache, the emotions were invisible and influenced their ability to control their headaches and maintain a perceived sense of normalcy. Melzack also hypothesized that higher central nervous system processes, such as emotions, anxiety, anticipation, and past experience, exert a powerful influence on the pain process and experience of pain. Children and adolescents in this study described multiple worries, concerns, and emotions related to their headache. They also reported difficulties concentrating in school and concern about missing out on social and family activities. All of these factors can potentially affect the headache experience and the prevalence of headache pain. The increased prevalence of headache for the
child and the adolescent with shunted hydrocephalus could potentially be an expression of their emotional and social pain.

Pediatric headache researchers have clearly stated that headache is multi-factorial (McGrath & Hillier, 2001). Kroner-Herwig, Morris and Heinrich (2008) substantiated that the child’s self-report of headache was highly predictive of many psychosocial and psychological variables. Kroner-Herwig et al. reported that increasing age, sex (females), marital status (single parent households), quarrelling in the family, dysfunctional child rearing, school stress, increased homework, number of friends, free play, and frequency of physical activity were all predictive of increased headache occurrence. Data were not collected on the other factors described by Kroner-Herwig et al. in the present study. Future exploration of headache in this population would need to incorporate these specific factors.

Within the present study, the majority of the child factors (e.g., number of shunt revisions, history of infection, age of insertion), were not statistically associated with headache occurrence. However, the differences in the reporting of headache in the qualitative results specific to age and sex highlighted the importance of collecting data using different methods, and of considering the role that emotional and affective factors may play in the child’s and adolescent’s headache experience.

**Predisposition to stress and stressful events.** Stress is also a factor precipitating or propagating headache (McGrath & Hillier, 2001; Marlowe, 1998, Kroner-Herwig et al., 2008) and is further substantiated in the neuromatrix theory of pain (Melzack, 1996). In the present study, the children and the adolescents with shunted hydrocephalus reported multiple stress-related factors that could have potentially predisposed them to headaches. These factors included (a) multiple hospitalizations and surgeries related to their hydrocephalus, (b) continual observation in clinic, (c) dealing with various challenges in the school system (cognitively and
socially), (d) dealing with unresolved emotions related to their headaches, and (e) constant micromanagement of their headaches throughout their daily activities.

The children were worried about their headaches in relation to shunt malfunction, were afraid of what the headache meant, and were frustrated with the unresolved headache pain and its impact on their daily activities (page 104). Headaches were a constant reminder of their underlying diagnosis. Inherent in this reminder was (a) the uncertainty associated with their diagnosis related to if and when the shunt will fail, (b) the possibility of surgeries and medical investigations, (c) disruptions to school, family, and social functioning, and (d) the reality that there may not be an explanation for their headaches and the need to live with unresolved pain. Stress experienced by the children and the adolescents with shunted hydrocephalus may be a factor in the increased reporting of headache pain.

In a questionnaire developed by Bandell-Hoekstra et al. (2002) and administered to children regarding stressful events (Bandell-Hoekstra et al.), children reported that a hard day at school or home, an unpleasant emotional situation, worrying a lot, unexpected excitement or pressure, tension, and happy or sad emotions were stress-related triggers (Levinton, Slack, Masek, Bana, & Graham, 1984). The children and the adolescents in the present study expressed many of these same emotions (page 101), and described many hidden challenges specific to the school environment (page 114). Consistent with Bandell-Hoekstra et al.’s study findings, the children and the adolescents with headache and shunted hydrocephalus experienced various emotions and hardships in relation to their schooling and their ability to cope with the challenges.

Appraisal of pain and the coping style adopted affect the pain experience (Alfven, Ostberg, & Hjern, 2008; Marlowe, 1998). In a review by Bandell–Hoekstra et al. (2000) on recurrent headaches, coping, and quality of life in children, headaches were perceived as
stressful, but coping with stress was also perceived as an important headache and pain expression trigger for the child.

Stress is also a vital component of the pain process and has physiological sequelae that could potentially result in recurrent pain episodes. According to the neuromatrix theory (Melzack, 1996), pain disrupts the brain’s homeostatic regulation system, thereby causing stress. The disruption of homeostasis subsequently activates neural, hormonal, and behavioural activity aimed at reestablishing homeostasis. During the rebalancing process, cortisol is released. If the cortisol output is prolonged during the re-balancing process, it produces destruction of muscle, bone, and neural tissue resulting in chronic pain conditions. Sex-related hormones, genetic predisposition, and psychological stress are all factors that influence cortisol release, amount, and patterns, and ultimately the effects it has on the body (McCance & Huether, 1998). The child and the adolescent with shunted hydrocephalus and headache experience multiple stress events that could potentially predispose them to experience increased pain or headache events.

**Frequency of headache.** Seventy percent of children and adolescents in this study reported they had headache between 1 and 5 days per month, and 7% reported daily headaches. According to the IHS classification of headache disorders, headaches occurring 1 day per month but less than 12 days per year are classified as infrequent; headaches occurring greater than 1 day per month but less than 15 days per month for 3 months are classified as frequent episodic; and headaches occurring greater than or equal to 15 days per month for 3 months are classified as chronic (International Classification of Headache Disorder, 2004). In the present study, 30.0% (48/163) of the children and the adolescents who reported having headache experienced infrequent (n = 100/163; 61.4%) and frequent episodic (n = 15/163; 9.2%) headaches. Twelve out of the 247 children and adolescents (4.8%) reported daily headache. Although these children and adolescents fit the profile of chronic headache, they could not be accurately classified as
having chronic headache because the headache report in the present study was limited to a 1-month (as compared to the 3-month IHS criteria) data collection period.

Frequency of headache occurrence is an important factor in the child’s and adolescent’s functioning and the burden of pain on their daily activity. Several studies have investigated the impact of pain in relation to the frequency of pain (Massey et al., 2009; Bandell-Hoekstra et al., 2002; Frare, Axia, & Battistella, 2002; Merlijin et al., 2006; Kernick et al., 2009), intensity of pain (Eccleston et al., 2007; Merlijin et al.; Kernick et al.), length of pain experience (McCracken, Gauntlett-Gilbert & Eccleston, 2010; Merlijin et al.; Simons, Claar & Logan, 2010; Konijnenberg, Ulterwaal & Kimpen, 2005), coping strategies (McCracken et al.; Eccleston et al.; Kashikar-Zuck et al., 2001), and perceived vulnerability associated with the diagnosis (Merlijin et al.; Meijer et al., 2000; Konijnenberg et al.). Among the variables studied, frequency of headache has been the one positively associated with the impact on school, social, and family functioning (Massey et al.; Bandell-Hoekstra et al.; Frare et al.; Merlijin et al.; Kernick et al.). In the present study, children and adolescents described how their headaches affected their ability to function in the school, and social and family environments. However, the frequency of headache specific to school life, social life, and family life was not formally addressed. Specific details pertaining to the temporal aspects of the headache (e.g., the time course of headaches), in relation to the frequency of the headaches, were also beyond the scope of this study. The frequency and the influence of headache on the school, social and family environments need to be addressed in future research.

Nature of headaches. Among the 66.0% of study participants reporting headache, approximately 13.0% reported headaches that were tension-like in nature, 33.0% reported headaches that were migraine-like in nature, 39.0% reported headaches of a mixed description, and 14.0% reported unclassifiable headaches. In the pediatric headache research, headache
classification for healthy children and adolescents between 7 and 18 years of age ranged from 18.0% to 24.0% for tension-type headaches and 4.0 to 18.0% for migraine headaches (Hershey, Winner, Kabbouche & Powers, 2007; Fendrich, 2007; Kroner-Herwig et al., 2007; Sillanpaia & Antilla, 1996; Koenig et al., 2002; Bandell–Hoekstra et al., 2001; Shivpuri et al., 2003; Gallelli et al., 2005; Lateef et al., 2009). Although the prevalence of tension-type headaches in this study sample was similar to the prevalence of tension-type headache in the general pediatric population, the incidence of children and adolescents who reported migraine-like headaches far exceeded the 4.0% to 18.0% that has been reported in the headache research on healthy children. However, it is difficult to compare the classification of the headaches across studies because of the modified IHS headache criteria used in classifying headache types. Furthermore, the variability in headache classification may be related to (a) the modified classification scheme used (excluding specific temporal aspects of the headaches), (b) the number of reported mixed headaches and unclassifiable headaches, (c) a possible genetic predisposition or hypersensitivity related to headaches, and (d) the psychosocial issues described in the qualitative interviews that can affect the headache experience.

Classification of headache in this study was based on a structured interview. All the key components in the IHS headache classification criteria for primary headaches were incorporated except for the time component. The use of the IHS criteria (International Headache Society, 2004) to develop the structured interview and describe the nature of the child and adolescents headache was a strength of the present study. Previous studies have been critiqued because of the classification criteria used to classify the headaches. The IHS Criteria (International Headache Society) are considered the gold standard for reporting on headache types. However, the temporal aspect in the present study was modified because the intent of the study was to describe the nature of the headache experience, not to diagnose the headaches. Diagnosing headaches as
migraine- or tension-type, which was beyond the confines of this methodology, would have required a thorough neurological exam and a detailed account of the headache history (retrospective and prospective) incorporating environmental, dietary, physiological, and psychosocial components.

Unalp et al. (2007) described the nature of headache prevalence using modified IHS headache classification criteria (excluding the temporal factors) and reported hyperinflation of tension-type and migraine headaches. Unalp et al. found that when classifying headache prevalence for tension- and migraine-type headaches, the prevalence was dependent on the criteria used to classify the headaches. The authors first classified the headaches using the recent IHS criteria and found the prevalence to be 21.3% for migraine-type and 5.1% for tension-type headaches. However, when the headaches were reclassified using the same IHS criteria excluding the number and duration of headaches, the prevalence increased to 29.9% for migraine-type and 15.0% for tension-type. These discrepancies indicate that the clinical description of headache affects the reporting of headache.

A reliable classification of the frequency of headaches would require a prospective study design incorporating the use of reliable and valid methodologies to capture the time component. An example of an appropriate data collection strategy would be the use of a validated real-time capture diary (Stinson et al., 2006). This methodology was not incorporated in the present study as the focus was to describe the prevalence, nature and headache experience of the child and the adolescent and not specifically the frequency of the headache events.

In the present study, 7.0% of the children reported different types of headaches. Koening et al. (2002) and Seshia (2004) reported that between 45.0% and 64.0% of children with headaches have superimposed headache types, which increase the complexity of the headaches. The much lower prevalence in the present study versus the general pediatric headache research
could possibly be related to the child’s and the adolescent’s inability to differentiate between headaches, and the modified classification system used in this study to classify the headaches. Furthermore, Seshia et al.’s study involved hospitalized children so their headache report may have been reflective of other pain events or occurrences during their hospitalization such as being in a strange environment, or not having family members present.

Children reporting unclassifiable types of headache has also been a common finding in the pediatric headache research (Hershey, Kabbouche, & Powers 2006; Kroner- Herwig et al., 2007; Koenig et al., 2002; Gallelli et al., 2005; Lateef et al., 2009; Wang et al., 2009; Zwart et al., 2004; Seshia, 2004). The main reason for the difficulty in classifying some of the headaches types has been related to the IHS criteria and their applicability to childhood headaches. The IHS criteria have been previously criticized with respect to sensitivity; specifically in migraine in the pediatric population (Rosi, Vajani, Cortinovis, Sprefico, & Menegazzo, 2008; Ozge et al., 2003). Revised criteria were developed in 2004 that incorporated developmentally sensitive changes, allowing for broader applicability to children and adolescents while maintaining specificity (27.9%) and improving sensitivity (84.1%) (Ozge et al.; The International Classification of Headache Disorders, 2004).

**Child Factors**

**Age and sex.** Headache prevalence increases with increasing age and among females (Stanford et al., 2008; LeResche et al., 2005). Based on this research and the clinical practice of the investigators, age and sex were hypothesized to be significant. However, these child factors were not statistically supported in the quantitative component of the present study. These findings were inconsistent with previous pediatric headache studies where there was increased report of headache with increasing age, and in females compared to males (Sunblad, Saartok, & Engstrom, 2007; Slater et al., 2009; Laurell et al., 2004; Zwart et al., 2004; McGrath & Hillier,
The increased prevalence of headache in females compared to males has been consistently found over time after the age of menarche (Bille, 1997, LeResche et al). The increased report rate among females has been hypothesized to be related to hormonal differences, coping differences and social roles (Sunblad et al; Slater et al; Rubin et al., 2006; Laurell et al.; Zwart et al.; McGrath & Hillier). The age distribution of the present study population indicated that 70.0% of study participants were between the ages of 11 and 18 years, and that male and females were equally distributed. Despite age and sex having been well-represented, there were no statistically significant differences with respect to age, sex and headache occurrence. The discrepancy of the study findings, when compared to the general pediatric headache research, may have potentially been attributed to the fact that (a) hydrocephalus is not sex specific, and male and females are educated and socialized with respect to headache in the same way, (b) developmental changes occurring during adolescence were not captured in the present study participants, and (c) data relating to specific sex-related psychosocial variables were not included in the analysis. Further analysis of age and sex variables in relation to pain by incorporating various aspects of pain (e.g., pain intensity), is needed.

When triangulating the qualitative and quantitative data, the report of a pain event differed from the description of a pain experience, where sex and age seemed to play a greater role. Male and female adolescents described invisible emotions and challenges related to their headaches. However, females were far more descriptive and articulate in describing their headache experience. They were also more articulate about the emotional and psychological impact of their headaches. Females described being more affected by headaches than their male counterparts and were more apt to describe the frustrations and inconveniences related to their headache experience. The sex-related difference in the reporting of the pain experience raised question about the role of sex and age, in relation to the reporting of pain, versus the description
of a pain experience. Sex and age have been factors that influence the reporting of pain (Strong, 2009; Savedra et al., 1981, 1985, 1988; Cheng, Foster, Hester, & Huang, 2003; Keogh & Eccleston, 2006; Kortesluoma, & Nikkonen, 2004; Kortesluoma & Nikkonen, 2006; Jerrett & Evans, 1986; Vervoort et al., 2009, Virtanen et al., 2007). In the present study, consistent with previous study findings (Jerrett & Evans), older children’s descriptions of pain were more introspective and abstract (involving physiological and psychological aspects of pain) than the descriptions of younger children. Females were more forthcoming about the affective component of their headache pain and expressed greater emotion related to their headaches. Males tended to speak more concretely regarding their headache pain.

The differences between the sexes have also been well-established in the adult pain research. These differences were possibly due to (a) sex and role expectations (Strong et al., 2009), (b) females having superior language performance in comparison with their male counterparts (Cheng et al., 2003), or (c) biological, social and psychological factors related to pain (Keogh et al., 2006; Slater et al., 2009). Keogh et al. reported that females exhibited an increased self-report of pain. The increased reporting has been hypothesized to be related to hormonal differences, coping differences, and social roles. Although much research has been related to the adult population, in the present study, approximately 70.0% of the study population were in their teenage years and may have been transitioning, or had already transitioned, to adult forms of conversation. From the qualitative interviews, it appeared as though sex and age had in fact played a role in the headache pain experience of children and adolescents with headache and shunted hydrocephalus.

**Etiology.** Etiology of hydrocephalus was the only child factor statistically related to the child’s and adolescent’s self report of headache. Within etiology, the subcategories of (a) children and adolescents with congenital without myelomeningocele, and (b) children and
adolescents with tumours had a decreased tendency to report headache when compared with the congenital with myelomeningocele group (Table 11). These findings further support the hypothesis that children with shunted hydrocephalus potentially have a genetic or biological predisposition to headache pain. Furthermore, children with congenital hydrocephalus not related to MMC have been generally diagnosed at less than 6 months of age (Greenberg, 1997), have potentially exhibited an increased number of unresolved headache events, and have been more vulnerable to the psychosocial factors influencing headache pain. An increased reporting of headache related to etiology being congenital in nature may be due to (a) the increased attention given to headache in the context of shunt malfunction, (b) the constant reinforcement of the importance of headache by health care professionals, and (c) the congenital nature of hydrocephalus and its association with the central nervous system. However, children and adolescents with the etiology of congenital without MMC had decreased report of headache in comparison to the congenital with MMC Group. A key difference may have been the psychosocial issues of children with MMC compared to children without MMC, and the multiple unresolved pain episodes experienced by children and adolescents with myelomeningocele (Clancy et al., 2005). Clancy et al. indicated that 56% of children with myelomeningocele reported experiencing pain once per week or more and that the pain had most frequently occurred in the head, back, abdomen, neck, shoulder, leg, and hands. Children with MMC often have visible disabilities, and experience multiple unresolved pain events that could potentially increase their vulnerability to the psychological and emotional impact of pain and their report of pain. Gauging from the qualitative analysis in this study, within the theme of normalcy and control, the decreased reporting of headache by children with the diagnosis of congenital hydrocephalus not related to MMC may have been a coping strategy and control tactic with respect to their headache management. It could have been that these children had experienced
multiple episodes of unresolved pain and had settled with the reality that unresolved pain was part of their diagnosis that they had to live with. Therefore, they maintained the invisibility of their headaches as a means of protecting and maintaining a sense of normalcy.

In contrast, the children with tumor had a decreased tendency to report headache based on clinical experience. This under-reporting may be related to (a) an older age at time of diagnosis, (b) a shorter headache history, (c) the surgical and medical management specific to children and adolescents with tumor, and (d) the acknowledgement and pre-emptive management of the psychosocial issues inherent in the diagnosis that can contribute to headache pain. For children in the general population with tumor, the average age of diagnosis is 7 years of age (Greenberg, 1997). Children with tumors prior to their diagnosis may be headache naïve and may have not developed a psychological hypersensitivity to headache compared with other children with headache and shunted hydrocephalus. Their headaches are predominantly event based and surgically managed. For the majority of children with tumours, once the tumour is surgically removed, the headaches subside (McLone, 2001). Furthermore, the medical management of these children often involves serial imaging to assess for tumour recurrence. Because of the surveillance monitoring, children may be less inclined to develop a headache related to tumour progression and report having headache. Radiographic changes often supersede the development of symptoms; therefore, hypothetically the psychological and emotional impact of having a tumour and headache is potentially small because the potential worry regarding tumour recurrence is addressed with the imaging.

For children and adolescents with tumour, other psychosocial factors that could have possibly affected the reporting of pain may have potentially been diverted as children with tumours often receive multiple supports to help manage psychosocial issues inherent in their diagnosis. Tumour management incorporates pre-emptively addressing physiological and
psychological limitation inherent in the diagnosis. Children and adolescents with tumours are often linked with Interlink nurses and social workers that help the child and family re-integrate into the school, social and family settings.

**Description of Headache**

When the children and the adolescents were first asked to describe their headaches, they predominantly spoke about the sensory component of their pain in association with their shunt. The initial sensory description and the relating of their headache to their underlying diagnosis were consistent with previous studies that described how children speak about pain (Jerrett & Evans, 1986; Kortesuloma & Nilkkonen, 2006; Savedra et al., 1985). How children describe their pain is affected by both developmental and experiential factors. Children between the ages of 4 and 18 years possess a pain vocabulary and are able to articulate their pain experience (Savedra et al. 1982). Savedra et al. found that when children described pain, they generally used sensory words more often than affective and evaluative terms. Initially, children describe their pain using sensory descriptors illustrating the use of their senses to describe their pain (Jerrett & Evans). The sensory descriptions generalize the pain experience (Jerrett & Evans).

According to Kortesluoma et al., children initially described their pain in sensory terms with affective terms as young as 7 or 8 years; becoming more affective with age. Nikkonen and Kortesuloma reported a pattern of language development related to pain description in 4- to 11-year olds. The pattern incorporated three levels of progression: paraphrasing, generalization and specification. Paraphrasing involved describing pain in sensory terms with simple descriptions. Generalizing involved describing emotions or affective components of the pain experience, and the negative consequences associated with it. Specification involved transitioning from concrete thinking about pain to a more abstract way of thinking that integrated the whole experience. At the specification level, there was integration of mood and pain.
Gaffney et al. (1986) also studied how children described pain. Pain concepts corresponded with Piaget’s model of cognitive development and pain descriptions changed with age. Initially, pain was spoken about in concrete terms. Pain then was described in semiabstract terms incorporating feelings and sensations, and making reference to unpleasant physical properties. Subsequently, pain was spoken about in abstract terms, incorporating the physiological, psychological and psycho-physiological definitions of pain.

In the present study, children and adolescents frequently used metaphors when describing their headache pain (e.g., “feels like being punched in the stomach,” and “it’s like being kicked in the teeth”). The metaphors provided a pictorial image of the overwhelming and all-encompassing nature of the headache pain. The use of metaphors by children to describe pain has been substantiated in previous study findings. Jerrett and Evans (1986) described the use of metaphors as a way of making pain visible and colouring the pain experience. According to Bieri and colleagues (1990), the use of metaphors in the younger age group is developmentally appropriate, as children as young as 7 years can reliably process a metaphor. Using metaphors to describe pain provides a unique function: they offer a different way of understanding, allow the inexpressible to be communicated by something already known, and suggest an association with visual images (Jerrett & Evans; Bieri et al.). Ultimately, the use of metaphors by children to describe pain is a way of making pain visible and associating it with images created through language. They allow the child to describe and disclose tacit knowledge in relation to their pain. The use of metaphors by the child shows how pain scales that incorporate common terminology to describe pain are not all-inclusive, and may not capture the indescribable component of the child’s pain experience.

Sex-related characteristics that were related to describing pain within the qualitative interviews were consistent with conversation characteristics in the general pediatric and adult
populations and with health care professionals. Women see conversation as a way to create intimacy and closeness through the sharing of emotions and feelings (Owens, 2005). Males see conversation as goal-focused; speaking concretely of the topic, keeping it in its place, and dismissing topics as being either trivial or unimportant (Owens). With respect to pain and medical procedures, men tend to use fewer words and are less graphic (Strong et al., 2009). Conversely, women tend to be more willing to describe pain (Owens). Their descriptions had higher emotional content and a stronger social and holistic focus.

When describing communication styles in the medical context, Strong et al. (2009) stated that women used more evocative language and were more talkative. Therefore, the differences highlighted in the qualitative interviews with respect to age and sex has raised questions as to whether the description of the pain events is reflective of sex- and age-related differences specific to the reporting of pain, and to whether the variability in the reporting is indicative of fundamental age and sex differences in relation to language and conversation in general. Therefore, the question that needed to be asked was: How much of the description was actually about the pain? Since pain is a subjective phenomenon, was the pain experience reflected in the actual content of the description, or in how the description was given?

In the present study, the initial sensory description of headache addressed the experiential component of pain. Other researchers have reported that some of the children required probing to describe the sensory component of their pain. This was not the case in present study. When the children and the adolescents were first asked to describe their headache, all study participants immediately launched into a description of the sensory aspect of their headache pain, describing it in relation to the shunt. This finding reflected how children with shunted hydrocephalus have been socialized regarding the context of headache as sensory symptoms and as being shunt related.
Children learn through experience specific words to describe and perceive pain (Kortesuloma & Nikkonen, 2006). Children tend to describe pain in the specific area and within the context of their underlying diagnosis (Kortesuloma & Nikkonen, 2003). The language used by children living with pain is influenced by their current health status and modes of verbal and embodied communication learned through their own experiences and by observing others (Jongudomkarch, Aungsupajom & Camfield, 2006). Jerrett and colleagues (1986) found that pain descriptions incorporated linguistic and societal points of view. He also found that when children described pain, they had a tendency to associate their pain with a biological process, and saw pain as a symptom of their illness. In their study looking at pain descriptions of hospitalized versus non-hospitalized patients, Savedra et al. (1985) reported that children's reports of pain were not so much a function of age and sex, but rather of whether they had been hospitalized or not. Hospitalized patients tended to describe pain related to medical procedures and diagnosis.

The tendency for the children and the adolescents in the present study to describe their headache in relation to their shunt and underlying hydrocephalus was potentially a reflection of the context of headache within the neurosurgical culture. Anecdotally, within the neurosurgical clinic setting, it has been observed that the language used within the neurosurgical culture in association with headache applies a template within a medical specialty which does not address the uniqueness of headache outside of shunt functioning. When the shunt is functional, it is assumed that the child is out of harm’s way, and so headache is rarely explored. There is limited opportunity to further discuss or describe headache outside of shunt functioning. However, in the qualitative interviews, there were many invisible emotions and challenges experienced by the child and the adolescent with shunted hydrocephalus that were not revealed or substantiated as part of their headache experience. The inattention paid to the psychological and emotional components of their pain within the neurosurgical context may have been related to (a) the
therapeutic uncertainty and lack of expertise by the medical team in the management of headache outside of a surgical intervention or (b) the belief that headache unrelated to shunt functioning does not carry the same risks and sense of urgency with respect to morbidity and mortality.

Within the neurosurgical context, the emotional, affective and psychosocial factors described by the children and the adolescents in the qualitative interviews have remained invisible to their healthcare providers. Children deal with multiple hidden emotions and struggles within the school system that were not readily spoken about. They have primarily learned to speak about their headaches in relation to shunt function. Hence, they found it difficult to describe their headaches outside of the sensory experience and outside of the context of the shunt.

There are numerous other factors that impact the reporting of pain. Leaper and colleagues (2007) reported that the topic, speaker, hearer, context, and purpose of the conversation influence how individuals speak about pain. Power dynamics can affect the interview experience for children. Cheng and colleagues (2003) also found that the sex and the status of the assessor can change subjects’ responses when reporting pain. Issues related to status and power were addressed within the design of the present study; the context of the interview within the clinic setting (physically in the hospital setting) may have contributed to the clinical and sensory descriptions of the child's and the adolescent's headaches. Furthermore, the child’s and adolescent’s descriptions of their headaches in relation to shunt functioning, and their use of sensory descriptors may have also been a coping strategy used to maintain a sense of normalcy and control with respect to their headaches. An example is how headache was described by some as an “other” (page 86) in the qualitative interviews.

**Emotions in relation to headache pain.** Children and adolescents expressed multiple emotions related to their headache experience. The emotions were part of the invisibility
associated with the child and adolescents’ headache experience, have been well-substantiated, and were consistent with findings reported in the headache and pain research (Meldrum, Tsao, & Zeltzer, 2009).

Meldrum et al. (2009) identified multiple emotions related to pain in children including anger, sadness, worry, anxiety, fear, and frustration (Meldrum et al.; Jerrett & Evans, 1986). These emotions were more commonly expressed in older children who had been experiencing pain for a shorter duration. Furthermore, children were often frustrated and distressed by pain and the frustration was often associated with anger, anxiety, and sadness, and was reported more frequently in older children who had experienced pain for a longer period of time. For many children, chronic, recurrent pain set them apart from other children, blocked them from their favourite activities and the futures they had imagined for themselves, and they felt their pain was something they weren’t easily able to share (Meldrum et al.; Jerrett & Evans.). In the present study, frustrations and resentment described on page 103, and the missing out described by the children and the adolescents on page 113, were congruent with the Meldrum et al.’s findings. Many of the children and the adolescents in the present study expressed frustration related to their headaches and the lack of resolution. Frustration experienced in chronic pain has often been affiliated with the medical team (Nutkiewicz, 2008). The frustration described in the present study potentially stems from the inability to discuss headaches outside of the context of the shunt.

Many children and adolescents experiencing recurrent pain have felt that physicians did not help, failed to understand the pain problem, failed to diagnose or prescribe helpful treatment, and offered information that was false (Meldrum et al., 2009). Meldrum et al. also described how doctors and children have two different vocabularies and orientations when speaking about pain. Physicians and the healthcare team have a tendency to emphasize the biomedical aspect of
pain, whereas the child’s language is based on the experience of pain; it is more emotive and requires acknowledgement from the medical team (Nutmiewicz, 2008). From the child’s perspective, the experience of pain and emotions is not of interest to the doctor (Nutmiewicz). A search for a diagnosis becomes the child’s total experience with the medical team. Children who have not had success with treatment, as has been the case for many children with headache and shunted hydrocephalus, quickly understand the unfortunate reality of searching for a diagnosis, and find it very frustrating. They find the doctor focuses on “a set of things to do, rather than the problem of pain” (Meldrum et al.). For the child, medical failure is not the inability to provide a diagnosis but rather the inability to provide help (Dell’api, Rennick, & Rosmus, 2007). The child sees the doctor as someone applying a treatment template based on the specialty, and who fails to address the specificity and uniqueness of the child’s pain experience (Dell’api et al.).

In Meldrum et al.’s (2009) study, pain was not physical for many of the children; it was perceived as personal and was a hidden burden that changed their lives and self-perception; it was a symptom of something more. Consistent with the invisibility described by the children in the present study (page 113), headache unrelated to shunt functioning was overpowering and burdensome for the child and the adolescent with shunted hydrocephalus. The children in Meldrum et al.’s study saw their lives as an ongoing struggle with pain, which added to the many other stressors they were experiencing. Consistent with Meldrum et al.’s findings, children and adolescents in the present study were constantly contending with multiple stressors related to their headaches. Outside of headache pain and management, the children and the adolescents with shunted hydrocephalus were dealing with other stressors including school, self-expectations, social relationships, and family conflicts. These stressors have been well-substantiated in the headache research as stressors for the well child ( Dufton et al., 2008, Meldrum et al.). Other researchers reported children feeling overwhelmed with the pain and
struggling alone (Meldrum et al.; Jerrett et al., 1986). These reports are consistent with the overpowering nature of headaches described by participants in this study. Children have also reported that pain prevented them from continuing the activities they loved or achieving the goals they saw as important (Meldrum et al.), and forced immobilization (Jerrett & Evans.). Children often described missing out on multiple activities (page 113), and the influence of headache on their present and future academic endeavours (page 117).

Hypothetically, the silent emotions experienced by children and adolescents with headache and shunted hydrocephalus could impede their ability to achieve and maintain a perceived sense of normalcy. Keogh, Ellery, Hunt, and Hannent (2001) reported that emotions related to pain were predictive of pain-related disability. In the general pediatric research, emotions have influenced pain and the individual’s ability to cope (Keogh et al.; Bandell-Hoekstra et al., 2000, Boston & Sharpe, 2005). Keogh et al. concluded that the attentional processing of pain was related to a vulnerability factor influenced by emotions. The impact of emotions on pain experience has been further substantiated by researchers addressing how the meaning of pain influences the pain experience, the ability to cope with unresolved pain (Arntz et al., 2004; Barkwell, 1991; Martin, McGrath, Brown, & Katz, 2007), and how emotions modulate the perception of pain (Melzack, 1965). The manner in which people cope with their pain or illness has been directly related to the personal meaning they ascribe to it, and to their attitude (Barkwell). Interpretations are essential for looking at how perceptions are processed, and, therefore, how meaning is capable of influencing the perception of pain (Arntz et al.; Melzac; Barkwell).

Researchers have also found that the interpretation of pain as a life threatening process increased the experience and reporting of pain (Nash, Williams, Nicholson, & Trask, 2006, Harkins & Baker, 1987; Arntz, 2004). Based on research by Nash et al., and Arntz, one would
expect that children with tumours would show an increased reporting of pain, as tumours are a life threatening process. However, this was not the case in the current study. As discussed previously, the medical surveillance, management, and psychosocial supports may have been a factor influencing the headache experience of children and adolescents with tumours.

In the present study, females tended to be more emotional when speaking about their pain and more likely to express their emotions, consistent with previous research (Savedra et al., 1988; Lynch, Kashikar-Zuck, Goldschneider, & Jones, 2007). Savedra et al. reported that school-age females, more than males, reported feeling like crying and feeling more out of control. They also stated that they felt sad more often. Keogh et al. (2006), in a study looking at sex roles and pain in school-aged children, concluded that there was no relationship between the report of pain and pain chronicity. Regardless of the chronicity of the pain experience, females consistently reported higher pain episodes. This finding could indicate that females tend to be more forthcoming with their pain experiences than their male counterparts, relating to the increased emotion experienced and expressed by females in relation to pain and sex role expectations. Cheng et al. (1993) found males less willing to report pain or to report being in pain. In contrast to females, males saw emotional aspects of pain as less credible than sensory aspects of pain and often omitted details of pain to conform to socially constructed roles (Strong et al., 2009). The difference in the reporting of pain is consistent with the sense of normalcy described predominantly by males in the qualitative results. Male adolescents also reported less emotion when describing headache pain and, as part of coping and pain management, developed a keep-going attitude to uphold a perceived normalcy.

**Impact of Pain**

The children and the adolescents in the present study described how their headaches influenced their school, social and family environments. They were most notably affected in the
school and social realms. Developmentally, the headaches hypothetically posed a threat on the adolescents’ development as they strive towards independence. Eccleston et al. (2007) reported that chronic pain for the adolescent hinders their independence and autonomy. Pain for the adolescent increases their exposure to dependent relationships, compromising their independence.

The consequence of pain on school, social and family functioning as described by the children and the adolescents in the present study were consistent with other research related to the influence of chronic pain on children and adolescents (Eccleston et al., 2007; Kashikar-Zuck et al., 2001; Simons, Claar, Logan, & Stein, 2010; Meijer et al., 2000; Konijnenberg et al., 2005). Knojenberg et al. reported headache pain to be the most common pain symptom with the greatest effect on school and social functioning. Consistent with the present study, children with headache have reported the greatest amount of difficulty with physical functioning, daily functioning, leisure activity, and social and school functioning (Bandell-Hoekstra et al., 2002; Frare et al., 2002; Massey, Garnefski, & Gebhardt, 2009; McCracken et al., 2010; Eccleston, et al.; Simons et al.; Kernick et al., 2005; Vannatta et al., 2008; Carlsson et al., 1996, Brna, Gordon, & Dooley, 2008).

Kernick et al. (2009) performed a systematic review on the impact of paediatric headache on healthy children and found that children were most affected in the school environment. Although not captured in this study, school days lost were reported as the most notable consequence associated with headache (Breuner, Smith, & Womack, 2004). Breuner et al. (2004) reported that students who missed school due to headache had higher depression scores, lower academic performance, lower self-esteem, more discipline problems, and fewer positive relationships with peers. Researchers who addressed the consequences of headache on school function have also indicated that children with headache found it difficult to concentrate on
difficult subjects and to manage with noise and disorder in the classroom, and were more tired during the day (Odegaard, Lindbladh, & Hovelius, 2001; Carlsson et al., 1995). These findings were further substantiated in the present research as the children and the adolescents described their difficulty focusing and getting their schoolwork done (page 115).

Within the pediatric headache studies on healthy children, the impact of pain on daily activity and functionality has been investigated in relation to the frequency of pain (Massey et al., 2009; Bandell-Hoekstra et al., 2002; Frare et al., 2002; Merlijin et al., 2006; Kernick et al., 2009), the intensity of pain (Eccleston et al., 2007; Merlijin et al.; Kernick et al.), the length of pain experience (McCracken et al., 2010; Merlijin et al.; Simons et al., 2010; Konijnenberg et al., 2005), coping strategies (McCracken et al.; Eccleston et al.; Kashikar-Zuck et al., 2000), and the perceived vulnerability associated with the diagnosis (Merlijin et al.; Meijer et al., 2000; Konijnenberg et al.). Except for the frequency of headache or pain being positively associated with the effect on school, social and family functioning (Massey et al.; Bandell-Hoekstra et al.; Frare et al.; Merlijin et al.; Kernick et al.), the other variables were inconclusive. The lack of consensus related to the study findings further highlighted the complexity of headache pain. The majority of the research regarding the impact of headache within the general pediatric research literature was related to healthy children. Children and adolescents with shunted hydrocephalus were not only experiencing headache pain, but they were potentially also dealing with many issues inherent in having a chronic illness. Therefore, headache and the implications of having a chronic illness could have hypothetically increased the burden and the impact of their headaches on their school, social, and family functioning.

Researchers have also indicated that healthy children with headache have poorer quality of life and a higher incidence of depression and anxiety disorders (Massey et al., 2009; Frare et al., 2002; Merlijin et al., 2006; Kernick et al., 2009; Odegaard et al., 2003; Hershey, 2005;
Hunfield et al., 2000; Huguet, Eccleston, Miro, & Gauntlett-Gilbert, 2009). Although depression and anxiety were not assessed in the present study, the consequences of dealing with unresolved pain and the impact on the child's and the adolescent's quality of life were apparent. Powers, Patton, Hommel and Hershey (2003) specifically looked at the quality of life of children with migraines in comparison to children with other chronic illness and found that the affect of pain related to migraine headache on children was similar to that of children with arthritis and cancer. Kulkarni and colleagues (2007) have begun to address quality of life issues for children and adolescents with shunted hydrocephalus, and reported that the children’s mean overall health score based on the validated and reliable hydrocephalus outcome questionnaire was 0.68 (worst quality of life being 0 and best quality of life being 1.0). Predictors of low quality of life were (a) increased seizure frequency, (b) increased length of stay for initial treatment, (c) increased length of stay for shunt infection and overdrainage, (d) increased number of proximal shunt catheters in situ, and (e) increased distance of the family residence from the pediatric neurosurgical centre.

**Pain management and maintaining normalcy.** The children and the adolescents in this study saw themselves as central figures in making their pain better, and incorporated many self-initiated actions and behaviours to manage their pain (Frare et al., 2002). Many of the pain management strategies they described (e.g. pharmacological management and distraction techniques) have been studied in the headache research. Positive coping strategies include behavioural strategies, acceptance, accommodating, engaging, seeking social support, and being self-reliant (Massey et al., 2009; Bandell-Hoekstra et al., 2002; Frare et al.; McCracken et al., 2010; Boston et al., 2005). Negative strategies involve catastrophizing, disengaging, and avoidance (Boston et al.; Frare et al.; Merlijin et al., 2006; Claar, Baber, Simons, Logan, & Walker, 2008). The children and the adolescents did describe multiple coping strategies in the
present study. These were primarily positive coping strategies; however, there were a few adolescents that described behaviours that were consistent with negative coping strategies.

Recently, researchers have indicated that it is not the actual strategy implemented which impacts the child’s function, but rather it is the appraisal of the pain event and the belief in one’s ability to manage it in their daily lives (Claar et al., 2008; Massey et al., 2009). Massey et al. (2009) did not find a relationship between coping strategies and headache occurrence. They did not find the specific coping strategy to be of importance, but the child's belief in their ability to cope with the headaches was important ($p = 0.05$, t-test $2.22$). Claar et al. examined the consequence of abdominal pain on the child’s daily routine and reported similar findings that indicated the appraisal of pain had significant effects on the child’s symptoms and disability. In both studies, the effect of headache on the child’s functioning was related to the stress experienced from the headache pain (Claar et al.; Massey et al.). Although, in the present study, a direct relationship could not be made between stress, headache, and the influence on daily activity, (a) there were multiple stressors inherent in the profile of the child and the adolescent with shunted hydrocephalus that could have influenced their daily activities, (b) children and adolescents described multiple stressors in relation to their headache experience (page 103), and (c) children and adolescents described their ability to partake in school, social and family activities was affected by their headaches. Therefore, headache, stressful events and coping warrant further investigation and understanding in children and adolescents with shunted hydrocephalus.

The children and the adolescents described how the headaches affected their school, social, and family functioning, but predominantly denied headaches affecting their school, social and family functioning. This contradiction or disconnect was consistent with other study findings relating to chronic pain and may be a coping strategy used to manage the headaches.
Meldrum and colleagues (2009) reported that 62.0% of children with pain tried to hide or mask the intensity or frequency of pain from others in an effort to be seen as normal or to keep from becoming anxious. The child used this false profession, claiming that they were not affected by the headaches, as both a coping mechanism and as a means of maintaining normalcy and avoiding stigma. This behaviour was consistent with the perceived sense of normalcy described in the present study. Children reported that they often hide or mask the intensity of their pain because they feel their pain isolates them and sets them apart from their peers. They also practiced gatekeeping because they thought that others would not understand them or would act differently towards them because of their pain (Meldrum et al.). This hiding or gatekeeping was also described in the present study by the children and the adolescents experiencing headache (page 98). Researchers have indicated that children feel judged, disbelieved, and perceived as difficult by health care members when speaking about their pain (Dell’Api et al., 2007). According to the children, the disbelief was stressful for the child (Dell’Api et al.). Children refrained from telling their parents about the intensity and frequency of their pain because they thought there was little their parents could do about it, and they did not want to cause their parents undo stress (Meldrum et al.). Furthermore, children told their friends about their pain, and even when friends were supportive, many children still felt alone and set apart (Meldrum et al.; Dell’Api et al.).

According to Jerrett and Evans (1986), stigma produced by an illness or injury intensifies the degree of suffering and personal stress (Meldrum et al., 2009; Tarask & Eakin, 2002). When stigmatized, the individual senses that he or she is constantly under attack and therefore feels the need to constantly legitimize their personal integrity (Tarask & Eakin.). In the disability research, being seen as disabled has overshadowed personal identity, and normalization has been seen as an attempt to adjust to society (Susman, 1994; Lundberg, Styf, & Bullington, 2007;
Being seen as disabled, which has been defined as any restriction or lack of ability to perform an activity, implies that the individual is damaged, defective, and ultimately less socially marketable (Susman). Normalization is therefore a way of interacting with “normals”, which does not allow for the internalization of a devalued personal identity (Susman; Tarask & Eakin; Lundberg et al.). It could be hypothesized that the disconnect in the interviews in relation to the impact of headache and to whether their headache affected their daily activities, may have been a coping mechanism used by children and adolescents and a means of maintaining a perceived sense of normalcy.

In summary, the increased prevalence of headache for children and adolescents with shunted hydrocephalus, as compared with healthy children, was dependent on and affected by multiple factors. These findings are consistent with the theoretical constructs associated with this study and current research findings in the general pediatric headache literature.
Chapter 8

Implications, Future directions, Knowledge Translation and Study Summary

This chapter is divided into three sections. In the first section, the significance of the study, its strengths and limitations are reviewed. In the second section, research, clinical, and educational implications of the study findings are discussed. In the third section, knowledge dissemination, and knowledge translation strategies are examined. The chapter concludes with a summary of the study.

Significance of Study, Study Strengths, and Limitations

Significance of the study. This study was the first to address the headache experience of children and adolescents with shunted hydrocephalus with a presumed functional shunt from the child's and the adolescent's perspective. More specifically, the prevalence, frequency, and nature of headache within the shunted hydrocephalic pediatric population were reported for the first time. Children and adolescents described their headaches and headache experience, and the effects of headache on their school, social, and family functioning.

The child’s and adolescent’s reality involved living with unresolved headache pain that had not been previously investigated. The headache affected the child’s and adolescent’s ability to partake in their daily activities. The inattention to children's and adolescent’s headache pain outside of the medicalized meaning attributed to shunt malfunction has placed them at risk for the untoward psychological, physiological, and emotional repercussions of unresolved pain. Headache in the study population has been predominantly investigated and understood in relation to shunt function. Therefore, the present study findings have challenged and broadened our present understanding of headache for children and adolescents with shunted hydrocephalus.
Ultimately, new knowledge and a new perspective to the headache experience of children and adolescents with shunted hydrocephalus with a presumed functional shunt have been generated. Sixty-six percent of children and adolescents with shunted hydrocephalus experienced headache outside of shunt functioning. Furthermore, the headaches affected the child's and the adolescent's ability to take part in their daily activities, most profoundly in the school environment. Recognizing and acknowledging the headache experience for children and adolescents with shunted hydrocephalus is the first step in broadening our understanding of headache for these children and adolescents.

Presently, due to the morbidity associated with shunt malfunction, headache within the neurosurgical context has been predominantly described in relation to ICP and shunt functioning. The study findings have enhanced our understanding of headache in this patient population by exploring the prevalence, nature, frequency, and experience of headache for these children and adolescents with a presumed functional shunt. They fill a gap in our present understanding of headache for children and adolescents with shunted hydrocephalus. The study findings will guide practice and policy change to improve the assessment, management, treatment, education, and support to families of and children and adolescents with shunted hydrocephalus. Furthermore, the study findings highlighted areas for future development in the research and theoretical arenas.

**Strengths.** The major strengths of this study were the uniqueness of the research questions, the use of a prospective mixed method study design, the age range of the study participants, the multi-theoreticalconceptual foundation, and the focus of new knowledge from child and adolescents perspective.

The research questions, derived from the general pediatric headache literature and the IHS criteria, provided unique data from the patient’s perspective. The research questions also
provided an opportunity to put the headache experience of this patient population in context with the general pediatric headache population. The findings highlighted the complex nature of headache pain for children and adolescents with shunted hydrocephalus irrespective of shunt malfunction and intracranial pressure changes. This component of the child's and the adolescent's headache experience has not been previously investigated due to the clinical importance and morbidity associated with headache and shunt malfunction.

The mixed methods design incorporated both qualitative and quantitative research questions focusing predominantly on characterizing and describing the headache experience of children and adolescents with shunted hydrocephalus with a presumed functional shunt. Pain is a subjective and complex experience that incorporates many psychological, physiological, and psychosocial factors. Therefore the use of a mixed method study design addressed the multidimensional aspect of the child's and the adolescent's pain experience and offset the disadvantages of using one method over the other.

The use of a mixed method study design provided an opportunity to explore both clinical factors associated with and the experiential component of headache for these children and adolescents. Children’s and adolescents’ detailed descriptions of their perspectives were obtained within the qualitative interviews. Possible clinical factors influencing the headache experience and the prevalence, frequency, and nature of the headache for this study population were obtained in the quantitative survey. The use of both the quantitative and qualitative methods provided for the development of a diverse set of data which allowed for a comprehensive characterization and description of the child's and the adolescent's headache experience, and allowed for the triangulation and integration of the qualitative and quantitative findings.
Triangulation predominantly occurred in the discussion chapter of the research study. The research questions were answered and addressed incorporating both the qualitative and quantitative findings. Triangulation occurred using matrices and through comparison of both of the research findings in the discussion. In some instances (e.g., headache prevalence), the quantitative findings failed to explain the increased headache prevalence for these children and adolescents compared to the general pediatric headache population. However, the qualitative findings provided insight and potential reasons for the increased headache prevalence.

Triangulation enhanced the understanding of the relationship between the qualitative and quantitative findings, and the comparing and contrasting of the study findings with the general pediatric headache research. Triangulation also allowed for the complexity of the pain experience to be addressed by incorporating the physiological, psychological, and psychosocial aspects of the headache experience.

The multi-theoretical conceptual foundation was also a strength of the current study. The GCT of pain (Melzack, 1965), the neuromatrix theory of pain (Melzack, 1996) and the IHS headache criteria (International Headache Society, 2004) provided a comprehensive theoretical basis for exploring and describing the child’s and adolescent's headache experience. Within the GCT of pain (Melzack, 1965), sensory, emotional and affective factors that can modulate a pain experience were highlighted. Within the neuromatrix theory of pain (Melzack, 1996), the possibility of a genetic predisposition or central predisposition to pain in the absence of a physical stimulus was explored. The use of the IHS criteria allowed for the headaches to be characterized in accordance with headaches described within the general pediatric headache population. The conceptual framework of the study incorporated physiological, psychosocial, emotional, and genetic factors relating to headache pain that have not been previously investigated in this study population.
Conceptualizing the problem of headache in children and adolescents with shunted hydrocephalus using the two pain theories and the headache criteria provided an opportunity to expand upon our present understanding of headache pain for this study population. The use of the multiple theoretical constructs within the models and the IHS criteria allowed for the headache experience of children and adolescents with shunted hydrocephalus to be explored in relation to what is already known and understood about headache in the general pediatric patient population.

**Limitations.** The primary method of data collection was by way of the child's and the adolescent's self-report of their headache experience when attending a neurosurgical follow-up appointment. Children and adolescents were asked about headache experienced in the past month, and were only interviewed once regarding the impact of their headache. Recall, self-report, and reporting bias were the limitations of this method of data collection that could have potentially introduced error into the study, or under- or overinflated study findings. The child's and the adolescent's ability to recall their headache experience within the last month could have potentially overinflated or underinflated the frequency of headache reported by the children and the adolescents. Children and adolescents were asked at a single point in time to retrospectively recall their headache and headache experience over the last month. Telescoping or compression bias, defined as recalling an event as having occurred more recently than it actually did (Coughlin, 1990) was a potential bias for this study. Strategies used to help with recall (e.g., the use of calendars of the past month) were implemented to help overcome this potential bias. The questionnaire related to the headache characteristics was designed with a list of possible responses to help with the recall (Coughlin). The use of introductions to the study questionnaires (Coughlin) was also a strategy used to help with recall of the headache events. In most pediatric studies, self-report measures have been used that ask children to recall their headache complaints
over the past month or year (van den Brink, Bandell-Hoekstra, & Abu-Saad, 2001). Van den Brink et al. (2001), in a study addressing the occurrence of recall bias in pediatric headache the authors reported that younger children are no less able than older children to recollect information from long term memory. The authors recommend that recall errors occur when children are asked to report on their headaches and that errors can occur in the duration and intensity of headache pain. To minimize bias authors recommend along with self report the use of a diary.

Children and adolescents were asked about their headaches after having a neurosurgical appointment or in the context of a neurosurgical follow-up appointment where headache was discussed in relation to their shunt. Within this context and environment, headache has been viewed as a symptom of shunt function. Therefore, children and adolescents would have been asked about headache in relation to shunt functioning. Even though the majority of children were asked if they had had headache within the last month prior to being seen by the neurosurgeon, the environment and anticipation of the clinic appointment may have impacted the reporting of headache. Due to the nature of the follow-up visit and its focus on shunt functioning, the children and the adolescents may have had an increased awareness of headache, which could have introduced reporting bias (Fletcher, Fletcher & Wagner, 1996) with respect to headache occurrence. Furthermore, because the qualitative interviews asking about the headache experience took place after the clinic appointment, any initial description of headache in sensory terms and in relation to shunt function may have been reflective of the context of the neurosurgical environment and clinic appointment.

Due to the nature of the study and the methodology used for data collection relating to frequency of headache, we were unable to make comparisons to other studies addressing frequencies, types of headache and the burden of headache associated with frequency. The
exploratory and descriptive nature of the research questions specific to temporal data relating to the child and adolescents headaches were not collected. Headache for the child and the adolescent outside of presumed shunt functioning had not been previously investigated.

The purpose of this study was to generally explore headache in children and adolescents with shunted hydrocephalus as an initial stage of scientific inquiry. Therefore, the methodology used within this study was appropriate for the exploratory and descriptive nature of the research questions. The intent of the study findings were to provide direction to further define and delineate research questions related to headache pain for this study population. The methodology for the present research study was not intended to focus solely on the frequency of the headache experience. The intent of the present study was to explore and describe headache pain in children and adolescents with shunted hydrocephalus from the child's and the adolescent's perspective, and then to provide direction for future study. Once the general landscape for the headache experience of children and adolescents with shunted hydrocephalus has been laid, future studies could more thoroughly address headache burden in relation to headache frequency.

Data pertaining to the child factors such as age at the time of shunt insertion, number of shunt revisions, and history of shunt infections, were obtained from chart review and were retrospective in nature. Therefore, reporting bias, related to the reliability and consistency of the chart data, could have been introduced into the study. As multiple healthcare professionals were documenting in the chart, the different interpretations and ways of documenting various shunt-related variables could have potentially introduced bias into the study. The use of standardized definitions and criteria for the various child factors helped to circumvent this potential bias. The reporting bias could potentially have affected the statistical analysis and significance of the child factors.
When describing their headache experience in the interview, participants answered the questions reflecting their actual experiences and feelings, rather than describing what they felt might be expected. Due to the nature of interviewing children, strategies were put in place to circumvent potential power imbalances and social desirability allowing for children and adolescents to honour their experience as opposed to saying what they felt might be expected of them. Despite preemptively implementing various strategies to help with power imbalances and social desirability, it was difficult to comment on their effectiveness. The impact of the power imbalances were assessed in the consistency of the answers, and in the comfort of the interview.

Social discussion was used prior to starting the interviews to provide a nonthreatening approach to the interview. Children were told prior to the interview that there were no right and wrong answers, that they were the experts on this topic, and that the intention of the questions was to learn from their experience. There was variability in the thickness of the qualitative data despite the strategies having been consistently used throughout the qualitative interviews.

During the interview, the strategies used to ensure the children felt that their thoughts and perspective were being heard were (a) active listening, (b) summarizing what the children had said and repeating it back to them to ensure understanding of what was said, (c) asking the child to choose the location of the interview, and (d) conducting the interview in a nonthreatening, easy going manner. Further limitations to the qualitative interviews were the sample characteristics. The majority of the interview participants were female adolescents; therefore, the qualitative findings potentially are more reflective of the female and adolescent perspective.

The variability in the data could also have been a reflection of many other issues involved in the interview process, specifically, if it was the participant's first time speaking about the topic, if the participant was comfortable being interviewed alone, and if the participant was
comfortable speaking with the interviewer. Although it is difficult to control for all potential factors affecting the interview process, the use of a standard questionnaire and consistent strategies for all study participants (Creswell & Plano-Clarke, 2007) were ways of increasing the validity of the interviews.

Another limitation may have been where and when the interviews took place. Interviews took place before or after clinic appointments and predominantly within the clinic setting. Therefore, children and adolescents may have been predisposed to speak about headache clinically, and in the context of the shunt. Children and adolescents were given the opportunity to decide where the interviews would take place. For the majority of the children and the adolescents, the interviews took place outside of the clinic examination room. However the temporal association of the interviews taking place before or after the clinic visit may have affected the description of the headaches, predisposing the participants to speak about their headaches from a sensory or physiological perspective.

For many of the children, the interviews may have been the first time they had been asked to speak about their headaches outside of the context of the shunt. Therefore, the one-time interview may not have allowed the child or adolescent to think and reflect on their responses. This could have potentially affected the richness of the qualitative data. In order to address this issue, future studies should incorporate follow-up interviews to allow for further thought relating to the headache experience, and to provide children and adolescents time to possibly reflect on their headache experience outside of the context of shunt functioning.

Finally, the use of modified IHS headache criteria could be considered a limitation to the study as the headaches described by the children and the adolescents were not able to be classified according to the IHS criteria. A modified headache classification system was used based on the IHS criteria and excluded the temporal aspect of the headache experience. The
temporal aspect excluded from the IHS criteria was the duration of the headache reported in hours. All other aspects of the headache experience relating to location, quality, pain intensity, aggravation relating to physical activity, nausea, vomiting, photophobia, and phonophobia were captured allowing the headaches to then be classified as tension-like or migraine-like, excluding the temporal characteristics. Therefore, headaches were only described to have characteristics consistent with the various headache types as the criteria were modified to exclude the temporal aspect of the headaches. This modification could have influenced the reporting of headaches as tension-like, migraine-like, mixed or unclassifiable.

Implications for Research, Clinical Practice and Knowledge Translation

Implications for research. Future research is required to further delineate and characterize the prevalence, frequency, and psychosocial correlates related to the headache experience of children and adolescents with shunted hydrocephalus with a presumed functional shunt. The study findings were the first to define the headache experience of children and adolescents with shunted hydrocephalus within a one month period. Based on the exploratory nature of the study as an initial stage of scientific inquiry, knowledge gaps warranting further investigation included (a) defining the prevalence and frequency of headache for these children and adolescents in relation to various other aspects of hydrocephalus and in relation to various physiological, psychosocial, and psychological factors, (b) investigating both physiological, psychosocial and emotional factors affecting headache pain, (c) investigating the relationship between the frequency of headache on the child's functionality within the school, social, and family environment.

The design of the present study was descriptive and exploratory in nature. However, given the limitations of this study, future prospective studies should be developed incorporating appropriate methodologies to capture the frequency and prevalence of headache for this patient
population. Prospective designs over a 3-month period, using diaries as a method of data collection, would yield data to more specifically define and characterize the headaches in accordance with the IHS criteria. The prospective study design would allow for data to be collected relating to the temporal aspects of the headache experience, thereby fulfilling the temporal aspects of the IHS headache criteria. The use of an electronic diary (Stinson et al., 2006) would be instrumental in overcoming many of the disadvantages associated with the use of compliance-related diaries, and in determining when the diaries are filled out and by whom, thereby ensuring the accuracy of the data. Diaries enable children to track pain on a day-to-day basis, improving recall of minor pain episodes and reducing recall bias (Schnanberg et al., 2003). Diaries also help with the temporal sequencing of the pain events, making it possible to assess the relationship between burden of pain on the child's and the adolescent's functioning.

Furthermore, by obtaining the temporal data relating to the headache experience, the headaches could then be classified in accordance with the IHS headache classification system, along with the other criteria obtained relating to the nature of the headaches, and a thorough physical and neurological assessment could be carried out. Once classified appropriately, headaches within this study population could then be compared and contrasted with results pertaining to children and adolescents in the general headache literature.

Furthermore, studies specifically addressing frequency are important to better understand the influence of headache on the child's and the adolescent's daily activities. In review of the present study findings, data relating to frequency should include number of headache occurrences in a day, number of headache occurrences in a week, and how long each headache lasts. Frequency of headache was an important variable addressing the burden of headache on functionality and the influence of headache on the child's and the adolescent's school, social, and family functioning. A longitudinal prospective study design looking at headache and school
attendance is an example of a study design that could be used to address headache burden in the pediatric population.

Future research also needs to be developed to thoroughly address the psychosocial, affective, and emotional factors influencing the headache experience of children and adolescents with shunted hydrocephalus. The present study findings illustrated the psychosocial component of the children's and the adolescents' headache pain, highlighting this as an important area for further study in order to delineate key psychosocial factors specific to the study population. Studies using standardized measures and headache assessment tools within the general pediatric headache literature should be applied to this study population to further develop and understand the psychosocial and emotional affects of headache on the quality of life of these children and adolescents. The use of standardized measures would allow for a comparison to research findings within the general pediatric headache population and among children in other patient populations dealing with pain. The use of standardized measures (e.g., the State-Trait Anxiety Inventory for children (STAIC) (Spielberger et al. 1995) the Pediatric Functional Disability Inventory (PFDI) (Claar & Walker, 2006) and the Pediatric Quality of Life Inventory (PEDSQL) (Varni et al., 1999) would help to further explore key emotions such as fear, anxiety, and depression related to the headache experience of children with shunted hydrocephalus in relation to the etiology of their hydrocephalus.

Future research needs to explore a possible genetic or, biological predisposition, or alteration in the CNS pathways that may contribute to increased headache prevalence in the child and the adolescent with shunted hydrocephalus with a presumed functional shunt. Genetic prothrombotic conditions (Bottini et al., 2005) angiotension-converting enzymes (ACE), matrix metalloproteinase (MMP) (Kara et al. 2007) and cytokines (Bo et al. 2008) have been linked to migraines. Therefore, future studies could incorporate (a) comparing cytokine levels of children
with hydrocephalus and headache with children with headache without hydrocephalus, (b) studying gene variants of MMP and ACE in children with headache and hydrocephalus and (c) screening for genetic prothrombitic conditions in children with headache and hydrocephalus.

Presently the majority of the research relating to headache in children and adolescents with shunted hydrocephalus has focused on ICP dynamics. The present study findings indicated a relationship between etiology and headache, specifically tumor and congenital hydrocephalus. Future studies could investigate headache in relation to specific characteristics related to various etiologies such as characteristics of the brain and skull, and specific areas of brain involvement. Future studies need to be developed addressing the relationship between etiology and headache from both the qualitative and quantitative perspective. Quantitative studies could look at other possible clinical indicators specific to various etiologies (e.g., to further subcategorize congenital without myelomeningocele, (e.g., aqueductal stenosis and tumours specific to tumor location and pathophysiology), and qualitative studies could be undertaken to further understand how specific etiologies impact the headache experience of these children and adolescents. For example, children with myelomeningocele could be asked questions relating to their functional limitations or to other pain experiences in relation to headache experience. Children with tumours could be asked about headache in relation to their treatment and management, and about psychosocial factors that could potentially impact headache such as change in routine and social interactions, stress and concern related to their tumour, and parental reaction to headache.

Finally, the present study illustrated the social context of headache associated with headache for these children and adolescents. Social context has been a key factor influencing headache in the general pediatric well patient population (Stanford et al., 2008; McGrath & Hillier, 2001). From the present study findings, the context of headache has been dominated by neurosurgical beliefs and education mainly focusing on shunt function. Future studies need to further address the
social context of headache for these children by incorporating the thoughts and the understanding of parents and healthcare providers, who are all integral parts of the child's and the adolescent's social environment. Once further insight has been gained into the social context of headache for children and adolescents with shunted hydrocephalus, the thoughts and experiences of parents and healthcare providers could be compared and contrasted, providing even further insight into the reporting of and impact of headache.

**Clinical practice implications.** The clinical practice implications relate to strategies to improve the assessment and management of headache in children and adolescents with shunted hydrocephalus. The most important area for development is legitimizing headache for children and adolescents with a presumed functional shunt within the neurosurgical environment.

Children and adolescents with shunted hydrocephalus have been accustomed to speaking about their headaches from a sensory perspective relating predominantly to shunt function. In order to adequately assess, educate and manage headache for these children, assessment of headache within the clinic setting needs to be more thorough and extend beyond headache and shunt functioning. Questions relating to school function (marks, attendance) and ability to take part in social and leisure activities could be asked as part of their routine follow-up visits. As a result of the study findings, an algorithm (together with members of the health care team and consulting services) would be developed to address headache, incorporating physiological and psychosocial factors. The algorithm would clearly delineate medical assessment of headache for children and adolescents with shunted hydrocephalus, and also incorporate assessment and management of headache with a presumed functional shunt incorporating psychosocial factors and management strategies. The health care team, specifically the neurosurgeons, residents, fellows, and nurses need to be educated regarding the reality of headache for this patient population beyond headache as a result of shunt malfunctioning. The complexity of headache pain and assessment
in this patient population is something that should be incorporated into the neurosurgical health practitioner's training and education. A systematic review of educational strategies as a knowledge translation tool for clinical practice highlighted that large conferences have shown mixed effects, and that small group education with active participation has yielded positive effects (Grol & Grimshaw, 2003). Furthermore, the use of multifaceted interventions has improved the sustained effect of the intervention or clinical change indicated. Therefore, small education session for neurosurgical trainees and staff would be a knowledge translation strategy that could be used to improve headache assessment and management. The education sessions would provide opportunity to practice assessment skills in relation to headaches, and to become familiar with an algorithm with respect to headache assessment and management. Reminders and algorithms of the headache assessment would be posted in the clinic areas and feedback would be given regularly to the clinicians and surgeons in their performance review with respect to their ability to integrate the headache algorithm into their practice. Residents and fellows would be given feedback at their 6 months review and staff surgeons would receive feedback as part of their yearly institutional review. Audits would incorporate reviewing charts for documentation stating that the algorithm was used as part of the headache assessment.

Clinic visits need to provide an opportunity for the child and the adolescent to express the emotional, psychosocial, and affective descriptions of their headache pain. The health care providers’ inquiry into the child's and the adolescent's headache beyond aspects of the shunt would allow for this opportunity. The health care providers headache assessment should include questions relating to the psychosocial factors often associated with headache pain (e.g., friends, leisure activities, and school performance). This strategy would ensure the health care provider has a better understanding of the child and adolescents’ headache experience, and would make appropriate referrals to help manage the headache pain. Providing opportunity within the clinic
setting for discussion of headache outside of the sensory descriptors may be permission-giving
for the child and the adolescent with headache to further describe and share their headache
experience. Not only would this discussion validate the headaches for the child and the
adolescent, but the open dialogue would further establish the relationship between the health care
provider and child. The open dialogue would allow for the child and the adolescent to be heard,
validating their headache experience. It would provide clinicians with an increased
understanding of the common issues affecting these children and adolescents in relation to their
headaches that have yet to be discovered. Children and adolescents should be asked about their
headaches beyond shunt functioning and how their headaches affect their ability to function in
the school, family, and social environments. Clinicians need to think beyond headache in
relation to shunt functioning and provide an environment to discuss the affective and emotional
components of headache pain. Clinicians need to incorporate psychosocial and emotional factors
in their headache assessment and ask specific questions relating to the child's and the
adolescent's ability to concentrate in school and take part in school, social, and family functions.
When educating the patients and their families about headache and hydrocephalus, health care
professionals need to acknowledge the reality of unresolved headaches for these children and
adolescents despite a functional shunt.

Clinically, headache algorithms or practice guidelines could be developed for headaches
unrelated to shunt malfunction. Based on factors reported in the general pediatric headache
research, practice guidelines could be developed to thoroughly evaluate and assess headache in
this vulnerable patient population. Rekate and Kranz, 2009 had proposed an algorithm relating
to headache assessment of children with shunted hydrocephalus. However, it focused
predominantly on assessing shunt function and management and did not incorporate the
assessment of headache beyond a functional shunt function. This was once again reflective of
the morbidity and mortality associated with shunt function. However, once the shunt has been deemed functional, an extension of the algorithm could entail assessment and management strategies with a presumed functional shunt. The practice guidelines would entail a referral system outlining adjunctive supports and referrals to be made (e.g., social work and headache clinic) for further assessment and management of the headaches outside of shunt functioning.

**Knowledge translation.** CIHR has identified two avenues for knowledge translation: integrated knowledge translation, and end-of-project knowledge translation (CIHR, 2010). Integrated knowledge translation strategies refer to research that involves collaboration between researchers and knowledge users throughout the research process (CIHR). End-of-project strategies refer to strategies used to sustain the activity of the project and to share research findings. End-of-project strategies involve dissemination, application and diffusion (CIHR). Integrated knowledge translation strategies have been used throughout the study. End-of-project knowledge translation strategies will be implemented to disseminate the study findings.

The purpose of the research questions was to broaden clinical knowledge pertaining to headache for children with shunted hydrocephalus. Hence, the study was developed with the health care practitioners being the primary target audience. Clinically, multiple health care practitioners within the neurosurgical specialty had recognized that headache for children and adolescents with shunted hydrocephalus with a presumed functional shunt required further investigation. Therefore, from study conception, there was interest in the project from the target audience and key stakeholders (mainly neurosurgeons), who remained engaged throughout the research process. Although allied health members (i.e., nursing and multidisciplinary team members) were aware of the project, it was important to primarily engage the neurosurgeons as they are the key stakeholders who would be required to implement clinical and practice changes. Furthermore, one of the members of the supervisory committee was the chief of neurosurgery.
This neurosurgeon has been one of the leading experts in the care of children with hydrocephalus, and has developed an interest in the pain assessment and management of children with shunted hydrocephalus and within the general neurosurgical pediatric population. Within the neurosurgical culture in which the study took place, the neurosurgeons buy in is key in order to facilitate change. The involvement of key stakeholders in the development of the study is an example of an integrated knowledge translation strategy.

Grol and Grimshaw (2003) discussed effective implementation of change in patient care, and highlighted that one of the key issues involved in making change is developing a critical platform to implement change. In this study, key health care providers had an invested interest in the research questions. By incorporating the key stakeholders (specifically the neurosurgeons) from the beginning, a shared interest and concern regarding the research project and the study findings emerged. Once again, other members of the healthcare team were very aware and interested in the study from its conception. They were updated regularly regarding the study's progress and results, and also showed an interest in the study results. However, the neurosurgeons were more actively engaged by the researcher as a knowledge translation strategy to facilitate change. Shared interest is paramount when implementing clinical change.

Grol and Grimshaw (2003) described three key contextual variables that impact knowledge translation within clinical practice: organizational context, social context, and professional context. Organizational context referred to the practice environment; social context referred to prevailing opinions; and professional context related to knowledge and attitudes (Grol & Grimshaw). Barriers to clinical change can act at different levels, so it is important to understand the contextual variables to implement strategies and allow for effective translation of the research findings into the clinical arena. All of the contextual factors influencing clinical
change (organizational, social and professional) were incorporated throughout the study as a means of enhancing the knowledge dissemination of these important clinical findings.

With respect to organizational context, the organizational culture of the institution where the study took place has mandated pain as a high priority in regards to maintaining a high standard of patient care. The present study was consistent with the strategic plan of the study institution. Therefore, the study was in alignment with the vision of the institution to provide the best in complex and specialized care—which incorporated pain assessment and management—to children and adolescents.

The study institution has developed a centre for pain management, research and education. The vision of the pain centre was to enhance children’s pain outcomes, professional and consumer education, collaborative research initiatives, and local, national, and international leadership (The Hospital for Sick Children Centre for Pain Management, Research and Education, 2008). This study was therefore in alignment with the mission of the pain centre and the strategic direction of the institution. Furthermore, the Registered Nurses Association of Ontario (RNAO) has pain listed as one of their Best Practice Guidelines. Currently the study institution has working groups actively developing initiatives incorporating the recommendations of the RNAO Best Practice Guidelines into clinical practice, and actively developing research and other strategies to improve present pain practices. Therefore, the timeliness and objectives of the present study fit the present organizational initiatives and context. Furthermore, the neurosurgical unit itself, over the years, has been very proactive and at the forefront of pain management for their pediatric neurosurgical population. The unit culture, within the organizational context has already mandated pain assessment and management as a priority for their patients. Therefore, the study and study findings fit the present unit culture and are an
extension of the unit culture with respect to pain assessment and management outside the
inpatient setting.

With respect to the clinical and social context, many strategies were implemented to
allow for effective dissemination of the research findings into the clinical arena. The primary
investigator had many informal discussions with members of the neurosurgical team, which
established the importance of the research questions and heightened the awareness of headache
in children and adolescents with shunted hydrocephalus. Within the local neurosurgical team,
headache had been recognized as an issue requiring further exploration, and the clinical
importance of the research topic had been well established.

Secondly, the primary researcher has given multiple talks at international meetings on the
topic of headache and the neurosurgical pediatric patient. This broader focus has heightened the
awareness and concern of headache for children and adolescents with shunted hydrocephalus
with a presumed functional shunt. Although presentations at large meetings have not been
recognized independently as a very effective means of implementing change (Grol & Grimshaw,
2003), the meetings had involved clinicians who were primarily providing care to children and
adolescents with shunted hydrocephalus. Therefore, they had an invested interest in the topic. In
addition, the meetings provided the opportunity to have discussions with many neurosurgical
colleagues regarding the study. One-on-one interaction and discussions in the research
translation literature is the most persuasive means of communication (Soumerai & Avorn, 1990).
Overall, presentations were not the only knowledge translation strategy used to disseminate the
research findings, and in this study, a multimodal approach to knowledge translation was used.
The use of a multimodal approach for knowledge translation increased the potential for effective
translation of evidence into practice (Grol & Grimshaw).
Thirdly, one of the key stakeholders and thesis committee members, the chief of neurosurgery, would be seen as a champion within clinical practice moving forward the assessment and management of headache in the study population. Overall, the key stakeholders involved in the management of the pediatric neurosurgical patient population were aware of and very supportive of the research endeavour. In general, it has been well-substantiated within knowledge translation research that early and ongoing involvement of relevant decision makers in the conceptualization and conduct of a study is the best predictor of its utilization (Lomas, 2000).

Fourthly, the primary researcher was also a nurse practitioner within the neurosurgical service, and often highlighted the issue of headache within her practice. Throughout the research process, she was intimately aware of the neurosurgical culture, and had taken this culture into consideration when making decisions regarding the study design and implementation. She was regarded as a pain expert within the pediatric neurosurgical patient population, and had implemented many clinical changes within the inpatient environment optimizing pain assessment and management for the study population. As an advocate for pain assessment and management the nurse practitioner was seen as a leader in pain management and assessment. She provided educational opportunities, she was involved in multiple initiatives for pain assessment and management, and she was a role model to nurses and members of the health care team with respect to pain assessment and management.

Finally, with respect to the professional context, the research findings were disseminated to target clinicians and members of the multidisciplinary team using multiple avenues. A multimodal KT approach was used to disseminate the research findings within the clinical realm. Education outreach strategies were used including newsletters, conferences, seminars, lab exchanges, one-on-one meetings, presentations to decision makers and health care professionals,
and discussions with health care professionals. Examples of these efforts included presentations within the hospital to the neurosurgical team, to the nursing team during grand rounds, at lunch-and-learn sessions, and during lab meetings associated with the Pain in Child Health CIHR strategic training in health research group. Outside of the hospital setting the findings were presented at international neurosurgical meetings in both the nursing and medical forums, and at pain conferences. Research findings were also published in pediatric, pain and neurosurgery peer reviewed journals.

Using effective knowledge translation strategies, clinicians were educated and made aware of the affective, emotional and sensory components of headache pain, and the multiple factors influencing the headache experience of children and adolescents with shunted hydrocephalus so that associated practice changes could be implemented. Families of and children and adolescents with shunted hydrocephalus, as part of the continuum of care, were also made aware of the study findings. As part of the hydrocephalus teaching within the ambulatory and inpatient setting, families and children will be told about the reality of headache in this patient population with a presumed functional shunt. The study findings will be integrated into the pamphlets given to the families as part of their hydrocephalus education. The pamphlets will address the importance of headache in this patient population and the signs and symptoms associated with shunt malfunction. However, the pamphlets will also incorporate information relating to headache in this population outside of shunt functioning. It will also provide information for families with respect to keeping a headache diary for headaches so that when they do attend clinic they will be able to discuss the nature of the headaches being experienced. Study findings will also be shared with the Hydrocephalus Association, and findings disseminated via their publications and website.
Study summary. Hydrocephalus is a common pediatric neurosurgical condition affecting the body’s ability to produce and absorb cerebral spinal fluid. Treatment most commonly involves a diversionary procedure (ventriculoperitoneal [VP] shunt) that re-establishes cerebral spinal fluid flow within the central nervous system and alleviates increased intracranial pressure. Shunts are prone to malfunction with headache being a common presenting symptom. Currently, headache within the neurosurgical context is recognized predominantly as a sign of shunt function and intracranial pressure changes. Due to the morbidity associated with shunt malfunction, once the shunt is deemed functional, headache for the child and the adolescent is not commonly viewed as a pain event and is most often ignored. The present literature fails to expand on headache within this patient population as a pain event outside of a presumed functional shunt, and does not address the impact of the child's and adolescent’s headache experience from their perspective. Based on the study findings, headache, for children and adolescents with shunted hydrocephalus with a presumed functional shunt, is part of their reality.

The purpose of the present study was to describe the nature, prevalence and frequency of headache of children and adolescents with shunted hydrocephalus with a presumed functional shunt, and to describe from the child's and the adolescent's perspective the impact of headache on their school, social, and family functioning. There was an increased prevalence of headache for this vulnerable patient population occurring, for the majority of children and adolescents, one to four days a month. The nature of the headaches described by the children and the adolescents, once classified using a modified version of the IHS (International Headache Society, 2004) headache classification criteria, was predominantly migraine-like, tension-like and mixed in nature. Therefore, interpreting headache only as a sign of ICP changes and shunt functioning has left these children and adolescents vulnerable to the physiological and psychosocial implications of unresolved headache pain. From the qualitative interviews, outside of the sensory component
of their headache pain, the children and the adolescents described and spoke about the emotional and affective components of their headache experience. The described multiple invisible emotions, the overpowering nature of the headaches and missing out on activities. Furthermore, they described not being able to fully function in their school, social, and family environments because of headache. Drawing on the tenets of the GCT of pain (Melzack, 1965) and the neuromatrix theory of pain (Melzack, 1996), it is evident that the etiology of headache for these children and adolescents with shunted hydrocephalus is likely complex and multifactorial.

The use of a mixed methodology study design provided an opportunity to comprehensively explore headache for these children and adolescents from their perspective, further characterizing the nature, frequency, and prevalence of their headaches. Headache outside of shunt malfunction is a complex entity and a reality for children and adolescents with shunted hydrocephalus. The study’s significance lies in providing useful insight into the headache experience of children and adolescents with shunted hydrocephalus and a presumed functional shunt. The insight gained from this study fills gaps in our present understanding of headaches in these children and will provide further direction to health care providers to improve assessment, management, treatment, education and support to the children and the adolescents with shunted hydrocephalus.
References


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Melzack, R. (1999). From the gate to the neuromatrix. *Pain (Supplement 6), s121-s126.*


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doi:10.1177/104973200129118183


Appendix A

The International Headache Societies Classification of Headache Disorders

INTERNATIONAL HEADACHE SOCIETY
Company limited by guarantee, registered in England no. 2988368
Registered charity no. 1042574

The International Classification
of Headache Disorders
2nd Edition
(ICHD-II)

Abbreviated pocket version
for reference by professional users only,
prepared by
the Headache Classification Subcommittee of the
International Headache Society
Jes Olesen (Chairman), Marie-Germaine Bousser,
Hans-Christoph Diener, David Dodick, Michael First,
Peter J Goadsby, Hartmut Göbel, Miguel JA Lainez,
James W Lance, Richard B Lipton, Giuseppe Nappi,
Fumihiko Sakai, Jean Schoenen, Stephen D Silberstein,
Timothy J Steiner.

International Headache Society 2004

Introduction to Abbreviated Pocket Version

The International Classification of Headache Disorders, 2nd edition, is published by International Headache Society in Cephalalgia 2004; 24 (suppl 1): 1-160 and at www.i-h-s.org. This abbreviated version, including the most common or important headache disorders, is an aide memoire for those familiar with the classification principles and experienced in their application. It lists the diagnostic criteria but omits explanatory introductions, descriptions, notes and comments which in many cases are key to proper and accurate usage.

Classification

PART 1. THE PRIMARY HEADACHES
1. [G43] Migraine
   1.1 [G43.0] Migraine without aura
   A. At least 5 attacks fulfilling criteria B–D
   B. Headache attacks lasting 4-72 hours (untreated or unsuccessfully treated)
   C. Headache has at least 2 of the following characteristics:
      1. unilateral location
      2. pulsating quality
3. moderate or severe pain intensity

12

4. aggravation by or causing avoidance of routine physical activity (eg, walking or climbing stairs)

D. During headache at least 1 of the following:
   1. nausea and/or vomiting
   2. photophobia and phonophobia

E. Not attributed to another disorder

1.2 [G43.1] Migraine with aura

A. At least 2 attacks fulfilling criterion B

B. Migraine aura fulfilling criteria B–C for one of the subforms 1.2.1–1.2.6

C. Not attributed to another disorder

1.2.1 [G43.10] Typical aura with migraine headache

A. At least 2 attacks fulfilling criteria B–D

B. Aura consisting of at least 1 of the following, but no motor weakness:
   1. fully reversible visual symptoms including positive features (eg, flickering lights, spots or lines) and/or negative features (ie, loss of vision)
   2. fully reversible sensory symptoms including positive features (ie, pins and needles) and/or negative features (ie, numbness)
   3. fully reversible dysphasic speech disturbance

C. At least two of the following:
   1. homonymous visual symptoms and/or unilateral sensory symptoms
   2. at least one aura symptom develops gradually over ≥5 minutes and/or different aura symptoms occur in succession over ≥5 minutes
   3. each symptom lasts ≥5 and ≤60 minutes

D. Headache fulfilling criteria B–D for 1.1 Migraine without aura begins during the aura or follows aura within 60 minutes

E. Not attributed to another disorder

1.2.3 [G43.104] Typical aura without headache

As 1.2.1 except:

B. Aura consisting of at least 1 of the following, with or without speech disturbance but no motor weakness:
   1. fully reversible visual symptoms including positive features (eg, flickering lights, spots or lines) and/or negative features (ie, loss of vision)
   2. fully reversible sensory symptoms including positive features (ie, pins and needles) and/or negative features (ie, numbness)
D. Headache does not occur during aura nor follow aura within 60 minutes

2. [G44.2] Tension-type headache (TTH)

2.1 [G44.2] Infrequent episodic tension-type headache
A. At least 10 episodes occurring on <1 day/month on average (<12 days/year) and fulfilling criteria B–D
B. Headache lasting from 30 minutes to 7 days
C. Headache has at least 2 of the following characteristics:
   1. bilateral location
   2. pressing/tightening (non-pulsating) quality
   3. mild or moderate intensity
   4. not aggravated by routine physical activity such as walking or climbing stairs
   D. Both of the following:
      1. no nausea or vomiting (anorexia may occur)
      2. no more than one of photophobia or phonophobia
   E. Not attributed to another disorder

2.2 [G44.2] Frequent episodic tension-type headache
   As 2.1 except:
   A. At least 10 episodes occurring on ≥1 but <15 days/month for ≥3 months (≥12 and <180 days/year)
      and fulfilling criteria B–D

2.3 [G44.2] Chronic tension-type headache
   As 2.1 except:
   A. Headache occurring on ≥15 days/month on average for >3 months (≥180 days/year) and fulfilling criteria B–D
   B. Headache lasts hours or may be continuous
   D. Both of the following:
      1. no more than one of photophobia, phonophobia or mild nausea
      2. neither moderate or severe nausea nor vomiting
Appendix B
Consent and Assent Forms

**Title of Research Project:**

Headache for Children and Adolescents with Shunted Hydrocephalus.

**Investigator(s):**

Tina Petrelli RN MN ACNP PhD Candidate

**Co-Investigators:**

Dr. Bonnie Stevens, RN PhD (PhD Supervisor)
Dr. James Drake, (MD, FRCS(C))
Dr. Patrick McGrath, Psychologist (OC, PhD, FRSC, FCAH)
Dr. Jan Angus, RN PhD

**Description of the Research:**

The purpose of this study is to find out more about the headache experience for children and adolescents with shunted hydrocephalus. The study will involve three parts. The first part of the study is a screening question asking if you have headache. The second and third parts of the study involve interviews asking questions about describing your headache and how your headache impacts your school, social and family life. Part of the interview will be audio taped. A separate consent will need to be signed asking permission to audiotape the interview. You may not be asked to participate in all parts of the study. The interviews all take place at one time after your clinic appointment and will take approximately 45 minutes (e.g. like watching a television program such as the Simpsons). Your hospital chart will be reviewed for this research study. All information collected will be destroyed upon study completion.

**Potential Harms:**

We know of no harm that taking part in this study could cause you.

**Potential Discomforts or Inconvenience:**

The only inconvenience associated with participating in the research study is that your visit to the hospital will be longer than a regular clinic visit.

**Potential Benefits:**

**To individual subjects:**
You (your child) could potentially benefit by discussing their headache experience. Depending on the description of the headache experience a referral may be made to the headache clinic at the affiliated hospital for further assessment and management strategies.

**To society:**

The information you provide will help further our understanding of headache for children with shunted hydrocephalus. This information and the results of the study could possibly help in the assessment and management of other children who have headaches and hydrocephalus.

**Confidentiality:**

We will respect your privacy. No information about who you are (your child is) will be given to anyone or be published without your permission, unless required by law. For example, the law could make us give information about you if a child has been abused, if you have an illness that could spread to others, if you or someone else talks about suicide (killing themselves), or if the court orders us to give them the study papers.

Sick Kids Clinical Research Monitors or the regulator of the study may see your health record to check on the study. By signing this consent form, you agree to let these people look at your records. We will put a copy of this research consent form in your patient health record and give you a copy as well.

The data produced from this study will be stored in a secure, locked location. Only members of the research team (identified above) will have access to the data. This could include external research team members. Following completion of the research study the data will be kept as long as required then destroyed as required by Sick Kids policy. Published study results will not reveal your identity.

The results of the tests we describe in this form will be used only for this study

**Reimbursement:**

Study participants received and Tim Hortons certificate and parking reimbursement if taking part in the qualitative interviews.

**Participation:**

It is your choice to take part in this study. You can stop at any time. The care you get at Sick Kids will not be affected in any way by whether you take part in this study.

**Conflict of Interest:**

There is no conflict of interest to declare in relation to this study.

**Consent:**
By signing this form, I agree that:

1) You have explained this study to me. You have answered all my questions.

2) You have explained the possible harms and benefits (if any) of this study.

3) I know what I could do instead of taking part in this study. I understand that I have the right not to take part in the study and the right to stop at any time. My decision about taking part in the study will not affect my health care at Sick Kids.

4) I am free now, and in the future, to ask questions about the study.

5) I have been told that my medical records will be kept private except as described to me.

6) I understand that no information about who I am will be given to anyone or be published without first asking my permission.

7) I agree, or consent, to take part in this study.

___________________________
Printed Name of Participant & Age

Participant’s signature & date

__________________________
Printed Name of person who explained consent

Signature of Person who explained consent & date

_______________________________________
Printed Witness’ name (if the subject/legal guardian does not read English)

Witness’ signature & date

If you have any questions about this study, please call Tina Petrelli at

If you have questions about your rights as a subject in a study or injuries during a study please call The Research Ethics Manager at
Assent Form*

**Title of Research Project:**

Headache experience for the Child and Adolescents with Shunted Hydrocephalus.

**Investigator(s):**

Tina Petrelli RN MN ACNP PhD Candidate

**Co-Investigators:**

Dr. Bonnie Stevens, RN PhD (PhD Supervisor)
Dr. James Drake, (MD, FRCS(C))
Dr. Patrick McGrath, Psychologist (OC, PhD, FRSC, FCAH)
Dr. Jan Angus, RN PhD

**Why are we doing this study?**

We would like to learn more about the headache experience of children with headaches who have shunts.

**What will happen during the study?**

To find out about what it is like for you to have a headache I will be asking you questions about your headaches. It will probably take about 45 minutes, about the length of a Television show (e.g. like watching a television program such as the Sponge Bob or the Simpsons). We will meet after clinic and sit and talk together. We will talk about things you like to do, your friends, school and about your family. If you would like, your mom or dad can stay with us while we talk. I will be using a tape recorder for part of the time we talk to help me remember the things you have said. What you say is private. All the information you tell me will be kept safe in a locked and safe place.

There is another piece of paper I have asking permission to use a tape recorder to tape part of our interview and have another person listen to it.

**Are there good things and bad things about the study?**

There are no bad things about the study. The good thing is we hope to learn more about what it is like to have a headache for children like you with a shunt which will help the doctors and nurses take better care of you.

**Who will know about what I did in the study?**

What you tell me in the talks we have will be kept private. Everything you tell me about yourself will not be given to anyone who is not working on the study. Your name will not be
printed or used in anything written about the study. If we feel your health may be in danger, we may have to report your results to your doctor.

**Can I decide if I want to be in the study?**

Yes, if you do not want to be in the study that is okay. Nobody will be angry or upset if you do not want to be in the study. We are talking to your parent/legal guardians about the study and you should talk to them about it too.

**Assent:**

The following section must be included at the end of the assent form:

"I was present when ____________________________ read this form and said that he or she agreed, or assented, to take part in this study”.

______________________________
Printed Name of person who obtained assent

______________________________
Signature & Date
## Appendix C:

### Refusal Log

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Appendix D:

Demographic Data Collection Sheet

Study #:__________

Age (years):__________

Sex (male; female):__________

Etiology of Hydrocephalus: congenital___ spina bifida_____ intraventricular hemorrhage___ meningitis ____ tumor____ trauma____

Number of Shunt revisions:____________

Age at initial shunt insertion (years and months) __________

Date of most recent revision (D/M/YR): __________

School Placement:  Mainstream _____
Appendix E

Interview Guide for Screening Question

Interview Guide for Screening Question for 7-10 year of age:

Introduction:

Hello, my name is Tina. I am a nurse and today I would like to learn about headaches in children who have shunts. This information will be very helpful for the doctors and nurses who take care of you and your shunt.

Do you know how long a month is? (Show calendar and talk about a month, if interview is around a special occasion use this to help describe a month). Now that we know how long a month is, I would like to ask you one question, and there is no right or wrong answer.

“Have you had a headache in the last month?”

Closure: If the child answers no:

Thank you for taking the time to answer the question for me. This information will be extremely helpful. I have no further questions for you, you are a superstar. Thanks and have a great day.

If the child answers yes:

I would like to ask you a few questions about your headaches and how they affect the things that you do. There is no right or wrong answers, and this is not a test. I just want to know more about you and your headaches and you are the best person to tell me. I will want to tape record some of your answers to help me remember what you have told me so that I can better understand the headaches you have. I will be asking you to sign a form asking for your permission to use the tape recorder. I will tell you when I will be turning the tape recorder on and if you want me to turn it off at any time please let me know and I will do so. Your mom or dad can stay with us while we talk a little bit more about your headache. Are you okay with all of that?

Great! Let’s begin.

(Proceed to interview 1)
Interview Guide for Screening Question for 11-18 years old:

Introduction:

Hello, my name is Tina. I am a nurse and I want to learn about headaches that children have who have shunts. This information will be very helpful for the doctors and nurses who take care of you and your shunt.

Let me begin by asking you one question:

“Have you had a headache in the last month?”

(Depending on time of study, describe one month or show a calendar)

Closure:

If the Adolescent answers no:

Thank you for taking the time to answer the question for me. This information will be extremely helpful. I have no further questions for you.

If the adolescent answers yes:

I would like to ask you a few questions about these headaches and how they affect the things that you do. There is no right or wrong answers, and this is not a test. If there is anything that you don’t want to answer, please let me know. I really just want to know more about you and your headaches and you are the best person to tell me. I will want to tape record some of your answers to help me better understand the headaches you have. I will tell you when I will be turning the tape recorder on and if you want me to turn it off at anytime please let me know and I will do so.

Are you okay with all of that?

Great! Let’s begin.

(Proceed to interview 1)
Interview guide for Interview #1

Interview guide for Interview #1 (7-10 year old)

I am going to ask you 9 questions about your headaches this will take approximately ten minutes. Less than one Arthur show/Sponge bob show. I would like to hear the answers from you so if you could answer that would be great, if not we can ask mom and/or dad for help. Again these questions are going to help me understand your headaches. Some children have more than one type of headache. I am interested in hearing about any type of headache you may have. I will not be turning the tape recorder on yet.

Let’s begin:

Do you have more than one type of headache?

If yes, what names should we give to the different types of headaches you have?

I am going to ask you questions to better understand each of your headache types.

1) During the 30 days in a month (Show calendar again). How many days would you say you get a headache? ______________

2) Can you show me where on your head you get the headache? Is it on one side or both sides? ______________

3) Would you say that your headache feels like it is pulsating (pounding, beating, thumping) or more like a pressing and tightening feeling?

4) Have you used a pain scale before? (If no, the child will be given instruction regarding the Numerical rating scale and the Anchors.) What number would you give your pain when you get a headache?

5) Do your headaches get worse when playing sports or running around?

   Yes_____    No_______

6) When you have these headaches, do you feel sick to your stomach or vomit?

   Yes _____    No_______

7) When you have these headaches, does light bother you?

   Yes ____    No_______

8) When you have these headaches, do noises bother you?

   Yes _____    No_______

9) When you have these headaches do you ever:
a) see flickering lights (i.e. like fireworks?), spots or lines or can’t see?
   Yes _____  No_______

b) feel pins and needles (ginger ale or pop bubbles in your arms and legs?) and you can’t feel your arms or legs?
   Yes ______  No______

c) couldn’t speak?
   Yes ____    No_______

If the child answered yes to any of the items in question 10,

   How long did it last?

You have given me some great information about your headaches, thank you for that. I now would like to ask you a few questions about you and your headaches. Once again you are the best person to answer these for me and I really want to know how the headaches affect you and the things you do like school, playing with your friends and being with your family.
Interview guide for Interview #1 (11-18 year old)

I am going to ask you 9 questions about your headaches this will take approximately ten minutes. Again these questions are going to help me understand your headaches. Some children have more than one type of headache. I am interested in hearing about any type of headache you may have. I will not be turning the tape recorder on yet.

Let’s begin:

Do you have more than one type of headache?

If yes, what names should we give to the different types of headaches you have?

I am going to ask you questions to better understand each of your headache types.

1) During one month (Show calendar again). How often would you say you get a headache? __________

2) Can you show me where on your head you get the headache? Is it on one side or both sides? __________

3) Would you say that your headache feels like it is pulsating (pounding, beating, thumping) or more like a pressing and tightening feeling?

4) Have you used a pain scale before? (If no child will be given instruction regarding the Numerical rating scale and the Anchors.) What number would you give your pain when you get a headache?

5) Do your headaches get worse with physical activity, playing sports or running around?
   Yes_____   No_______

6) When you have these headaches do you feel sick to your stomach or vomit?
   Yes_____   No_______

7) When you have these headaches does light bother you?
   Yes_____   No_______

8) When you have these headaches do noises bother you?
   Yes_____   No_______

9) When you have these headaches do you ever:
   a) see flickering lights, spots or lines or lose your vision?
      Yes_____   No_______
   b) feel pins and needles and/or numbness in any of your arms and legs?
Yes ______  No______

c) loose your ability to talk?

Yes ___  No_______

If the child answered yes to any of the items in question 10, How long did the symptoms last?

You have given me some great information about your headaches, thank you for that. I now would like to ask you a few questions about you and your headaches. Once again you are the best person to answer these for me and I really want to know how the headaches affect you and the things you do like school, being with your friends playing in sports and being with your family.
Appendix G

Interview Guide for Interview #2

Interview Guide for Interview 2 (7-10 years of age)

This part of the interview is about you and will take about 30 minutes (further describe such as 2 Arthur shows/Sponge Bob half an hour). Your mom and dad can stay with us but I would like to hear the answers from you. I will be turning the tape on for these questions because what you say is really important and I don’t want to miss any thing. If you want it turned off at anytime, please let me know. I may also write a few things down while you are speaking to help me remember things. I am really interested to hear about you and your headaches and you are the best person to tell me.

Do you have any questions?

Great! Let’s begin.

To start, I would like to know a little bit more about your headaches:

Everybody has different headaches, so I want to know all about what it is like for kids who get them. This means that I want to know exactly what you think about headaches.

When I say the word “headache” what does it mean for you?

Tell me a little bit about your headaches. What is it like when you get a headache?

- How do they make you feel?
- Are there different types?
- When do you usually get your headaches?
- What do you do when you get a headache?

What do you think about when you get a headache?

Social/Leisure:

Tell me some things that you like to do.

- How do the headaches affect the things that you like to do.
- Do the headaches change how you play with your friends?
- How do the headaches affect any sports or other activities you usually like to do?

School:
• What happens when you get a headache at school?

• What changes for you at school when you have a headache?

• How do the headaches affect your schooling?

• Do you miss a lot of days of school? How do you decide if you need to miss school?

• How does it affect you doing your homework and concentrating?

• How do you participate in school when you have a headache?

Family:

• What happens when you tell somebody in your family that you have a headache?

• What happens in your family when you say you have a headache?

Is there anything else you wanted to tell me about your headaches?

Closure:

Thank you so much for answering all the questions. I really appreciate you taking the time and helping me better understand what it is like for you to have a headache. Everything you have said will be extremely helpful. Thank you for sharing with me.
Interview Guide for Interview 2 (11-18 years of age)

This part of the interview is about you and will take about 30 minutes (half an hour). I will be turning the tape on for these questions because what you say is really important and I don’t want to miss anything. If you want it turned off at anytime please let me know. I may also write a few things down while you are speaking to help me remember things. Like I said before, I am really interested to hear about you and your headaches and you are the best person to tell me.

Do you have any questions?

Great lets begin.

Because everyone has different headaches and different ways of dealing with them, I want to know all about your unique experiences.

When I say the word “headache”, what does it mean for you?

- How do they make you feel?

What different types?

- When do you usually get your headaches?
- What do you do when you get a headache?
- What do you think about when you get a headache?

Social/Leisure:

- How do headaches affect how you interact with your friends?
- How do the headaches change the things you like to do in your spare time?

School:

- What happens when you get a headache at school?
- What changes for you at school when you have a headache?
- How do the headaches affect your schooling?
- Do you miss a lot of days of school? What happens when you get a headache at school? How do you decide if you need to miss school?
- How does it affect you doing your homework and concentrating?
- Can you participate fully when you are at school?
Family:

- What happens when you tell somebody in your family that you have a headache?
- What happens in your family when you say you have a headache?

Is there anything else you wanted to tell me about your headaches?

Closure:

Thank you so much for answering all the questions. I really appreciate you taking the time and helping me better understand what it is like for you to have a headache. Everything you have said will be extremely helpful. Thank you for sharing with me.
Consent for Audio-taping

Research Ethics Board
Video/audio taping & photography consent form template

**Title of Research Project:**

Headache experience for the child and the adolescent with shunted hydrocephalus.

**Investigator:**

Tina Popov RN MN ACNP PhD Candidate

**Co-Investigators:**

Dr. Bonnie Stevens, RN PhD (PhD Supervisor)
Dr. James Drake, (MD, FRCS(C)
Dr. Patrick McGrath, Psychologist (OC, PhD, FRSC, FCAH)
Dr. Jan Angus, RN PhD

**Confidentiality:**

The pictures or tapes produced from this study will be stored in a secure, locked location. Only members of the research team (and maybe the SickKids monitor, or employees of the company sponsoring the study or the regulator e.g., Health Canada) will have access to them. Following completion of the study the tapes/pictures will be kept as long as required in the SickKids “Records Retention and Destruction” policy. They will then be destroyed according to this same policy.

**Consent:**

By signing this form,

1) I also agree to be taped/photographed during this study. These tapes/photographs will be used to better understand the headache experience of children with shunted hydrocephalus.
2) I understand that I have the right to refuse to take part in this study. I also have the right to withdraw from this part of the study at any time. e.g., before or even after the tapes or photographs are made. My decision will not affect my health care at SickKids.
3) I am free now, and in the future, to ask questions about the taping/picture taking.
4) I have been told that my medical records will be kept private. You will give no one information about me, unless the law requires you to.
5) I understand that no information about me (including these tapes/pictures) will be given to anyone or be published without first asking my permission.”

6) I have read and understood pages 1 to 2 of this consent form. I agree, or consent, to having my picture taken/being taped as part of the study.

________________________________________
Printed Name of Participant

________________________________________
Participant’s signature & date

________________________________________
Printed Name of person who explained consent

________________________________________
Signature & date

________________________________________
Printed Witness’ name (subject does not read English)

________________________________________
Witness’ signature & date

In addition, I agree or consent for this tape(s)/photograph(s) to be used for:

1. Other studies on the same topic
2. Teaching and demonstration at SickKids.
3. Teaching and demonstration at meetings outside SickKids.
4. Not to be used for anything else.

In agreeing to the use of the tape(s)/photograph(s) for other purposes, I have been offered a chance to view/hear the tape(s)/photograph(s). I also have the right to withdraw my permission for other uses of the tape(s)/photograph(s) at any time.
Appendix I

Numerical Rating Scale

The Numerical Rating Scale (NRS) is a self report tool appropriate for school aged children and adolescents. Children must be capable of counting up to 10 and understand the concepts of classification and seriation. They must also have sufficient language comprehension and production, and understanding of emotional states.

Instructions:

Ask the child/adolescent to assign a number to his/her headache with 0 representing no headache and 10 representing the worst pain ever.

Cut off scores: 0-3 mild pain, 4-6 moderate pain, 7-10 severe pain.
Appendix: J

Example of Matrix for Qualitative analysis: Pain descriptors and sex

<table>
<thead>
<tr>
<th>Sex</th>
<th>Physical descriptors</th>
<th>Emotional descriptors</th>
<th>Affective Descriptors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>Concrete very direct</td>
<td>Worry (very concrete related to shunt and headache at present)</td>
<td>Practical, pragmatic-headache, why do they have it, do they need to go the hospital.</td>
</tr>
<tr>
<td></td>
<td>Very medicalized, focusing on physical</td>
<td>Annoying, Sad</td>
<td>Impacts the here and now</td>
</tr>
<tr>
<td></td>
<td>Head pain</td>
<td>Sense of acceptance, very matter of fact</td>
<td>State they can forget about them</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Talk about stress relating everything</td>
<td>Very concrete when they talk about them, not as much hostility</td>
</tr>
<tr>
<td>Female</td>
<td>Increased description</td>
<td>Worry –about present headache and management, know which to worry about, increased insight into headaches, anticipatory worry…”If it doesn’t get better”</td>
<td>More of a struggle, speaking with them you can feel the struggle, empathize</td>
</tr>
<tr>
<td></td>
<td>Very concrete related to shunt and</td>
<td>Scared</td>
<td>Clearly articulate impact, passionate</td>
</tr>
<tr>
<td></td>
<td>headache at present)</td>
<td></td>
<td>increased anger, resentment</td>
</tr>
<tr>
<td></td>
<td>Verbose, describe similar to males with</td>
<td></td>
<td>Clear in recognizing what they are missing out on, move beyond present</td>
</tr>
<tr>
<td></td>
<td>concrete medical terminology</td>
<td></td>
<td>Very aware of limitation, concern of continuing to lose abilities, can’t participate in daily activities</td>
</tr>
<tr>
<td></td>
<td>Expand on intensity, physical symptoms,</td>
<td></td>
<td>Elevates all of their emotions</td>
</tr>
<tr>
<td></td>
<td>moves beyond the head incorporating whole</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>body</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Descriptors beyond physical, medicalized</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>terms “repulsive”</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Anticipatory, seeing beyond here and now,</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>moves beyond the headache, “if not managed, if never stops”</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>