

UNDERSTANDING AN INVISIBLE DISABILITY

CHIARI I MALFORMATION

By

BRIDGET GARRETT

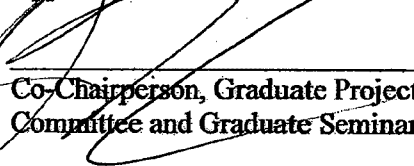
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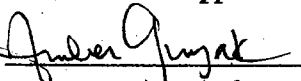


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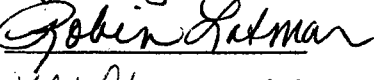
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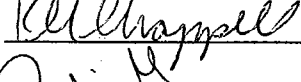
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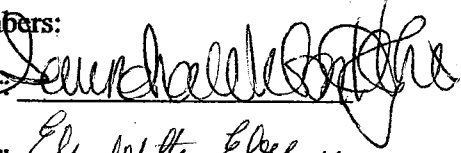
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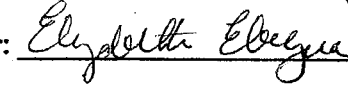
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Dedication

I would like to dedicate this final project to my wonderful family who has stood by my side during my journey:

To my dear husband, Matt, I thank you for your patience, your never-ending support and for all of the sleepless nights spent editing this final project.

To my precious son who has been my constant reminder that it is important to take breaks and play. Without play, our lives lack happiness. Thank you, Graham, for reminding me to play.

To my baby girl who is not much of a baby anymore. I began this master's program right after you were born four and a half years ago. Your daily smiles and hugs were just what I needed to keep me going. Thank you, Grace, for your daily dose of sunshine.

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Running head: Understanding Chiari I Malformation

Understanding an Invisible Disability

Chiari I Malformation

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Abstract

Through an extensive literature review, symptoms commonly associated with Chiari I Malformation (Chiari) that have the potential to obstruct a student's ability to succeed in an educational environment are identified. To study how these symptoms affect students, twenty-two persons with Chiari were asked to respond to thirty open-ended questions. Responses to the written questionnaire provide insight into the challenges facing students with Chiari and may assist educators in their efforts to develop appropriate modifications and accommodations in Individual Education Plans or Section 504 plans.

Understanding an Invisible Disability: Chiari I Malformation

CHAPTER I

INTRODUCTION

How do schools service students for a disability that is unknown to not only those in the educational field, but those in the medical field too? Prior to the enactment of the Individuals with Disabilities Education Act of 1997 (IDEA), many disabled children were prevented from having successful educational experiences in regular school programs because their disabilities were undetected. For many with disabilities, much has changed since the enactment of this act. However, children with unique or rare disabilities that are not fully understood, or even recognized, by the medical and educational communities, continue to face an uphill battle to obtain proper services that will allow them to succeed in school. Children with Chiari (pronounced Kee-AR'-ee) I Malformations (CMI or Chiari) and their families frequently fall into this category and face unique challenges that must be overcome to ensure that these children are able to maximize their educational opportunities.

Chiari I Malformation is a neurological disorder which afflicts approximately 1 in 1,000 people, causing debilitating headaches, neck pain, weakness and numbness in the limbs, balance problems, visual disturbances, and a host of other symptoms (C & S Patient Education Foundation, 2005). Symptoms present during infancy, but they may also delay until adolescence or adulthood (National Organization for Rare Disorders (NORD), 2005). “Most people with Chiari look and act normal until fatigue sets in, they overdo it physically, or they experience pressure changes” (Curtacci, 2006).

Students with this condition, like all students, are entitled to a free and appropriate education. *Appropriate* is defined as educational services designed to meet the individual education needs of students with a disability as adequately as the needs of nondisabled students are met (Office of Civil Rights, 1999). An Individualized Education Plan (IEP) or Section 504 Plan will ensure that students with Chiari I Malformation receive appropriate accommodations and modifications so that their educational needs are, in fact, met as adequately as nondisabled students. In order to do so, however, parents, educators, doctors, and students must first understand what Chiari is, how it affects a particular student in a classroom environment, and how non-extraordinary measures can be taken to meet the student's individual educational needs.

Statement of the Problem

Research reveals that individuals diagnosed with Chiari face physical and cognitive difficulties that are often unnoticed or misunderstood. These individuals struggle with obtaining the proper treatment and medical care because their symptoms are difficult for others to see and understand. As a result of this, students with Chiari may be deprived of services that meet their individual educational needs as adequately as those provided to nondisabled students.

Purpose of the Study

The purpose of this study is to examine, in detail, symptoms commonly associated with Chiari to determine whether they affect a student's educational experience and if so, what accommodations and modifications are needed to maximize these students' educational opportunities. This examination will be based on questionnaires of students

with Chiari as well as an extensive review of available literature. The questionnaires will be used to identify common themes among the responses and to develop a list of appropriate accommodations and modifications needed to help students with Chiari succeed in an educational setting.

Questions of the Study

The following questions will guide the focus of this study:

1. What symptoms are commonly associated with Chiari?
2. How do these symptoms affect a student's success in school?
3. What accommodations or modifications are needed in the school setting to meet the needs of students with Chiari?

Limitations

With any study, there are limitations. Because the participants come from fifteen different states, the researcher is unable to meet face-to-face with those involved. The second limitation is that all of the participants will self report this medical condition and may be inherently biased because they are interested in the outcome. Finally, this study is limited to the fifteen-week time schedule set by the Multicategorical Special Education Program at Governors State University.

Educational Significance of Study

There are very real adverse consequences to students, teachers, and parents if any student's educational needs are not met, and this remains true for students who suffer from Chiari. Students with Chiari may fail due to their struggle with daily symptoms. Additionally, they may feel frustrated if they perceive that nobody fully understands their

symptoms or even accepts that their symptoms are genuine. In an article written about a teenager with Chiari, the author wrote, “Megan and young people like her have to deal with fellow students, some educators, and even some doctors who do not believe their symptoms are real” (Curtacci, 2006). Parents may feel equally frustrated if their child’s teachers are not equipped to meet or even understand their child’s unique needs. Without a basic understanding of Chiari and its symptoms, teachers cannot adequately address their student’s needs.

Definition of Terms

Brainstem. The stemlike portion of the brain connecting the cerebral hemispheres with the spinal cord (Dorland's illustrated medical dictionary twenty-sixth edition, 1981).

Central Nervous System. The portion of the nervous system consisting of the brain and spinal cord (Dorland's illustrated medical dictionary twenty-sixth edition, 1981).

Cerebellum. The rounded portion of the brain, situated above the brainstem, that controls balance and coordination of movement (Random house webster's college dictionary, 2001).

Cerebrospinal fluid (CSF). A fluid, rich in glucose, that circulates in the brain and the spinal column (Random house webster's college dictionary, 2001).

Cervical Spine. The neck region of the spinal column (Random house webster's college dictionary, 2001).

Disability. A disadvantage or deficiency, especially a physical or mental impairment that prevents or restricts normal achievement (The American Heritage Stedman's Medical Dictionary, 2004).

Dysarthria. Difficulty in articulating words due to disease of the central nervous system (The American Heritage Stedman's Medical Dictionary, 2004).

Dysphagia. Difficulty in swallowing or inability to swallow (The American Heritage Stedman's Medical Dictionary, 2004).

Dizziness. A disorienting sensation such as faintness, light-headedness, or unsteadiness (The American Heritage Stedman's Medical Dictionary, 2004).

Dura. The tough, outermost covering of the brain (Dorland's illustrated medical dictionary twenty-sixth edition, 1981).

Foramen Magnum. The opening of the skull through which the spinal cord emerges (The Chiari Institute, 2006).

Nystagmus. An involuntary rapid movement of the eyeball (Dorland's illustrated medical dictionary twenty-sixth edition, 1981).

Occipital bone. A curved, compound bone at the back of the head forming part of the base of the skull (Random house webster's college dictionary, 2001).

Ocular. Of or relating to the sense of sight (The American Heritage Dictionary of the English Language, Fourth Edition, 2004).

Oscillopsia. The sensation that viewed objects are moving or wavering back and forth (The American Heritage Stedman's Medical Dictionary, 2004).

Other Health Impairment. A special education category that “means having limited strength, vitality, or alertness with respect to the educational environment that is due to chronic or acute health problems” (ISBE).

Posterior fossa. It contains three important neurological components: the brain stem, cranial nerves, and cerebellum. The brain stem contains the nerve centers that control eye movements, feelings and movement of the face, hearing, swallowing, shrugging the shoulders, and movements of the tongue. From these nerve centers run the cranial nerves. The brainstem also has nerve centers that control heart and breathing functions. The cerebellum, attached to the back of the brain stem, regulates coordination and fluidity of movement (Oro, 2003).

Section 504. Section 504 of the *Rehabilitation Act of 1973* protects the rights of individuals with disabilities in programs and activities that receive federal funds. Section 504 provides that: “No otherwise qualified individual with a disability in the United States . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance. The Section 504 regulation defines a person with a disability as any person who (i) has a physical or mental impairment which substantially limits one or more major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment (Office of Civil Rights, 1999).

Symptomatology. The combined symptoms of a disease (Dorland's illustrated medical dictionary twenty-sixth edition, 1981).

Syrinx. A cyst that forms within the spinal cord (The Chiari Institute, 2006).

Tachyarrhythmia. An irregularity in the normal heart rhythm (Dorland's illustrated medical dictionary twenty-sixth edition, 1981).

Tinnitus. Ringing in the ears (Dorland's illustrated medical dictionary twenty-sixth edition, 1981).

Valsalva maneuvers. Forcible exhalation effort against nostrils and a closed mouth (Dorland's illustrated medical dictionary twenty-sixth edition, 1981).

Vertigo. A sensation of irregular or whirling motion, either of oneself or of external objects (The American Heritage Stedman's Medical Dictionary, 2004).

Summary

Children with unique or rare disabilities, like Chiari I Malformation, that are not fully understood or recognized by the medical and educational communities, continue to face an uphill battle to obtain proper services that will allow them to succeed in school. Students with this condition, like all students, are entitled to a free and appropriate education (Office of Civil Rights, 1999). The purpose of this study is to examine, in detail, symptoms commonly associated with Chiari to determine whether they affect a student's educational experience and if so, what accommodations and modifications are needed to maximize these students' educational opportunities in order to provide an appropriate education for these individuals.

CHAPTER II REVIEW OF LITERATURE

Definition of Chiari I Malformation

Chiari Malformation is due to a developmental failure of the brain stem and the upper spine, in the cervical region, with no known cause (National Organization for Rare Disorders, 2005). Many researchers believe that the malformation results from an underdevelopment of the lower part of the skull in which the posterior fossa is too small and does not provide the room needed for the cerebellum and lower part of the brain stem (Oro, 2003). Chiari is characterized by abnormalities in the area where the brain and spinal cord meet that cause part of the cerebellum to protrude through the bottom of the skull (foramen magnum) into the spinal canal and it interferes with the flow of cerebral spinal fluid to and from the brain (NORD, 2005).

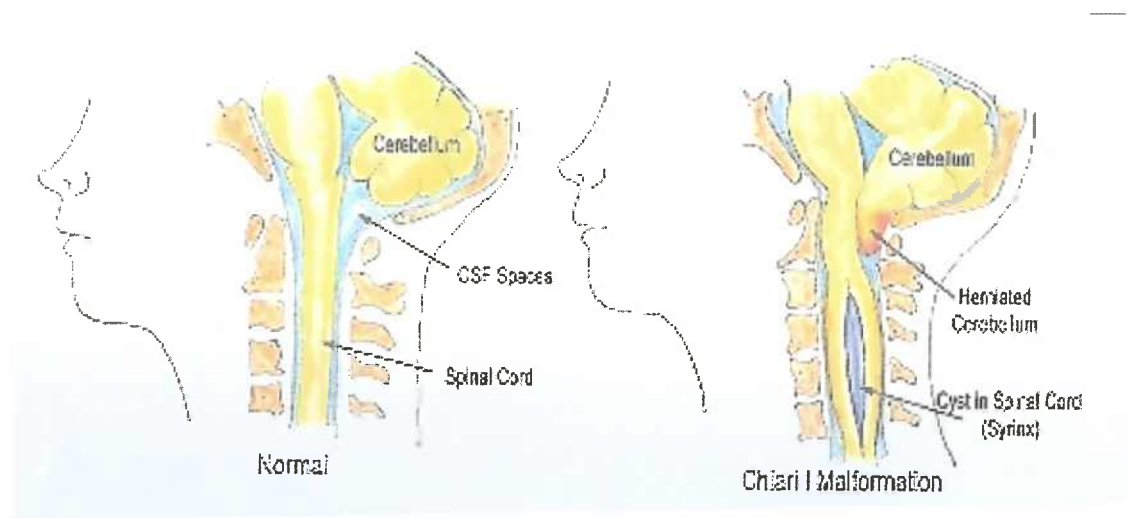


Figure 1 Picture comparing a normal brain to a brain with Chiari I Malformation
From The Chiari Institute Patient Handbook

Symptoms of Chiari I Malformation

The review of literature reveals a complex symptomatology associated with Chiari I Malformation (CMI). The most common constant feature of CMI is a volumetrically small posterior fossa, which predisposes patients to hindbrain overcrowding (Milhorat, 1999). This overcrowding or displacement of PCF contributes to the symptoms. The symptoms develop because of the pressure in the upper cervical spinal canal by the herniation of the cerebellar tonsils down into the cervical canal (The American Association of Neurological Surgeons (AANS) , 2001).

Suboccipital Headaches

The review of literature reveals suboccipital headache as the most common symptom of CMI. This severe headache may possibly be accompanied by neck pain (National Organization for Rare Disorders, 2005). In Milhorat's study of 364 symptomatic Chiari patients from January 1994 to December 1997, these were experienced by 296 patients (81%) and they were described as a heavy, crushing, or pressure-like sensation at the back of the head that radiated to the vertex and behind the eyes and inferiorly to the neck and shoulders (1999). He reports that these headaches are accentuated by physical exertion, Valsalva maneuvers, head dependency, and sudden change in posture (Milhorat, 1999). Garland and Robertson (2001) reported a frequency of 81% of clients with CMI complaining of suboccipital headaches.

Ocular disturbances

Ocular disturbances are disturbances to the sense of sight. Milhorat's study reported that 283 patients (78%) had ocular disturbances (1999). The specific symptoms were

retro-orbital pressure, visual phenomena such as floaters or flashing lights, blurred vision, photophobia, diplopia, and visual field cut and symptoms were also accentuated by physical exertion, Valsalva maneuvers, head dependency, and sudden change in posture (Milhorat, 1999). Pieh and Gottlob describe the cases of two patients. The first patient, with a initial complaint of decreased vision, was reported to have nystagmus on the downward lateral gazes with a bilateral weakness of the rectus muscles and the second patient complained of visual disturbances consisting of blurred vision (2000).

Hypersensitivity to bright lights has also been reported (AANS, 2006).

Neurological disturbances

Not only does physical exertion, Valsalva maneuvers, head dependency, and sudden change in posture cause headaches and ocular disturbances, but also neurological disturbances. Seventy-four percent of the patients in Milhorat's study (1999) experienced symptoms of dizziness, disequilibrium, pressure in the ears, tinnitus, decreased hearing loss, vertigo, and oscillopsia. Garland and Robertson (2001) determined a frequency of 57% of patients with a complaint of dizziness. After sneezing, a nineteen year old male presented with persistent numbness and burning in his right shoulder, face and neck, had an MRI and was diagnosed with Chiari (Strayer, 2001). Disorders involving the cerebellum, like Chiari, can include unsteady gait, balance problems, and difficulty with fine motor tasks (Oro, 2003).

Anxiety Disorder

A study of a 34 year old mother revealed panic disorder associated with Chiari I Malformation. She experienced episodes of dizziness, hand tremors, palpitations, chest

tightness, hot flashes, and a cold, clammy feeling (Chrisholm, Valamoor, Chandarana, & Cochrane, 1993). The study concluded that Chiari may have acted as a trigger for her episodes of anxiety. Although these attacks were infrequent, each one was followed by a monthly long persistent fear of having another attack (Chrisholm, Valamoor, Chandarana, & Cochrane, 1993).

Cranial nerve, brain stem, & cerebellar disturbances

A study of 364 patients, 191 reported symptoms of dysphagia sleep apnea, dysarthria, tremors, palpitations, and poor coordination (Milhorat, 1999). In recent years, there have been several publications linking Chiari to an unusually high rate of sleep apnea (Labuda, 2007b). In a study of forty MRI confirmed Chiari patients, 73% of the adults and 60% of the children suffered from sleep apnea (Dauvilliers, et al., 2007). Lubuda (2007b) reports that the precise mechanism by which Chiari is linked to sleep apnea is not known. However, Chiari affects the brainstem and cranial nerves which are critical for breathing during sleep (Dauvilliers, et al., 2007).

Spinal Cord Function

Syringomyelia is a chronic disease of the spinal cord characterized by the presence of fluid-filled cavities and leading to spasticity and sensory disturbances (Dorland's illustrated medical dictionary twenty-sixth edition, 1981). In Milhorat's study (1999), 94% of those with syringomyelia had spinal cord disturbances. Sixty-six percent of those without syringomyelia also had spinal cord disturbances like muscle weakness, spasticity, and impaired fine-motor function of the hands.

Cognitive Difficulties

There is strong anecdotal evidence that Chiari patients may suffer from cognitive problems due to elevated cerebrospinal fluid pressure or even chronic pain. (Labuda, 2007a). Long-term increase in intracranial pressure, which is common with Chiari, can have far reaching cognitive effects (Labuda, 2006). Many Chiari patients report experiencing a “brain fog” which effects their memory and ability to think clearly, and developmental delays or problems in school are sometimes the early warning signs to a Chiari Diagnosis (Labuda, 2007a). Because the cerebellum, the central player in Chiari, is involved in many higher order brain functions, Labuda stated, “It is reasonable to speculate that the compression of the cerebellum as it is jammed into the spinal cord may affect its ability to function and result in cognitive deficits” (2007a).

Psychogenic Frustrations

Chiari symptoms can mimic so many other conditions that patients are often told that their chronic headaches and muscle weakness are psychosomatic, or that the symptoms are all in their head (AANS, 2006). A majority of the patients in Milhorat’s study (1999) complained that their symptoms had been ascribed to psychogenic causes. Katlyn Webb, a young adult with Chiari and Syringomyelia, explains that,

Many of us with Chiari I Malformation and Syringomyelia experience the disbelief of others not familiar with CM/SM. I have had a lot of pain, but it doesn’t hurt me as much as the disbelief. It hurts to hear people say *but she looks so good, so how could she be in pain?* (Webb, 2007).

Many patients have symptoms for years before they are diagnosed with Chiari I

Malformation (Oro, 2003).

Red Flag Symptoms

The red flag symptoms are those which need immediate medical attention. Dr. Paolo Bolognese, associate director of the Chiari Institute in New York, reports on the Chiari Connection International website that the red flag symptoms are related to brainstem compression (1997). He reports these symptoms to be severe swallowing problems, tachyarrhythmia, severe nausea, and central sleep apnea (Bolognese, 1997).

Other symptoms

Nonspecific symptoms also occur with those who have Chiari I Malformation. Vocal cord disturbances, sleep apnea, and nasal congestion became increasingly apparent in an otherwise healthy thirteen year old male with CMI (Ruff, Oaks, Fisher, & Spock, 1987). In Milhorat's study, patients struggled with chronic fatigue, impaired recent memory, lower back pain, and episodes of nausea or vomiting (1999). Tinnitus, a sound in one ear or both ears, such as buzzing, ringing, or whistling may also occur (The American Heritage Stedman's Medical Dictionary, 2004). Effects of the Chiari Malformation on the respiratory and heart centers can cause shortness of breath, chest pain, episodes of rapid heart rate, black out spells, and hypertension (Oro, 2003). Drop attacks, collapsing to the ground due to muscle weakness, have also been reported (AANS, 2006). Abdominal symptoms may include nausea, abdominal pain, or vomiting (Oro, 2003).

Chiari-Related Disorders

Syringomyelia

Chiari I Malformation is the leading cause of syringomyelia (sir-RING-o-my-elia) because it is thought to be related to the interference of normal cerebrospinal fluid (CSF) pulsations caused by the cerebellar tissue obstructing flow at the foramen magnum (AANS, 2006). This condition arises when CSF forms a cavity or cyst within the spinal cord and as the fluid cavity expands, it can displace or injure the nerve fibers inside the spinal cord (AANS, 2006). Syringomyelia may also cause pain in the shoulder or weakness in the arms or trunk (AANS, 2001). Loss of sensation in an area served by several nerve roots is one typical symptom, as is the development of scoliosis (AANS, 2006).

Hydrocephalus

Hydrocephalus is an accumulation of serous fluid within the cranium due to obstruction of the moment of cerebrospinal fluid, often causing great enlargement of the head (Random house webster's college dictionary, 2001). Of all Chiari patients, fifteen to twenty percent will have hydrocephalus (Strayer, 2001). Shunting is done, usually alleviating most of the patient's symptoms (Strayer, 2001).

Tethered Cord Syndrome

Some individuals with Chiari also have a tethered spinal cord. Tethered spinal cord syndrome is a progressive disorder caused by tissue attachments, which cause an abnormal stretching of the spinal cord, and limit the movement of the spinal cord within the spinal column (NINDS, 2007). Those who suffer from progressive or severe pain,

loss of muscle function or deterioration in gait, or changes in bladder or bowel function usually require an operation for it (Walker, 2001). A tethered spinal cord appears to be the result of improper growth of the neural tube during fetal development (NINDS, 2007).

Treatment Options

Surgical Treatments

A review of literature reveals that primary treatment for symptomatic Chiari I Malformation is surgery. It is usually when the malformation becomes symptomatic or progresses, possibly resulting in syringomyelia that treatment is required (AANS, 2001). Some adults with Chiari may benefit from surgery to enlarge the opening in the back of the skull (National Organization for Rare Disorders, 2005). This is done by a procedure called a posterior fossa decompression (Oro, 2003). The objective of surgery is to stop the progression of symptoms by a decompression of the brain stem, cerebellum and spinal cord, as well as re-establishment of spinal fluid circulation (AANS, 2001). The surgery is performed by creating an incision at the back of the head into the upper part of the neck, spreading the muscles to either side, leaving the occipital bone and the back of the C1 vertebrae exposed (Oro, 2003). Decompression may be achieved by removing the occipital bone, opening the dura and inserting a graft, and removing the bone forming the back of the vertebra (AANS, 2001). This allows for decreased pressure on the cerebellum and normalization of cerebral spinal fluid (Strayer, 2001). The decompression provides more space for the brain stem, spinal cord, and descending cerebellar components (AANS, 2006).

Nonsurgical Treatments

An alternative to surgery is to follow the patient with repeated MRIs. The MRIs must be reviewed with careful attention to worsening symptomatology (Strayer, 2001).

Physical therapy or evaluation by a chronic pain specialist may be of help in some patients or medications such as analgesics, anti-inflammatories, sedatives, anticonvulsants, diuretics or steroids may be helpful to others (Oro, 2003).

Difficulty of a Diagnosis

Oro (2007) reports that the average duration between the onset of symptoms and a correct Chiari diagnosis is six years. He explains that this delay is attributable, in part, to the fact that little time is spent in medical school on Chiari. A definitive diagnosis may further be delayed because the clinical presentation of CMI consists of a broad range of variable and non-specific symptoms. Oro also comments that Chiari is often mischaracterized by radiologists as an “*incidental*” or non-consequential finding. Because the determination of whether or not a finding is “*incidental*” is a clinical decision, it should not be made by a radiologist who has not taken a complete clinical history and neurological examination of the patient (Oro, 2007).

Summary

Chiari is a neurological condition most commonly characterized by a volumetrically small posterior fossa that predisposes patients to hindbrain overcrowding (Milhorat, 1999). This overcrowding contributes to a variety of neurological symptoms such as physical pain and cognitive impairments. Treatment options for patients with Chiari include surgery, medication, pain management, and physical therapy.

CHAPTER III

METHODOLOGY

Introduction

This qualitative study followed a phenomenological research model that analyzes participants' narrative descriptions of their own perceived experiences given in response to a pre-formed written questionnaire (Willis, 2007). Because the purpose of this study was to examine, in detail, a wide range of non-specific medical symptoms associated with Chiari that may affect a student's classroom experience, the researcher chose this phenomenological model because it allows for a more complete understanding of the participants' actual experiences associated with these symptoms (Patton, 1990). The structured format of a written questionnaire was chosen because it allows for the comparability of data across sources and reduces the possibility of the questioner's bias contaminating the data (Maxwell, 1996). There was also a small amount of quantitative information collected from the demographics portion of the questionnaire. This chapter will discuss the participants, instrumentation, procedures, data collection, and data analysis of the study.

Participants

Target participants for this study were children in grades kindergarten through twelfth grade with a medical diagnosis of Chiari Malformation. For some younger participants, questionnaires were completed by their parents. Due to the rarity of the condition, a convenience sample was needed. The researcher selected Chiari Connection International (CCI) Website as a forum for soliciting responses to the written questionnaire. CCI is an

on-line support and information sharing group that is dedicated to providing support and information to those who are diagnosed with Chiari Malformation so that members can gain a more complete understanding of the various aspects of the condition, its related disorders, and available treatment options. As of December 8, 2007, 1004 persons are registered members of CCI. The researcher posted a written invitation on the CCI forum and invited CCI members to submit their responses to the researcher via e-mail.

Instrumentation

The pre-constructed written questionnaire included thirty open-ended questions. The open-ended format discouraged leading questions and thereby strengthens the validity of the study while allowing participants to reveal their own perspective (Maxwell, 1996). The questions were organized into six sub-sections. The questions in the first sub-section were targeted towards collecting background and demographic information while the remaining questions focused on the participants' experience, or lack of experience, with symptoms most commonly associated with Chiari Malformation as revealed in the literature review, thereby reinforcing its content validity. The questionnaire also permitted participants to reveal any additional Chiari-related symptoms or experiences that affect their educational experience. The questionnaire was approved by a panel of peers prior to distribution.

The demographic section asked participants to provide their gender, grade level in school, current GPA, and city. Participants were also asked to disclose certain information related to their diagnosis of Chiari and treatment procedures they had undertaken. Specifically, participants were asked to identify their age of diagnosis, any

surgical procedures that had been undertaken as treatment for Chiari, and whether they were currently receiving any accommodations at school.

The second section of the questionnaire consisted of six questions that focused on gathering information related to the physical pain, if any, that participants associated with Chiari Malformation. This section was chosen because the literature review identified that physical pain is a commonly associated symptom of Chiari Malformation and this pain can be triggered by several mechanisms associated with overcrowding of the posterior fossa leading to brain stem compression.

Since the literature review also revealed that brain stem compression from Chiari may cause speech issues, participants were asked three questions regarding their speech.

Lubuda (2006) reported that long-term intracranial pressure, which is common with Chiari, can have far reaching cognitive effects. Participants were therefore asked four questions regarding their ability to remain attentive or concentrate in a classroom setting.

The literature review further revealed that neurological and ocular disturbances associated with Chiari frequently lead to occipital headaches, dizziness, and vision issues.

The last section of the questionnaire, therefore, asked participants whether they experienced any of these symptoms. Finally, in order to identify appropriate modifications that can be made to help students with Chiari succeed in a classroom environment, participants were asked to identify any coping strategies that allow them to deal with symptoms at school and what, if anything, the school can do to further assist the student.

Procedures

Data Collection

The researcher posted a message on the CCI website, <http://www.chiariconnectioninternational.com>, stating the purpose of the study. Interested individuals were invited to respond to thirty open-ended questions that were posted on the researcher's website at http://209.7.110.8/~bgarrett/webfolder/07research_project.html. The webpage included the following introductory comment:

This questionnaire is part of an educational research project that is being conducted to determine the proper accommodations and modifications needed to help students with Chiari I Malformation succeed in an educational setting.

Participants' names will be kept confidential.

On the webpage, participants were instructed to copy and paste the questions into an email message to the researcher together with their responses to each question. Twenty-two completed questionnaires were received via email by the researcher.

Data Analysis

The answers to these questions provided rich data that is detailed and complete and allows for a full and revealing picture of the participants' experiences (Maxwell, 1996). Each section of the questionnaire complements a section in the literature review. Data is organized by question rather than by individual. The data will be compiled into categories that directly relate to the symptomatology of Chiari Malformation as identified by a

review of available literature. This allows the researcher to suggest appropriate modifications to meet the needs of students with this condition.

Summary

The purpose of this study is to examine, in detail, symptoms commonly associated with Chiari Malformation and to determine whether they have the potential to affect a student's educational experience. Participants were children in grades kindergarten through twelfth grade with a medical diagnosis of Chiari Malformation. A thirty open-ended questionnaire was given and responses were divided into categories based on symptoms revealed in the literature review.

CHAPTER IV DATA COLLECTION AND ANALYSIS

Participant Demographics

Maxwell states (1996) that the conclusions need to adequately represent the entire range of variation. The twenty-two subjects in this study were students diagnosed with Chiari I Malformation ranging in age from kindergarten to a high school graduate reflecting on her school experience. The mean, or average, grade level was 7.6. The median age was grade 7.5. The mode, or grade level appearing most often, was kindergarten, grade eleven, and grade twelve. Thirty-six percent of the respondents were male while sixty-four percent were female. These participants represent Canada and fifteen states: New Jersey, New York, Illinois, Ohio, South Carolina, Kentucky, Georgia, Indiana, Maine, Virginia, Maryland, North Carolina, California, Massachusetts, Missouri, and finally Canada. Chiari reaches beyond our state of Illinois and even beyond our nation. In fact, the Chiari Institute, the world's first comprehensive, multidisciplinary center for the management of patients suffering from Chiari, reports that their patients represent all 50 states as well as 19 foreign countries (The Chiari Institute, 2006). Subjects were selected by convenience sampling. Maxwell (1996) argues that there are situations in which convenience sampling is the only feasible way to proceed. For example, "In attempting to learn about a group that is difficult to gain access to or a category of people who are *relatively rare* in the population" (Maxwell, 1996). The National Institute of Rare Disorders reports that Chiari malformation is a *rare* malformation of the brain that is sometimes, but not always, apparent at birth. Within this convenient sample, however, participants were purposefully selected. The researcher

posted a message on the Chiari Connection International website stating the purpose of the study. Interested individuals were directed to the researcher's website where they were instructed to answer thirty open-ended questions regarding their condition.

Participation was strictly voluntary and anonymous as stated in the letter of consent, although many participants chose to give the researcher their email and or phone number to contact for further information. Younger participants were assisted by their parents.

Eight of the twenty-two participants have had no Chiari related surgeries. However, nine have undergone a decompression surgery, two have had a fusion surgery, three have had a tethered cord surgery, two have had a shunt surgically implanted, one has undergone a odontoidectomy, and one a craniotomy. As far as academics, 27% report an A average, 32% a B average, 23% a C average, and 0% obtained a D or F average. The age of diagnoses among this sample size ranges from age three to a senior in high school.

Questionnaire Results

Since the purpose of this study was to examine, in detail, a wide range of non-specific medical symptoms associated with Chiari and how those symptoms may affect them in the classroom, the twenty-two participants gave narrative descriptions of their own perceived experiences in response to a pre-formed written questionnaire. Participant responses were then divided by question and analyzed by categories: background information, attendance, physical pain, speech, attention, and other relevant information.

Background Information

Have you had any Chiari-related surgeries? If so, please explain.

Participant 1. "Decompression -- 4 times --- looking at a further decompression.

Fusion - 1 time at age 8 -- looking to finalize this fusion with rods as now she is at full growth. Tethered Cord -- July 2006. Shunt surgery with one revision.

Odontoidectomy"

Participant 2. "No, not as of right now"

Participant 3. "Yes, decompression surgery 2004"

Participant 4. "Chiari decompression surgery with a duraplasty"

Participant 5. "Yes decompression surgery 06/05/07 "

Participant 6. "Yes If so, please explain. Decompression surgery 2/15/07"

Participant 7. "Not yet " (*Participant 7 and 15 are siblings*)

Participant 8. "Spinal fusion for my scoliosis – possibly caused by Chiari."

Participant 9. "Decompression surgery (January 2007)"

Participant 10. "No"

Participant 11. "I had decompression with C-1 Laminectomy in September of 2005 which I greatly regret. It did not alleviate any of my symptoms."

Participant 12. "4 (2 craniectomies, one had failed; VP shunt placement, and cord detethering)"

Participant 13. "No"

Participant 14. "Yes, the Chiari Malformation Decompression in 2004"

Participant 15. "Not yet"

Participant 16. "Posterior fossa decompressed and tethered cord release."

Participant 17. "No"

Participant 18. "No"

Participants 19-22. "No for all." (*Participants 19-22 are siblings*)

Does your school have record of your condition?

Participant 1. "She has an IEP and all medical records are in the school files ---
however sometimes you feel they are not really read"

Participant 2. "Yes"

Participant 3. "Yes"

Participant 4. "Yes"

Participant 5. "Yes"

Participant 6. "Yes"

Participant 7. "No"

Participant 8. "Maybe written on some paper, but no one really ever looks at it."

Participant 9. "Yes"

Participant 10. "Yes"

Participant 11. "At the time I don't even think people really knew about ACM
[Chiari]. I rather think my record stated I was not working up to potential and/or
doesn't try."

Participant 12. "Yes"

Participant 13. "yes, homeschooled"

Participant 14. "Yes, but not much since I was at a different school during my surgery"

Participant 15. "Yes"

Participant 16. "Yes"

Participant 17. "No"

Participant 18. "Yes"

Participants 19-22. "Yes"

Do you currently receive any accommodations or modifications to help?

Participant 1. "She attends 1/2 day due to fatigue and pain. She has a one to one aide with her at all times to help her with the stairs and moving about through the school. The aide also helps by bringing her to the nurse for pain medication and to keep her on task."

Participant 2. "No"

Participant 3. "Yes, I have a 504 plan. I get more time on tests, I can get help with notes(if I need), my assignments can be broken down, they simplify sequenced directions, they read aloud to me, use multi-sensory instruction, they don't deduct points for handwriting errors, I get seated away from distractions, I am allowed oral responses, and I can have motor breaks to help muscle pain and focus."

Participant 4. "not anymore... right after surgery I was allowed to leave the classroom 5 minutes before class change to avoid bumping, an unlimited pass to go lie down whenever I needed it, and an elevator pass if stairs made me dizzy."

Participant 5. "They have her medication available if needed during school, her teachers know about her condition but have no accommodations for her, but to be fair one teacher offered to let her sit in his chair during class (additional head/neck support) and one teacher suggested requesting a specialized chair, like a recliner if necessary. The truth be told my 15 year old does not want any additional attention brought upon her."

Participant 6. "No"

Participant 7. "No"

Participant 8. "No"

Participant 9. "Receiving services for motor delays. The school knows all about Chiari and what to look/watch for "

Participant 10. "My child has restrictions on recess. There are a few pieces of playground equipment that would whip his head around too much. He is also encouraged and permitted to go to the nurses office to lay down or anytime he is not feeling well. (headache, numbness, fatigue)"

Participant 11. "I never did while I was in school."

Participant 12. "Preferential seating; adapted PE, extra time; healthcare plan"

Participant 13. "Yes, completes work when feeling well enough, often in recliner, naps when needs to, has book prop (to hold book up at eye level,) uses laptop computer on table so at best level for neck, also better than writing, starts school late in morning, because feels better with 10-12 hours sleep."

Participant 14. "I currently have an extra set of books in each classroom, but that is due to the bulging discs I have in my back. At the time of my surgery, I had a homebound tutor along with a math tutor, and I also went in for private tutoring with my teachers. I had basically no short term memory, so I was tested verbally immediately after I was relayed the information."

Participant 15. "Yes, has a 504 provision through the state of Georgia. It allows him to use a book prop, ruler to read, and sit in front of class. Also, no contact sports in PE."

Participant 16. "Yes, tutor, special cushion to sit on."

Participant 17. "No"

Participant 18. "Yes. No gymnastics and access to nurse as needed. Also have an extra set of books at home so I don't have to carry them back and forth. Also has option of preferential seating if needed."

Participants 19-22. "No"

Attendance

How many days of school, if any, have you missed due to Chiari-related symptoms?

Participant 1. "This varies year to year. She has already missed about 5 months in a school year due to hospitalizations -- surgeries. She has been on complete home instruction for a few years at a time due to her symptoms and multiple back to back surgeries."

Participant 2. "Last year my daughter missed approx. 28 days. This year, none related to her Chiari"

Participant 3. "I miss little bits of classes at a time, when I get headaches I go to the office for motrin, until I feel better. If I don't feel better I go home."

Participant 4. "last year I missed 1 month of school due to the surgery, and this year I've had to leave school sick due to Chiari pressure headaches."

Participant 5. "Last year she had about 5-10 for testing, and Dr. appointments. This year she has missed about 5, but will miss 3 next month to go to The Chiari Institute. Her surgery was during the summer so she did not miss any then, but would have missed at least 6 weeks. She missed many over the years for aches, pains, Dr. appointments with no results."

Participant 6. "10 days"

Participant 7. "Over 10 a year due to migraines, nausea."

Participant 8. "2-5 days a month for headaches."

Participant 9. "This school year 1 day. Last year in preschool about 3wks"

Participant 10. "First Quarter of this school year he missed 8 days."

Participant 11. "I missed quite a bit of school mostly due to head pain (I refuse to call it headache, there is a HUGE difference!), neck pain, and terrible fatigue. "

Participant 12. "3 months in first grade; 1.5 months 2nd grade; 3 days 3rd grade"

Participant 13. "2 of 8 weeks this year she has been unable to complete any work."

Participant 14. "I missed the entire second semester of my 8th grade year."

Participant 15. "Over 10 a year due to migraines, nausea"

Participant 16. "Last year – 42. This year – 24 so far."

Participant 17. "1"

Participant 18. "None"

Participants 19-22. "3-7 a month"

Physical Pain

Do you struggle with physical pain throughout the day?

Participant 1. "Yes, sometimes my legs feel very tight, my head hurts, arms/hands, back, neck. The problem for she is that the pain fluctuates and the nurse can't seem to understand just how the position of pain can change throughout the day or day to day."

Participant 2. "Headaches, and stomach aches."

Participant 3. "Neck, arm and knee pain."

Participant 4. "My neck gets sore very easily, especially when looking down to take a test or read extendedly. I also get random pressure headaches during school."

Participant 5. "Her back and neck almost always hurt, about 7-8 on a pain scale to from 1-10. She had terrible leg pains and stomach pains several years ago. She occasionally gets dizzy."

Participant 6. "Yes. Back pain, foot pain, headaches, pain in hands"

Participant 7. "Yes, all the above, head and neck causing migraine by end of school day."

Participant 8. "Headaches in the base of the skull – also hear really high frequency which also causes headaches."

Participant 9. "As of right now no"

Participant 10. "His arm drops when he is requested to write on the board at school. He cannot keep it up for long periods of time. He gets dizzy at school."

Participant 11. "I did and still do have 24/7, 365 head pain (now I am on a fairly strong pain medication and under the care of a pain management Dr. it does not kill all the pain but does give me some quality of life), neck pain, mind numbing fatigue (those are the two worst), I get very dizzy-vertigo, if I look up or side to side too far I go out like a dead light bulb, the tops of both feet are numb, confusion/brain fog, irregular heartbeat, difficulty breathing, difficulty swallowing, insomnia, visual disturbances, a feeling of being "disconnected" (I can see the people/things around me but I feel like a spectator at times, like no one else can see me or if I reached out to touch anything I would not be able to), the list goes on."

Participant 12. "Before cord surgery in 2006, pain in head, neck, legs left arm, dizzy, reflux/vomiting; had to wear a neck brace to school; very fatigued; apnea and heart arrhythmias"

Participant 13. "disabling headaches sometimes, daily lower level headaches, neck and shoulder pain....."

Participant 14. "I have been pain free for the past three years"

Participant 15. "Yes, all the above, but head and neck causing migraine by end of school day"

Participant 16. "Yes- headache, backache, dizziness, tingling in feet and arms"

Participant 17. "Yes, My hands are frequently tingly, and I have a lot of headaches near the back of my head. In addition to headaches, I also have neck pain and unsteady gait/balance so sometimes the halls are a little treacherous."

Participant 18. "Constant minor neck pain which is always there."

Participants 19-22. "Yes. Almost daily headaches, occasional dizziness, as well as periods of back, neck, arm, hand, leg and foot pain."

If you answered yes to number 10, do you feel this physical pain affects your ability to function in a classroom setting? Please explain.

Participant 1. "Oh yes, I can't get comfortable and sometimes the pain is so bad that all I can think about is the pain."

Participant 2. "She has problems in gym class."

Participant 3. "Yes, because I feel like I need to move around to stop the pain."

Participant 4. "just sometimes... if the headache is bad enough, I can't concentrate on anything else, and that's when I know I need to go home/nurses office. "

Participant 5. "Yes, it makes it hard to work."

Participant 6. "No"

Participant 7. "Sometimes I miss a lot of class because I'm in the nurses office, gets sick to stomach a lot"

Participant 8. "Yes, for sure. It's very hard to concentrate on anything when you have a horrible headache. All I do when I'm in pain is try not to cry – good luck actually trying to soak up learning material."

Participant 9. no response

Participant 10. "I feel that in my son's case he is able to get through the day and learn what he needs but I also do not send him to school when he is feeling bad and I know he is going to have a bad day."

Participant 11. "When I was in school I had a really hard time sitting for long periods of time. The pain in my head would get so bad at times that I had difficulty seeing the board. "

Participant 12. "Very hard to think when in severe pain; also pain killers make it difficult to concentrate"

Participant 13. "absolutely."

Participant 14. "N/A"

Participant 15. "Sometimes I miss a lot of class because I'm in the nurses office, gets sick to stomach a lot"

Participant 16. "YES – it hurts to sit in the seats all day and then I can't concentrate"

Participant 17. "Sometimes I think it does just because it distracts me from things that I want to accomplish during the day."

Participant 18. "No. used to it."

Participants 19-22. "Yes. It is hard to concentrate and stay on task when in pain."

If you answered yes to number 10, what do you find helps you make it through the day?

Participant 1. "Going to the nurse to get pain medication and being allowed to rest because I am so tired."

Participant 2. "She just tells me that her gym teacher"thinks she's faking""

Participant 3. "I get up and walk or stand up and I will feel better"

Participant 4. "Nothing really. Sometimes extra strength Tylenol works, but usually I need to lie down in a dark room without moving to feel better. I don't know why."

Participant 5. "Going home or to 3rd block (Geography) "I love that class". (note: she rests a lot at home)"

Participant 6. no response

Participant 7. "Whatever it takes."

Participant 8. "Time – sometimes it feels like I won't make it through the day – But the clock keeps ticking. Leaving and going home to go to sleep is the only way to get out of a headache for me."

Participant 9. no response

Participant 10. "I keep him home when he is feeling bad and the teachers are very aware of Chiari thanks to information that I provide through ConquerChiari.org. They keep an eye on him and his symptoms and they head off the problem by anticipation any activities that would create issues before they happen and we talk about them ahead of time such as watching a movie in the dark (head ache)etc. "

Participant 11. "Knowing that if I didn't, I had to face my mother when I got home."

Participant 12. "Mom coming early to get me; neck brace, being with friends, medicine for headache/nausea"

Participant 13. "a good nap, sitting in recliner, codeine"

Participant 14. "N/A"

Participant 15. "Whatever it takes."

Participant 16. "Sometimes go to nurse to lay down or I just have to go home. "

Participant 17. "If I focus more on what I want to accomplish rather than my illness, things are a lot better. I also try not to think of Chiari as an illness but as a gift, because it reminds me to be grateful for what I have."

Participant 18. no response

Participants 19-22. "Pain medication, distractions and frequent breaks."

Is there anything that the school/teachers could do to help minimize or understand this physical pain?

Participant 1. "Believing me when I say I have pain. I don't have pain the same time every day so it must be real pain. She could allow me to rest a little longer. She put a goal on my sheet that says I have to focus on class and it is so hard because of my pain and feeling so tired."

Participant 2. "It would help if they sent her to the nurse to lay down or call me."

Participant 3. "Let me get up without getting in trouble. One year I had a teacher who thought I was faking not feeling well."

Participant 4. "I think it would be really nice if they would let me prop my test up on something to avoid looking straight down."

Participant 5. " I don't know, people don't understand unless they have it"

Participant 6. "Stretching after sitting for a while"

Participant 7. "Just have the parents tell them that if they think the student is abusing going to the office because of pain to call parent, let parent make that decision."

Participant 8. "They act like attendance is more important than personal health. Some lenience would be nice. Some teachers make you lose marks for leaving early – it's not fair because it's beyond our control."

Participant 9. no response

Participant 10. "In my situation providing information and educating the school about Chiari gives the teachers an idea as to what to look out for and be aware of. I think the more knowledge the teacher has the better the child is taken care of at school. I had a meeting with the principal, the teachers and the nurses at the beginning of the school year and I brought tons of information along with a written plan of how I wanted things handled. This has proven to be very successful for me."

Participant 11. "To be honest I don't think there is a lot they could have done other than be understanding and believing what I told them. They often said I was "faking", lazy, or just being a problem student."

Participant 12. "BELIEVE ME; use a face scale to rate pain; have a plan if I need to lie down in the clinic"

Participant 13. "view ConquerChiari website will help to understand Chiari. Change attendance requirement so course credit is earned if course material is mastered, even if child is unable to attend class."

Participant 14. "At the time of my surgery/immediately before my surgery, I was in great pain. My teachers didn't seem to understand this, especially my Social Studies teacher. They could have been more compassionate, allowing me to rest my head

during the day, or even turn in assignments late, as I was basically unable to concentrate due to my headaches."

Participant 15. "Just have the parents tell them that if they think the student is abusing going to the office because of pain to call parent, let parent make that decision."

Participant 16. "Give me breaks without the whole class noticing. "

Participant 17. "I just think that if teachers (and general public) were more aware, then they would understand better."

Participant 18. "No"

Participants 19-22. "Yes. Make sure the student is placed so that their neck is at a comfortable position to see and/or work. Be sure a comfortable posture support chair is provided. Give the student frequent breaks to move and change position. With parents help learn to recognize symptoms and behavior of the student when in pain and set up first step coping strategies to implement during periods of pain. These could include suggesting and/or allowing the student to move their chair/position as needed, get water, or move around the room. Distraction tactics work well. Send the student on an errand or give them a project that can hold their interest and keep them busy. If the student is still in pain, validate their pain and proceed to second step measures such as administering medication if authorized or sending the student to the nurse."

Does this pain affect your performance in physical education class?

Participant 1. "She does not participate in physical education. However, the school district does provide finances for her to attend a physical therapy center in town to do

conditioning exercises. She also participates in a special needs t-ball team."

Participant 2. "Yes"

Participant 3. "Yes"

Participant 4. "not in gym anymore, fulfilled credits before onset of symptoms"

Participant 5. "yes, but I already disliked that class. (Maybe she dislikes it is because it causes her pain.)"

Participant 6. "Yes, sometimes the physical activity triggers the pain"

Participant 7. "You can't do basketball, dodge ball, volleyball, football, etc. [You] can't get hit in or knocked in head or neck."

Participant 8. "I gave up on physical education a long time ago. I don't have enough energy. I used to be very active."

Participant 9. "No problems in PE"

Participant 10. "My son is only in Kindergarten so he does not do PE but he will have restrictions next year when he is required to take PE. He cannot participate in contact sports and his neck needs to be protected."

Participant 11. "Recalling gym is horrible. I would dread that class so badly I would throw up. Because of my poor balance things like cartwheels, tumbling, the rings, uneven bars, basically anything involving balance or being upside down was virtually impossible. Little did the teachers know that when they forced me to do anything involving being upside down, everything went black-I was passing out!! They loved to single me out and accuse me (again) of being lazy. As a young child it would go far enough that I would start crying. Another problem was running and things like

jumping jacks. Running would cause my breathing difficulties to get really bad or start the irregular heartbeat and both that and jumping jacks made my head throb, I guess from the pounding. The only real thing I did really well in was swimming which I did in HS, I loved it and still do. "

Participant 12. "Definitely"

Participant 13. "My daughter is unable to participate in any physical activity except warm water physical therapy."

Participant 14. "I now can't do most PE activities because of my bulging discs. My Freshman year was the worst. My teacher knew I couldn't participate in most of what was graded on the exams, such as running or push-ups, etc., but nevertheless, my grade suffered for this."

Participant 15. "You can't do basketball, dodge ball, volleyball, football, etc. [You] can't get hit in or knocked in head or neck."

Participant 16. "Yes – lots of times, I can't participate in the sport due to the decompression or back pain and my hamstrings are so tight, I can't do a lot of physical activity. "

Participant 17. "I wasn't diagnosed at the time I was required to take P.E."

Participant 18. "No"

Participants 19-22. "Yes."

Are there any sports/activities that cause pain for you while in physical education class?

Please explain.

Participant 1. "She does have pain while she is on the t-ball team but uses her well chair during those periods -- if the pain is severe she stops playing for a little while."

Participant 2. "She has trouble running for long periods of time."

Participant 3. "Lifting arms above head(basketball), and some sore joints, and overheating"

Participant 4. "n/a"

Participant 5. "almost everything (they are on a block system so she will not have P.E. this year until the second semester)"

Participant 6. "Running makes hands and feet hurt. Hands hurt because of clinching my fists tightly, I am afraid I will fall."

Participant 7. "Yes, see above."

Participant 8. "Singing starts my headaches and I love to sing."

Participant 9. "No"

Participant 10. no response

Participant 11. "I guess I answered this in last question."

Participant 12. "Basketball, soccer, running and stretching exercises"

Participant 13. Every activity, any activity involving impact (ie running, soccer...often even looking down or up can be a problem. Crunches, other things that effect neck."

Participant 14. "I can't run because the repetitive motion kills my back, and sometimes hurts my head. Also, the sit and reach was miserable (my discs crunching together was audible), basically everything we did. Especially contact sports."

Participant 15. "Yes, see above."

Participant 16. "Running, stretching, climbing"

Participant 17. "N/A"

Participant 18. "No I don't do gymnastics."

Participants 19-22. "Yes. Experiences leg and foot pain after being on feet for 10-15 minutes. Bending torso causes back pain. Bending neck too much will cause neck pain. Jumping causes headaches or headaches to worsen."

Speech

Do you have any difficulties with your speech? (I.e. finishing your sentences, pronouncing words, getting your thoughts from your brain to your mouth, etc.) If so, please explain.

Participant 1. "Yes, sometimes I can't think of words or I use the wrong words."

Participant 2. "No"

Participant 3. "Yes"

Participant 4. "nope"

Participant 5. "kind of, sometimes I can't say what I'm thinking"

Participant 6. "Yes. I feel like I forget what I want to say."

Participant 7. "Not so much yet."

Participant 8. "All the time, but I always thought it was normal"

Participant 9. "Yes, speech delays but not significant enough to require services.

Sometimes calls Dad Mom, Mom Dad etc. Up until this year received speech therapy since 18mths old."

Participant 10. "My son does not have speech problems but he has swallowing problems that have to be monitored when he is eating or drinking."

Participant 11. "I suppose some of the problems may have come from memory issues, they are bad. But, often I transpose words, can't think of simple words, know what I want to say but for the life of me can not get it out right. I did love reading and still do. That is one subject I did very well in. It is something I can do at my own pace, go back and reread if I get lost (I often do) etc. Again, many teachers loved to give me a hard time about how I spoke."

Participant 12. "Yes; word retrieval, articulation problems, intermittent dyslexia-- seems to be related to pressure changes in brain"

Participant 13. "Word finding problems, sometimes has "brain fog" in general, ie can't think through things that would normally be easier."

Participant 14. "I have problems thinking of words. I know what I want to say, but I have a hard time remembering the word. Sometimes it takes me a few minutes to remember what I was thinking of."

Participant 15. "Not so much yet."

Participant 16. "If so, please explain. Just when I take my pain meds."

Participant 17. "Sometimes it is hard for me to finish thoughts or get out what I'm trying to say, but usually it's only for a split second."

Participant 18. "No"

Participants 19-22. "Yes. Speech is difficult at times but not consistently so. Trouble getting thoughts into words is becoming more frequent and more difficult. Possesses slow speech recognition."

If you answered yes to number 16, what do you find helps you?

Participant 1. "stopping a moment to think about it or asking the teacher for a suggestion for the word."

Participant 2. no response

Participant 3. "Sometimes I get my words mixed up"

Participant 4. "n/a"

Participant 5. "concentrating"

Participant 6. "Less noise"

Participant 7. no response

Participant 8. "Slowing down my speech and thought, drawing diagrams to explain things is much easier than using words. English is the only subject I ever failed."

Participant 9. "working with therapists"

Participant 10. no response

Participant 11. "Sheer stubbornness got me through many things. The problems teachers gave me made me so angry or upset that I would do something until I got it right no matter what. To this day I am the same way. One of my not so good traits is if I can't do something right, I won't do it at all. "

Participant 12. "Have to wait it out"

Participant 13. "Often being put on the spot makes it worse. So I would suggest that these children not be called on, as long as they participate when they are able.

Extended response time might help some kids. Being teased makes it much worse."

Participant 14. "I have to continually think of what I want to say until I can say it. If I don't, I will forget it. My memory is still horrible."

Participant 15. no response

Participant 16. no response

Participant 17. "If I slow down and think it through, that helps a lot."

Participant 18. no response

Participants 19-22. "Low stress situations. Time to think and process."

Is there anything that your school/teachers could do to help you with your speech?

Participant 1. "she already does sometimes and sometimes she just tells me to focus"

Participant 2. " no response"

Participant 3. "No"

Participant 4. "n/a"

Participant 5. "probably not"

Participant 6. "Less distributions/noise when I am talking"

Participant 7. no response

Participant 8. "Try, no one ever tried. They just say you're behind on your English so do more homework."

Participant 9. no response

Participant 10. no response

Participant 11. "Patience....patience....patience!"

Participant 12. "Extra time, know that if I suddenly have a deterioration in performance, give me extra credit chances when I am feeling better, neuropsych eval was helpful"

Participant 13. "Not that we've found."

Participant 14. "There isn't really anything they could do now."

Participant 15. no response

Participant 16. "No"

Participant 17. "Not really since it isn't very frequent."

Participant 18. no response

Participants 19-22. "Yes. Recognize that it takes longer to put thoughts into words verbally and on paper. Give the student the time necessary to form speech and make it as least stressful as possible. If it is appropriate and without being too obvious help the student find the word/s they are trying to use. Give the student encouragement and acceptance. If the student is finding it too difficult and becoming frustrated diffuse the situation with little notice."

Attention

Do you have difficulty focusing or maintaining your attention in class? Please explain.

Participant 1. "yes"

Participant 2. "No"

Participant 3. "Yes, I lose focus very easily...my mind wanders."

Participant 4. "yes, when I don't feel right because of symptoms I can't focus on what is going on in the classroom at all."

Participant 5. "yes, sometimes my head hurts so bad I just can't concentrate"

Participant 6. "Yes. I need less noise to hear and focus."

Participant 7. "YES , has ADD."

Participant 8. Yes, people always ask me if I have ADD. I've never been tested for it so who knows."

Participant 9. "No"

Participant 10. "This is not a problem for my son but the doctors have him on 150 mg of B6 and I think that helps with attention"

Participant 11. "I do know fatigue played a role in difficulties focusing. I would sometimes be so tired that I would sit there in a daze. Nothing being said to me made a bit of sense, and often nothing I said back made any more sense. Probably today they would have said I had ADHD and stuck me on drugs, who knows the speed that they give kids today may have kept me awake lol. "

Participant 12. "Especially when have a headache and before cord surgery; now not a problem"

Participant 13. "YES- some days are worse than others. When she has a bad headache it is much harder to focus."

Participant 14. "I do sometimes, but I don't think it's necessarily Chiari related."

Participant 15. "Yes, has ADD"

Participant 16. "Yes – the pain takes over so I don't hear the teacher"

Participant 17. "Not more than the average senior with senioritis. No."

Participant 18. "No"

Participants 19-22. "Yes. Maintaining focus and staying on task is becoming more difficult. At times focus jumps and at others staring episodes become prevalent. Distractions make focusing more difficult."

If yes, how frequently do you have difficulty focusing or maintaining your attention in class?

Participant 1. "all the time."

Participant 2. no response

Participant 3. "A lot everyday"

Participant 4. "probably about 4 or 5 times a month"

Participant 5. "a lot"

Participant 6. "9 or 10 times a day"

Participant 7. "Daily"

Participant 8. "It's like my mind thinks too fast for what's going on around me so I lose my attention with what's going on sometimes within the first two minutes class. This also made doing homework nearly impossible."

Participant 9. no response

Participant 10. no response

Participant 11. "Often times it depended (still does) on many different factors.

Weather plays a huge role in how I feel at any given time. I am a human barometer, bad weather=bad days. It also depended on whether or not I was able to get any sleep

the night before. It's strange, I used to through what now a days they would call remission I think. Sadly, I have not had one several years. I might go for days, weeks, and rarely months of feeling "ok". But, I also went through days, weeks, months, even years of feeling bad. But I would have to say difficulty focusing or paying attention was pretty much a daily issue at some point during the day."

Participant 12. no response

Participant 13. "Daily"

Participant 14. "At least a few times in class. I have to force myself to pay attention."

Participant 15. " Daily "

Participant 16. "Almost daily"

Participant 17. "N/A"

Participant 18. no response

Participants 19-22. "Always."

If you answered yes to number 12, what do you find helps you focus and maintain your attention?

Participant 1. "getting my pain medications, taking a rest, taking a walk"

Participant 2. " no response"

Participant 3. "Asking a lot of questions"

Participant 4. "nothing "

Participant 5. "to relax and then try to pay attention"

Participant 6. "Less noise"

Participant 7. "Vyvanse medicine"

Participant 8. "MP3 player – partners helping with the work.

Participant 9. no response

Participant 10. no response

Participant 11. "Nothing."

Participant 12. no response

Participant 13. "Gentle walk in cool air, caffeine."

Participant 14. "I have to think about what my teachers are saying and repeat it in my head. Then I am actively participating in the lecture."

Participant 15. Vyvanse medicine

Participant 16. "Not much at this point. "

Participant 17. "N/A"

Participant 18. no response

Participants 19-22. "ADD medication as well as few or no distractions. A comfortable position and pain control is very important."

Is there anything that your school/teachers could do to help you focus and maintain your attention?

Participant 1. "allow me to take a rest and sometimes she could talk a little faster.

When I am tired and she is slower I fall asleep."

Participant 2. no response

Participant 3. "Have more one on one instruction"

Participant 4. "nope"

Participant 5. "I don't know"

Participant 6. no response

Participant 7. "No"

Participant 8. Not that I can think of...."

Participant 9. no response

Participant 10. "no response "

Participant 11. "In all honesty I can't think of anything. When you're fatigued to the point of feeling numb....you're numb and nothing can really change that. Again, I think it is all about patience."

Participant 12. no response

Participant 13. "Provide lecture notes ahead of class, so if space out, will still have material."

Participant 14. "Make classes more interactive."

Participant 15. "No"

Participant 16. "Not sure = find a cure J"

Participant 17. "N/A"

Participant 18. no response

Participants 19-22. "Keep distractions to a minimum, provide a comfortable position, and recognize when the student is having difficulty so that if changes to improve the situation can be made they are implemented."

Other relevant information

Are there any other symptoms that you experience throughout the day? How do you handle these symptoms? Is there something that the school could do to help you with these symptoms?

Participant 1. "the bus ride doesn't help my pain."

Participant 2. " no response"

Participant 3. "Sometimes my neck feels like it can't hold up my head anymore. My teachers got me a slant board and it helps me a lot."

Participant 4. "not really"

Participant 5. "I get really tired. I open my eyes really wide. Make school a little less boring"

Participant 6. "Nausea, very cold, hard time getting comfortable in chairs and at nap time. Sometimes words on the paper move around (words look like they are moving in circles) . . . Move around a lot, try to forget the pain and being cold . . . More stretching, yoga and allow me to wear several layers of clothes"

Participant 7. no response

Participant 8. "My main problem is headaches and fatigue. It would help if they didn't give you guilt trips and detentions."

Participant 9. " Sometimes I have headaches, trouble walking, going down stairs.....but not on a daily/weekly basis. Just wants to lay down when having symptoms."

Participant 10. "My son has to urinate frequently due to brain stem compression, it is important to know that he needs to be allowed to use the restroom several times a day."

Participant 11. "Symptoms can vary so widely it is a hard question to answer. I might go or have gone while in school for days without one symptom but a different one is there. Or I might have multiple symptoms. The two I had on a regular basis were the head pain and fatigue (still do). But like I said, if a teacher made me run or do jumping jacks etc, it might make the pain in head worse. I don't think there is any way for teachers to help symptoms already there, but they can certainly prevent some by being aware. If a child says I can't run its hurts.....then it hurts! I think adults tend to dismiss what children say, they assume they are a kid. ...lots of energy, nice young healthy body. That is not always the case though. "

Participant 12. "adaptations as mentioned above"

Participant 13. "Urgency to urinate can be a problem, so allowing child to use bathroom when necessary. Extreme fatigue can set in, so allowing child to take a nap might help. Or, allowing the child to participate 1/2 day."

Participant 14. "There isn't anything now. At the time, while it sounds menial, the other students kind of criticized my pain. Many were very confused about what happened to me. I think that if the teachers would have taken some time to explain to the students what happened and why I was absent, a lot of questions and strange statements could have been avoided."

Participant 15. no response

Participant 16. "Severe backache. Probably give me a much better seat. "

Participant 17. "Tingly hands, I just try to ignore it, heachaches and neck pain, I try to ignore that as well. Not that I'm trying to ignore my illness but when it happens so frequently eventually you get used to having symptoms."

Participant 18. "No"

Participants 19-22. "Other symptoms include nausea, ringing in ears, fatigue (due to central sleep apnea), irritability, dizziness, poor hand coordination, vision disturbances, sensitivity to light and noise, and clinical depression. Personal handling of these symptoms; Nausea – Avoid big meals, small frequent snacks, and rest; Ringing in ears – Try to ignore and keep noise to a minimum; Fatigue – Oxygen at night for CSA, strict sleep schedule, naps as needed, and exercise; Irritability – A strict diet avoiding dyes, preservatives and processed foods, quiet time, and rest; Dizziness, get up and down slowly, and hold on to furniture and walls for support; Poor hand coordination – Using a voice recorder instead of note taking; Typing papers rather than writing them by hand; Vision disturbances – Depending on the severity, resting head or lying down; Sensitivity to light and noise – Avoid bright light and loud noise; Clinical depression – Medication and counseling; Ways school could help with these symptoms; Nausea – Allow student frequent opportunities for snacks; Ringing in ears – Keep classroom noise to a minimum; Fatigue – Recognize and allow student frequent breaks or a lie-down/rest period when possible; Irritability – Recognize and reduce stressors if possible. Allow for breaks and quiet time; Dizziness – Be aware situation and try to reduce occurrence of possible injury; Poor hand coordination,

Allow use of a voice recorder instead of taking notes by hand; Allow student to type papers rather than write them by hand; Vision disturbances – Allow student to rest head or lie down; Sensitivity to light and noise – Minimize bright light and loud noise in classroom; Clinical depression – Be aware of condition and notify parents of concerning behavior."

Do your Chiari symptoms impact your grades? If so, how?

Participant 1. no response

Participant 2. "Not as of right now."

Participant 3. "This year I have done a lot better than last year, but my mom and dad found out I have dyslexia and have me tutored for it. Tutoring has helped me a lot."

Participant 4. "I don't think so."

Participant 5. "yes, they make it hard to study"

Participant 6. "Noise would not bother me so much, would not be afraid of falling, could complete my sentences and thoughts, would not have to move so much to try to get comfortable "

Participant 7. "Yes, because I miss a lot of class time."

Participant 8. "Yes it made me generally fatigue which lowers your will to do anything."

Participant 9. no response

Participant 10. no response

Participant 11. "Big time Yes! After a long day of school all I wanted to do was go home and sleep but I often had hours of homework ahead of me. It is next to

impossible to do a good job on homework if you are constantly falling asleep while doing it. Also, what might be an hours homework to some students could be 3 hours for me. Or studying for a test, I might have studied as hard as I could and know the information inside and out...come test time, it might be gone! Completely and utterly gone. Even if it is information that is normal and everyday to most people, it might take me forever to retrieve that information from my memory. If I have to spend 15 minutes remembering one thing and only have an hour for a test....does not work out too well. That leaves time for 4 questions. Often my way of handling this was to run through and do any questions that I could answer right off. Then, I would go back and think on the ones that were missing from my memory. If I had been graded on the information I was able to retrieve at any given time, or given the amount of time I needed to complete something.....I would have been and A student rather than a C. "

Participant 12. "yes, grades aren't as good if I am in a flare or in pain"

Participant 13. "Even at home she has trouble completing all her work, and focusing on it well enough to learn all she could. She has a gifted IQ, but can't handle all the work."

Participant 14. "Before my surgery when I was in constant pain, my grades weren't low, but I made A's and B's. I could definitely tell a difference after my surgery and my symptoms went away. I now make straight A's. It's so much easier to do my work without being plagued with headaches."

Participant 15. "Yes, because I miss a lot of class time."

Participant 16. "Yes, I am missing so much school – I used to get all A's"

Participant 17. "I think that sometimes it does, because especially since I am a new Chiarian, there has been a lot of worry as far as how we are going to treat the symptoms which caused me to be less attentive to school work."

Participant 18. "No"

Participants 19-22. "Yes. It is hard to study and retain information when not feeling well or unable to maintain focus. It is difficult to keep up on a daily basis due to the impact of symptoms. Missing school due to symptoms and/or medical appointments compounds the difficulty."

What would you like your teachers/school nurses, principals, to know about your condition?

Participant 1. "That the pain level changes, that it is hard for me to focus a lot of times, I get dizzy, I need a rest a lot of times"

Participant 2. "As her Mother, I wish they researched this condition more. I feel that because it is not a well known illness they don't take me seriously. "

Participant 3. "That I don't fake not feeling good. And sometimes doing school work does give me headaches, and I don't feel good a lot of the time."

Participant 4. "nothing more than they already know, I guess, which is that it's a brain malformation that requires many doctors appointments, precautions, and sometimes I need to be able to go home without going through an hour long "checking out" process."

Participant 5. "That I am not anywhere near normal with this and things are really hard for me."

Participant 6. "Sometimes I just have bad days and I don't feel good. I may not be able to do everything everyone else can do. I am very smart even though I have a brain condition."

Participant 7. "What it is, it's not contagious, and it's a disease that is growing number wise fast, have patience."

Participant 8. "That it is beyond our control and we can only do what we can do. We're already in pain, there's no need to make us feel even worse about it."

Participant 9. "Everything"

Participant 10. "Every day is different. Pain can change rapidly."

Participant 11. "That these students are not "faking" or trying to get attention or lazy. Pain is pain whether you are 10 or 40 and it hurts. Fatigue is fatigue 10 or 40. Mostly be aware, be patient, and be kind. Understanding what these students are going through I am sure is not easy for "normal" people. I hate to use that word because I am not "abnormal", I am just not like someone without ACM. But I will be honest, sometimes I feel abnormal and as a child I felt that way often. I would wonder why my friends or fellow students were able to do all these things I wanted to do so badly. I really thought I was broken, defective, or just stupid. When teachers or anyone said I was lazy, I believed them. I think people live up to what they are told. If someone constantly tells a child your lazy, your slow, you're a hypochondriac etc etc, they begin to believe this and will live up those standards that are placed on them. Also, be aware of how other students are treating these kids. The other children who can run and jump and have unlimited energy have no idea what someone goes through that

cannot do these things. It is emotionally painful to feel left out or ostracized by your peers, and strangely enough it can make symptoms worse when someone is dealing with outside difficulties. "

Participant 12. "Understand how serious it is, that no two people have the same symptoms; that I may look okay, but I feel terrible"

Participant 13. "That it is a real condition, even though it is invisible, and causes real symptoms. She tries her best, but is very limited because of this condition."

Participant 14. "Mainly that it's not a "disease." Chiari patients are normal people who deserve every available activity so we can be equal with the other students."

Participant 15. "What it is, it's not contagious, and it's a disease that is growing number wise fast, have patience."

Participant 16. "The pain is real!"

Participant 17. "I think I would want them to know that this illness does exist, it isn't something that is just made up even though you can't see it outwardly(it's the brain LOL)."

Participant 18. "just be aware of it, which they are"

Participants 19-22. "What the condition is and how it impacts student's ability to function."

What academic activities do you find difficult?

Participant 1. "math and science"

Participant 2. no response

Participant 3. "Reading, writing"

Participant 4. "nothing related to the Chiari lol"

Participant 5. "Math and Physical Science"

Participant 6. "Writing numbers, reading and short term recall"

Participant 7. "reading, literature"

Participant 8. "English (Yes it is my first language)"

Participant 9. no response

Participant 10. no response

Participant 11. "I had always dreamed of joining extra curricular activities. I wanted to join cheerleading, drama, sports..anything, heck everything! But how do you remain after school to do these things when at the end of the day there is just no more left in you. It is so like the spoon theory that was written about. If you have not read it...you should. I have never seen a better way of describing how someone feels when he or she has health issues that are not obvious. It is hard to make others understand that you can't do what they can even though I look "fine". Getting through the day took everything I had and then some. Still does. I used to feel so guilty I would force myself to the point of being hospitalized because I wanted to do for my children all things other parents did for theirs. I ran them to sports, I helped with girl/boy scouts, I made cookies or volunteered and in the end I would use up not only the resources I had for that day but the ones available for the next month. In the end...all academic activities are difficult because they cost something and that cost has to be paid. Where most people have unlimited ability to do what they want, people who are dealing with some form of disability have to pick and chose what they can or cannot do. As a child I

would have to decide...ok my friends want me to go out and play but I have a test tomorrow, I can't do both. Which do I chose? I knew what I wanted to do, but in the end I knew what I HAD to do."

Participant 12. "Sitting for long times (hurts back and neck)"

Participant 13. no response

Participant 14. "Personally, English is my most difficult subject. It's so hard for my to write my essays when I have a hard time with word recollection and such."

Participant 15. "reading, literature"

Participant 16. "Sitting in class non-stop."

Participant 17. "I don't really find academics difficult unless my symptoms become severe and thankfully that has only happened once."

Participant 18. "none"

Participants 19-22. "Reading, writing, concentrating, organization, retaining information, speeches and discussions. "

Do you have a preferred seat/location in the classroom? Why? (front of the room, back of the room, etc.)

Participant 1. "Right now I sit in the back but I like the front"

Participant 2. "No"

Participant 3. "Yes, away from distractions"

Participant 4. "doesn't make a difference!"

Participant 5. "front – middle. It makes it easier to stay focused"

Participant 6. "Front, less distractions because everyone would be behind me and I can't see what they are doing"

Participant 7. "Front of room, can't see from back."

Participant 8. "The front because there is less distractions and you get closer to the teacher."

Participant 9. "Yes because of vision issues"

Participant 10. no response

Participant 11. "I do kind of have to laugh. My preferred seat was in the back so I could nap undetected. But I am sure this is not what you want to hear as a teacher."

Participant 12. "Front of room but not too close where neck is hyperextended."

Participant 13. no response

Participant 14. "I like to sit in the front of the room. It's much easier for me to concentrate."

Participant 15. "Front of room, can't see from back."

Participant 16. "No"

Participant 17. "No."

Participant 18. "no"

Participants 19-22. "A comfortable neck position is most important. Visual comfort is at about 6-12 feet. Adequate personal space is an important factor as it tends to influence the amount of distractions."

Does Chiari affect your vision? Please explain.

Participant 1. "Yes, sometimes it is blurry and tired"

Participant 2. "No"

Participant 3. "No"

Participant 4. "not yet"

Participant 5. "yes, sometimes it is really blurry."

Participant 6. "I think. I wear glasses and sometimes words move on a page."

Participant 7. "YES "

Participant 8. "I have amazing vision."

Participant 9. "Wear glasses. Have a vision score of 20/80 in left eye, 20/30 in right eye"

Participant 10. "When you have a bad headache vision can be disturbed but then again I do not send my child to school when he is like this."

Participant 11. "Sometimes yes. Tested by a Dr. my vision, as a kid was 20/15, very good. But, sometimes I would see double, or have other visual disturbances that as a kid I did not understand. Also, fatigue tended to blur my vision (still does). "

Participant 12. "Yes, have floaters ("eye bugs" or squiggles) that come and go"

Participant 13. "With bad headache gets double vision, or blurred vision."

Participant 14. "After my surgery, I was diagnosed with a pseudotumor cerebri, with caused my right eye to turn in due to the pressure on my optic nerve. I had double vision for 3 months. Now, I'm not sure if it resulted from either the PTC or Chiari, but my eyesight has gotten worse than it was beforehand."

Participant 15 "Yes, went from 20/20 to bi-focals in less than 8 months. His right eye muscle drops when he reads so he misses whole sentences, even paragraphs."

Participant 16. "No"

Participant 17. "Well, I have a nystagmus which is rapid, uncontrolled eye movements either horizontally or vertically, so that can be a little wierd sometimes. "

Participant 18. "no"

Participants 19-22. "Yes. Vision tends to blur, wave and bend at times. It also becomes painful. "

Is there anything else that you would like to share with me?

Participant 1. "I think it is very important that schools realize that these disorders are disorders that change moment to moment. It isn't like a child that has CP from birth, what you get is what you get. This CHANGES. The other big issue is that they could end up with two kids in their classes with any of these disorders and they could be very different in looks/symptoms. It would be wonderful if the professionals would realize that these kids are manipulative --- but not in the way they think. They are manipulative in order to be treated like normal kids. They don't like restrictions and they want to be allowed to do what others kids do."

Participant 2. no response

Participant 3. "When I get headaches I always get stomachaches and feel like I am going to throw up. I feel sharp pains in my back and then I feel like my body is on fire."

Participant 4. "My decompression was in November of my junior year and I missed school until after Christmas break"

Participant 5. "I'm really sensitive to light."

Participant 6. "I am filling this out for my daughter. Her decompression surgery really made a big improvement on her motor skills. We are still working to strengthen her grasp in her hands. She can finally hold a pencil tight enough to write."

Participant 7. "He will just pass out and stay paralyzed for hours then regain feeling and be fine. It is a very painful and weird disease. He can't ride roller coasters, or do karate. They just want to feel normal and do normal kid things. Has major kidney problems because of CMI."

Participant 8. "Not really – sorry."

Participant 9. no response

Participant 10. "I think it is the family's responsibility to educate the teacher and the school about the child's condition. Chiari has such a variable set of symptoms and each person presents differently. General Chiari knowledge is good but as far as having a student with Chiari it is up to the individual family to explain their child to the educator. One child will present differently than another. Making sure that the lines of communication are open and that there are meetings at the beginning of each semester to go over any changes in the condition. "

Participant 11. "Actually I want to thank you from the bottom of my heart for trying to understand these children with health difficulties. Not just ACM, but any health issue that is visually undetectable. To look healthy as a horse, and feel like a squashed bug isn't easy. Awareness is so important. Not all men are created equal as it is stated. Some have to deal with things in a little different way. Don't call extra attention to a student who is having a hard time, you may as well stick a target in the middle of their

forehead and hand the rest of the kids a gun. But do be aware. If a student seems to be going through a bad time it's ok to talk to them about it, just make sure your alone. Also, it is ok to expect the same from a challenged student as a "normal" just make necessary adjustments....discreetly. If a student is so tired they are falling asleep, don't point them out in front of the classroom, sometimes a short nap can work miracles. Sometimes."

Participant 12. "Went to due process trying to get a health care plan for Chiari and lost in Fairfax County Public Schools."

Participant 13. "This is a very complicated condition, that varies from person to person. I appreciate your trying to help these kids in school. Each child will need a very different IEP, I don't believe a 504 would cover the accomodations necessary."

Participant 14. "Chiari has forever changed my life. I can no longer ride roller coaster, which keeps me from being able to go to the local fair with my dad like I had been doing since I was 2. While this basically sucks, I wouldn't change me having Chiari for anything. It brought my family closer together and has molded me into what I am today. It has given me my optimistic outlook on life, along with many friends I wouldn't have had if I were "normal." God does everything for a reason, and even though mine involved intense pain, I'm glad it happened. Just to let you know, I was in 8th grade when everything happened, just to give you some insight on my answers. Thanks!"

Participant 15. "I bought a book holder prop for his desk. Helps a lot with the headaches. It folds up and fits in his backpack. He uses that daily along with he has to

read with a ruler so he doesn't lose his place and wear his glasses. He also can't do books online. He has to have a textbook which the school fought me on but e can't read the computer screen and keep place with a ruler. Also his eye doctor caught the problem. He can't ride roller coasters, or do karate. He can't just want to feel normal and normal and do normal kid things. Does play baseball. Has major kidney problems because of CMI."

Participant 16. no response

Participant 17. "I'm a new diagnosee, so this was interesting, and exciting to see that someone actually cares. If I could give one piece of advice to anyone, I would have to say don't let things stop you from being who you want to be, whether it be medically, or elsewhere. Instead of asking "why me?" ask "why not me?". Always keep a positive attitude. "

Participant 18. "No."

Participants 19-22. "Yes. It is extremely difficult to get professionals to recognize Chiari because it is so invisible. And that makes it that much harder for students dealing with the condition."

Data Analysis

Background Information Analysis

Of the twenty-two participants, eighteen reported that their school had a record of their condition, two reported that they did not, and the other two were unsure. When asked if they currently receive accommodations or modifications to help them succeed at

school, half of the respondents reported “yes” and the other half reported “no”. It is unclear whether the 50% that reported “yes” also receive a 504 or IEP.

Classroom attendance varied significantly from one participant to another. Specifically, participants’ responses ranged from one day to five months. Students who responded that they have undergone surgical treatment reported a higher frequency of absences.

Physical Pain Analysis

Nineteen of the twenty-two participants reported physical pain during the school day. The degree of pain varied among participants. They reported random pressure headaches or headaches in the base of the skull, stomach aches, sore neck, back pain, pain in hands and feet, leg pain, dizziness, shoulder pain, and painful tingling in arms and legs. Sixteen of the participants reported that the physical pain adversely affects their ability to function in a classroom setting. Participants gave the following reasons:

“I can’t get comfortable and sometimes the pain is so bad that all I can think about is the pain.”

“I feel like I need to move around to stop the pain.”

“If the headache is bad enough, I can’t concentrate on anything else.”

“All I do when I am in pain is try not to cry.”

“The pain in my head would get so bad at times that I had difficulty seeing the board.”

“Pain killers make it difficult to concentrate.”

Participants also described coping strategies that help them manage pain. Some of these strategies included taking pain medication, taking a nap or resting in the nurse’s

office, standing up or taking a short walk, sitting in a comfortable chair or recliner, and frequent breaks. Many participants also reported restrictions in physical education class. The majorities of respondents were instructed or chose to avoid contact sports such as basketball, dodge ball, and football. Many also avoid exercises that involve neck movement, looking up, or activities that require placing their head below their body. Running, jumping, warm-up exercises and gymnastics also causes headaches in some respondents. While the vast majority of respondents reported that restrictions were necessary in physical education class, two participants reported that no restrictions were needed. Suggested accommodations and modifications for this physical pain will be discussed in chapter five.

Speech and Attention Analysis

Many participants also reported adverse cognitive affects of Chiari. When asked if their speech was affected in some way, thirteen reported “yes”, six reported “no”, and three reported “sometimes”. Some participants further described their speech difficulties as follows:

“Sometimes I can’t think of words or I use the wrong words.”

“I forget what I want to say.”

“Received speech therapy”

“Know what I want to say, but for the life of me cannot get it out right”

“Struggle with word retrieval, articulation problems relate to pressure changes”

“Sometimes have brain fog – can’t think through things that would normally be easy”

“I know what I want to say, but I have a hard time remembering the word.”

“Sometimes it is hard to finish thoughts or get out what I’m trying to say.”

Those that responded that their speech was affected “sometimes”, explained that their speech impairments were either short in duration or were closely associated with taking pain medication. Less noise, working with therapists, extended time to respond to questions, and additional time to process information was identified as means for helping with this problem.

Participants were also asked whether they have difficulty focusing or maintaining their attention during class. Sixteen reported “yes”, four reported “no”, and two reported “sometimes”. Some respondents elaborated by saying that their ability to focus was dependent upon their ability to manage pain symptoms. Others reported that fatigue or noise affected their ability to maintain their attention. One participant even reported that weather and lack of sleep play a role in attentiveness. As Labuda (2006) reported, these cognitive effects could be due to long-term increase in intracranial pressure. Suggested accommodations and modifications for cognitive effects will be discussed in chapter five.

Analysis of Other Relevant Information

The final section of the questionnaire asked respondents to report any additional symptoms or to provide any additional information that they feel is relevant to understanding how Chiari affects their educational experience. Participants provided a wider range of responses related to additional symptoms. For example, one participant stated that riding the bus triggered pain symptoms. Another stated that her neck frequently felt too weak to hold her head. Additional symptoms reported included dizzy spells, frequent urination, back pain, and discomfort while sitting for prolonged periods.

One respondent, a mother of four children who all have Chiari, reported that they all of her children struggle with poor hand coordination, visual disturbances, and sensitivity to light and noise.

Difficulties with vision were frequently identified as a common symptom affecting students' abilities to succeed in the classroom. Indeed, twelve of the twenty-two respondents reported some type of visual disturbance such as blurred vision accompanied with head pain. Classroom seating varied from among participants. Those who were distracted by noise or had difficulty with vision preferred to sit near the front of the room while those who suffered from neck pain preferred the middle or back of the classroom to avoid hyper-extending the neck while looking up at the board or classroom teacher.

The last question posed to participants was, "Is there anything else that you would like to share with me?" This broad, open-ended question was intended to allow respondents to identify any additional information that they perceive as relevant to a full understanding of how Chiari affects their educational experience or to identify any unique aspects of any individual participant's experience. Despite the broad scope of this question, nearly every participant's response included a variation of at least one of two related themes: (1) Educators frequently do not understand what Chiari is, and (2) students with Chiari are not making up imaginary symptoms.

Many of the respondents took this time to stress the importance of teaching educators about Chiari. Many commented on the fact that people do not always believe them when they say that they do not feel well. Participant 10 responded that, "Chiari has such a variable set of symptoms, each person presents differently, and it is up to the individual

family to explain their child's [condition to the educators]. Participant 11 wrote, "To look as healthy as a horse and feel like a squashed bug, isn't easy." Participant 19 summarized this section best when she wrote, "It is extremely difficult to get professionals to recognize Chiari because it is so invisible, and that makes it that much harder for students dealing with this condition."

A similar response surfaced when analyzing responses to questions 25 and 29. These questions asked, "What would you like your teachers/school nurses, principals, etc. to know about your condition" and "Is there anything else that you would like to share with me?" An overwhelming majority of individuals expressed their desire that school personnel would simply believe them when they reported that they were not feeling well. Illustrative responses included

"[My] gym teacher thinks [I'm] faking."

"[Teachers should] believe me when I say I have pain."

"One year I had a teacher who thought I was faking not feeling well."

"If they think the student is abusing going to the office because of pain, call the parent and let the parent make that decision."

"They act like attendance is more important than personal health."

"[Educators should] be understanding and [believe] what I told them."

"[Educators] often said I was faking or being lazy."

"[I wish they would] believe me."

"I think that if teachers and the general public were more aware, then they would understand better."

“I feel that because it is not a well known illness, they don’t take me seriously.”

“I don’t fake not feeling good.”

“If a child says, I can’t run it hurts. . . then it hurts!”

“Sometimes I need to be able to go home without going through an hour long checking out process.”

“I am not anywhere near normal with this and things are really hard for me.”

“These students are not faking or trying to get attention or lazy.”

“I may look okay, but I feel terrible.”

“It [Chiari] is a real condition, even though it is invisible, and causes *real* symptoms.”

“I think that I want them [educators] to know that this illness does exist. It isn’t something that is just made up even though you can’t see it outwardly.”

“It is hard to make others realize that you can’t do what they can even though I look fine.”

“The pain is real.”

Summary

Based on the data collected from participants, students with Chiari experience a wide range of symptoms. While the symptoms affect each person differently, most persons with Chiari endure physical pain, particularly head and neck pain, and many also experience cognitive difficulties such as difficulty with speech or an inability to remain attentive for extended periods. Many individuals with Chiari also appear to have some degree of difficulty with vision, noise, and sensitivity to light. Lastly, because most, if not all, of these symptoms are not readily observable by third parties, students with Chiari

frequently report that teachers and administrators do not believe that the student is truly experiencing these symptoms despite the fact that symptoms are real.

CHAPTER V

CONCLUSIONS

Through an extensive literature review, symptoms commonly associated with Chiari that have the potential to obstruct a student's ability to succeed in an educational environment were identified. To study how these symptoms affect students, twenty-two persons with Chiari were asked to respond to thirty open-ended questions. The responses to the written questionnaire provided the researcher with a more complete understanding of the challenges facing students with Chiari. More importantly, the synthesis of the literature review and questionnaire responses provides invaluable insight regarding classroom accommodations and modifications that can be implemented to assist these students overcome any Chiari-related limitations.

Discussion

Federal law provides that all students are entitled to a free and appropriate education. (Office of Civil Rights, 1999). To ensure that students with disabilities receive the full benefit of this right, the law defines an "appropriate education" as including services designed to meet the individual educational needs of students with disabilities as adequately as the needs of nondisabled students are met (Office of Civil Rights, 1999). Students with disabilities, in turn, are defined as students who (i) [have] a physical or mental impairment which substantially limits one or more major life activities, (ii) [have] a record of such an impairment, or (iii) [are] regarded as having such an impairment (Office of Civil Rights, 1999). It follows, therefore, that if Chiari substantially limits one or more major life activities of a student, then that student is entitled to educational

services that are designed to meet the student's educational needs as adequately as the needs of students without Chiari. Through the development of an appropriate 504 plan or IEP, parents and educators can jointly design an education plan that ensures that this entitlement is fulfilled.

Based on both the literature reviewed in this study and the responses to the written questionnaire, it is plain that Chiari is capable of substantially limiting one or more of a student's major life activities so that customized educational services would be appropriate. For example, a student with Chiari may experience physical pain in their back, head, and neck that prevents them from sitting in a desk for long periods of time, concentrating, remaining attentive during class, or participating in physical education activities. Headaches associated with Chiari may also cause blurred vision or dizziness which prevents the student from seeing classroom notes displayed on a chalk board or overhead projector. Chiari may also lead to cognitive impairments that include difficulties with memory, word retrieval, comprehension, and speech. Whether considered individually or in the aggregate, these symptoms may substantially limit a student's ability to concentrate and remain attentive, communicate, stand, sit, walk, run or participate in physical activities. Therefore, it is beyond question that Chiari can qualify as a disability that substantially limits a student's major life activities. That is not to say that all students with Chiari will necessarily qualify as a disabled student. Indeed, many people with Chiari are completely asymptomatic. Obviously, such persons would not qualify as disabled. That being said, when a student's Chiari-related symptoms rise to the level that their ability to learn is adversely affected, they qualify as disabled and are

entitled to appropriate modifications to ensure that their educational opportunities are equivalent to those of non-disabled students.

These modifications may include efforts to minimize the student's symptoms in the classroom. For example, students who experience pain that is triggered by hyper-extending their neck should be permitted to choose a seat that will not require the student to look up at a steep angle. Similar accommodations may be made for students who identify other pain triggers. Perhaps even more importantly, teachers and school personnel should be well educated regarding Chiari's symptomatology so that they understand that the student's complaints of pain are real and that the student may require a visit to the nurse's office or other break.

Students who experience cognitive impairments frequently find it difficult to verbalize words that have formed in their heads. These students may not be able to promptly articulate verbal responses to questions despite the fact that they know the correct answer. Therefore, educators may need to allow additional time for these students to verbally respond to questions. Similarly, putting a Chiari student on the spot during a classroom discussion may cause them unnecessary stress or embarrassment. Such awareness and modifications may greatly increase a Chiari student's ability to succeed in the classroom.

Implications and Recommendations

Chiari, with its complex symptomatology, presents differently with each individual. Therefore, it is imperative that students, parents, and educators work together to formulate a plan that meets the unique needs of the individual student. This may be done by uniting with the school to develop a 504 plan. For some, a 504 plan may not be

necessary, but for others it may not be enough. Some students may need further modifications that can only be obtained with special education services through an Individualized Education Plan (IEP). For a student with a medical condition to be eligible for an IEP, it must first be determined that the medical condition is having an adverse effect on the student's education. Parents who would like to investigate this possibility should call their child's school and request that a case study be performed on their child. A written medical diagnosis from their child's doctor is also necessary before special education services can be provided pursuant to an IEP.

Listed below are possible accommodations and modifications, gathered from the twenty-two participants in this study, which could be used in most 504 plans or IEPs. It is important to recognize that these recommendations are based on the twenty-two participants. Many of the participants commented that Chiari affects individuals differently; therefore, these suggestions should be used as a starting point and catered to the individual needs of the student.

Suggested Accommodations and Modifications to Minimize Physical Pain

Allow student to rest in the nurse's office.

Sitting in a chair for long periods of time may be painful so allow movement.

Too much noise may trigger symptoms so allow the student to work in a quieter environment, like the school library, if necessary.

Looking straight down may cause headaches so give the student something, like a book prop or slant board, to place work or tests on during class time.

Make sure that the student is seated so that their neck is a comfortable position. To avoid hyper-extension of the neck do not seat the child in the front row where they will have to look up at the teacher or the board, post grades and assignments at eye level, adjust any computer chairs at eye level so the student does not have to look up or down at the screen, and come down to the student's level when they are seated at their desk so they do not have to look up at you when working one-on-one.

Brain stem compression may cause frequent urination. Allow bathroom breaks.

Allow student to type work.

Offer yoga or stretching, possibly with occupational therapist.

Seat the student away from noise and/or distractions.

Issue a second set of textbooks at home so the student does not have to carry the weight in his/her back pack.

Sit in a chair with high back and foot rest.

Allow soft cold compresses on the neck/brain joint area, top of the head, or on face to alleviate head and neck pain.

Avoid standing in lines or in one spot for long period of time.

Suggested Physical Education Accommodations or Modifications

No Lifting – It may aggravate headaches or dizziness.

Avoid contact sports such as basketball, football, and dodge ball.

Something as simple as looking *up* to shoot a basketball may aggravate symptoms.

Activities that cause the blood to rush to the head may be very painful: For example, telling the student to bend over and touch their toes, hanging upside down, or doing a hand stand, cartwheel, or somersault.

Running may be difficult. The impact that an individual's spine takes may cause head pain. Encourage walking.

Avoid jumping jacks, jumping rope or similar exercises. They may cause dizziness and/or head pain.

Encourage a modified sit-up. Crunches may aggravate neck pain and cause dizziness.

Stand up and sit down slowly to avoid dizziness.

Suggested Accommodations and Modifications to Minimize Cognitive Difficulties

Possible speech therapy

Give extended response time.

Encourage note taking to help with memory issues and word recall.

Avoid calling on student in unplanned situations in front of the class. Most of the time, they know the answer, but cannot get it out.

Offer copy of class notes or note taking assistance.

Allow voice recorder for class lectures.

Absences may be an issue so assign someone to gather missing work.

Offer strategies for short term memory recall.

Offer color overlay to remove the glare on paper when reading.

Extend time on tests.

Take test in alternate site.

Write assignments on chalkboard to assist with short term memory.

Allow additional time to make up missing work after longer absences.

Give a stretch or walk break during a long test or assignment.

Not all students with Chiari will need the suggested accommodations and modifications. Once catered to the student's individual needs, these suggestions will help a student with Chiari I Malformation succeed in an academic setting. All of the suggested modifications and accommodations were reviewed by a school IEP team consisting of a school administrator, school counselor, school psychologist, school social worker, speech pathologist, school nurse, general education teacher, and special education teacher.

Summary

Students with Chiari face a wide range of symptoms that have the potential to severely limit the student's ability to succeed in school. While these symptoms vary significantly among students, common symptoms include debilitating pain and cognitive difficulties. Moreover, the student's ability to succeed may be further complicated by the fact that the condition may not be fully understood by educators or even by the student himself. Nonetheless, a student whose ability to learn is adversely affected by Chiari is entitled to educational services that are designed to meet the student's individual educational needs. Parents and educators must work closely with one another to ensure that educators fully understand the condition in general and the unique symptomatology facing the individual student in particular. By doing so, they will be better equipped to develop an appropriate 504 plan or IEP to meet the student's needs.

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