SHUNT FAILURE IN CHILDREN WITH HYDROCEPHALUS:
IMPACT OF SOCIODEMOGRAPHIC PREDICTORS ON TIME TO MEDICAL
EVALUATION FOR SHUNT FAILURE AND THE ECONOMIC BURDEN
ASSOCIATED WITH SHUNT FAILURE

by

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VENTRICULO-PERITONEAL SHUNTS CONTINUE TO BE THE STANDARD SURGICAL PROCEDURE FOR TREATING CHILDREN DIAGNOSED WITH HYDROCEPHALUS, REGARDLESS OF ETIOLOGY. THE FAILURE OF THESE SHUNTS CAN CAUSE ACUTE MEDICAL PROBLEMS FOR THE CHILD REQUIRING IMMEDIATE MEDICAL CARE. IT IS KNOWN THAT HYDROCEPHALUS DIRECTLY IMPACTS A CHILD’S HEALTH STATUS, EDUCATIONAL ABILITIES, DEVELOPMENTAL OPPORTUNITIES AND EMOTIONAL WELL BEING. AN IMPORTANT GAP IN THE CURRENT LITERATURE IS THE EXAMINATION IN A HOMOGENOUS PATIENT POPULATION OF THE IMPACT OF SOCIODEMOGRAPHIC FACTORS ON THE MANAGEMENT OF SHUNT FAILURE AND THE ECONOMIC BURDEN ON THE FAMILY.

The objective of this dissertation research study was to better understand shunt failure among the children with hydrocephalus initially diagnosed, treated and managed at a pediatric acute care facility. With this study we determined the two-year shunt survival rate, and examined the sociodemographic factors that affect time to medical evaluation after the initial onset of shunt failure symptoms. Additionally this study examined the economic impact of a shunt failure episode on the families caring for a child with hydrocephalus.

Keywords: Hydrocephalus, Pediatrics, Ventriculo-peritoneal shunt, Shunt survival, Sociodemographic, Economic
DEDICATION

This work is dedicated in loving memory of my stepfather, Austin Travis Beatty, to my mother, Newana Blue Beatty, and to my siblings Travis, Kevin and Mary, whose continued support, understanding and love made it possible for me to pursue my dream and to the love of my life, Gregory Waters, for being my inspiration during the final stages of this process.
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<table>
<thead>
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<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>CHA</td>
<td>Children’s Hospital of Alabama</td>
</tr>
<tr>
<td>CSF</td>
<td>cerebrospinal fluid</td>
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<tr>
<td>CT</td>
<td>computed tomography scan</td>
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<td>LOC</td>
<td>loss of consciousness</td>
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<td>LOS</td>
<td>length of stay</td>
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<td>MR</td>
<td>magnetic resonance imaging</td>
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<tr>
<td>PPV</td>
<td>positive predicted value</td>
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<tr>
<td>SES</td>
<td>socioeconomic status</td>
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<tr>
<td>US</td>
<td>ultrasound</td>
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<td>VP</td>
<td>ventriculo-peritoneal shunt</td>
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OPERATIONAL DEFINITIONS

*Hydrocephalus*- An abnormal increase in the amount of cerebrospinal fluid within the cranial cavity that is accompanied by expansion of the cerebral ventricles and enlargement of the skull

*Acquired Hydrocephalus*- develops at the time of birth or at some point afterward and can affect individuals of all ages

*Congenital Hydrocephalus*- present at birth and may be caused by genetic abnormalities or developmental disorders such as spina bifida and encephalocele

*CSF*- clear fluid, which is made by tissue inside the ventricles within the brain

*Intracranial Pressure*- pressure exerted by the cranium on the brain tissue, cerebrospinal fluid (CSF), and the brain's circulating blood volume

*Shunt*- A passage by which a bodily fluid is diverted from one channel, circulatory path or part to another

*Ventriculo-Peritoneal (VP) Shunt*- small tubing that is placed inside the brain’s ventricle and tunneled underneath the skin to the abdominal cavity. The purpose of the VP shunt is to reduce the amount of cerebral spinal fluid (CSF) in the brain by draining it into the abdominal (peritoneal) space.

*Shunt Failure*- defined as any obstruction, disconnection, infection, overdrainage, or loculation requiring revision of the shunt system. See further detail below:
**Shunt malfunction**- (any of the following 3 definitions) 1) at least one sign/symptom (headache, nausea, vomiting, decreased level of consciousness, irritability, decreased school performance, or lost of developmental milestones) and at least one positive result on an ancillary test (e.g. CT, MRI, Ultrasound) confirmed by a neurosurgeon; 2) no signs/symptoms but the ventricles were increased in size and no clinical/radiography evidence that atrophy caused the ventricular enlargement.

**Shunt disconnection**-indicated by a separation of either 1) the proximal catheter from the rickham; or 2) the rickham from the valve; or 3) the valve from the peritoneal catheter; or 4) a combination of the above; or 5) a break in the peritoneal catheter anywhere along the shunt track

**CSF Shunt infection**-indicated by either 1) identification of organisms on culture or gram stain from CSF, wound swab, and/or pseudocyst fluid or; 2) shunt erosion (visible hardware); or 3) abdominal pseudocyst (even without positive culture)

**Other**- indicated by either 1) shunt overdrainage- supra-physiologic removal of CSF via the shunt system above and beyond the normal (physiologic) clearance indicated by either clinical symptoms of severe headache, dizziness, and emesis due to very low intracranial pressure or radiographic imaging identifying a subdural hematoma, or 2) loculated compartments- presence of a loculated portion of a ventricular system, enlarged more than normal

**Private Insurance**- for the purposes of this project private insurance includes BlueCross BlueShield (BCBS), military, commercial and HMO insurance
Public Insurance—for the purposes of this project public insurance includes Medicaid, The State Children’s Health Insurance Program (SCHIP), Alabama Department of Public Health Children’s Insurance Program (AllKids)
CHAPTER 1

INTRODUCTION

Hydrocephalus, a condition caused by excess accumulation of cerebrospinal fluid (CSF) in the brain, affects 1 in every 500 children. Shunting of the excess CSF from the brain to the abdominal (peritoneal) cavity is the standard treatment for hydrocephalus. Shunt failure causes acute medical problems for the child that requiring immediate medical care.

The clinical importance of the treatment and management of hydrocephalus is well documented. However, hydrocephalus has public health implications as well as clinical consequences. Increased risk of developmental and cognitive delays, lower quality of life, emotional and financial strain on the families and the potential for death are several implications that families are faced with daily while caring for a child with hydrocephalus. Learning disabilities, visual problems, coordination problems and difficulty interacting with their peers are associated with hydrocephalus. This population, on average, tends to score below 80 on standardized tests, requiring additional services and resources to meet their developmental and educational needs. There are financial burdens associated with caring for a child with hydrocephalus. As these shunts are not life long, many children must undergo multiple surgical interventions due to shunt failure throughout their lives. The costs associated with these hospitalizations extend past the hospital charges and the third party payer reimbursements. Families incur out-of-pocket
expenses associated with non-medical costs such as transportation and gas, lodging and food, and additional childcare for siblings.

In summary, hydrocephalus directly impacts a child’s health status, educational abilities, developmental opportunities and emotional well being. Also noted is the economic impact of managing and treating hydrocephalus. Because hydrocephalus is most prevalent in children and because they spend a lifetime dependent on both the public health and medical systems, we felt it was important to focus this project on the pediatric population. It is essential to gain a greater understanding of hydrocephalus the pediatric population in order to potentially improve the standard of care and reduce the financial burden to families. For this reason the purpose of this project is to better understand shunt failure among the pediatric hydrocephalic patient population followed at the Children’s Hospital of Alabama. With this study we will determine the one-year and two-year shunt survival rate, and examine the sociodemographic predictors that potentially delay medical evaluation after the initial onset of symptoms. Additionally this study will examine the economic impact of the treatment and management of hydrocephalic children requiring shunt revisions.

Specific Aims

**Aim 1:** To estimate the effect of risk factors (age at initial shunt insertion, weight at initial shunt insertion, gestational age, age at the time of shunt failure, etiology, insurance status, race, and gender) on the shunt survival rate associated with ventricular-peritoneal shunts placed in hydrocephalic patients treated at The Children’s Hospital of Alabama (CHA)
**Aim 2:** To examine the sociodemographic factors (maternal age, maternal education, maternal employment, household income, primary caregiver income, insurance status, number of adults living in the primary household, number of siblings living in the primary household, and distance to CHA) that delay seeking medical evaluation after initial onset of symptoms.

**Aim 3:** To evaluate the economic burden of a shunt failure episode.
CHAPTER 2

LITERATURE REVIEW

History of Hydrocephalus

Hydrocephalus has been recognized as a disease since the days of Hippocrates\textsuperscript{11,12,39}. It wasn’t until 1768 when Robert Whytt, President of the Royal College of Physicians in Edinburgh, published a descriptive paper recognizing hydrocephalus as a distinct disease\textsuperscript{39}. Since that time the field of neurosurgery has matured and we have gained a better understanding of the natural history of hydrocephalus from its etiology to the impact this disease has on the pediatric population\textsuperscript{14,35,36,67,68}.

By the mid to late 1970’s hydrocephalus was a common pediatric illness and the focus of many studies that evaluated the treatment and management of the disease. The expansion of pediatric neurosurgery as a subspecialty and the advancement of medical technology brought about increased survival rate of premature infants increasing both the incidence and prevalence of hydrocephalic children requiring a lifetime of health care services. Squeros et al. conducted a retrospective study (1974-1978) to assess the long term outcomes of children with hydrocephalus of who were shunted in the first two years of life. They found that this population experienced clinical complications throughout their childhood including blindness and heart failure\textsuperscript{52}. Serlo et al evaluated shunt
failure types by etiology and found that premature infants were more prone to shunt failure when compared to infants with congenital hydrocephalus. Piatt looked at the determinants of shunt survival and found that children originally shunted before two-years of age were more likely to have a shunt obstruction compared to children originally shunted after two-years of age.

Although the etiology of hydrocephalus can sometimes be difficult to determine, it usually falls within one of the following categories: intraventricular hemorrhage, myelomeningocele, brain tumor, aqueductal stenosis, CSF infection, or head injury. Left untreated however, hydrocephalus can progress to coma and death. The prognosis for hydrocephalus is dependent on the prompt diagnosis, intervention and treatment, and proactive follow up.

The ultimate goal of the treatment of hydrocephalus is to prevent or to reverse the neurological damage caused by the alteration of the brain from this condition.

**Shunting**

Shunt systems are used to divert the flow of CSF from within the central nervous systems to another area of the body so absorption can take place and pressure can be relieved. Surgical placement of a shunt system is the most common treatment for hydrocephalus. Shunt systems were developed during the mid 1700’s when the theory of decompressing the ventricular system by direct puncture as a treatment for hydrocephalus was first discussed. However this procedure was introduced before the use of aseptic techniques making it invariably fatal. The development of aseptic techniques in the mid
1800’s and the advancement of treatment options for hydrocephalus brought the first signs of mortality rate declines\textsuperscript{7,8,39}.

With further advances in biomaterials and shunt techniques as well as the development of pediatric neurosurgery as a distinct specialty, shunting has become a routine procedure for the treatment of hydrocephalus patients in pediatric acute care facilities across the United States today. Current shunt system consists of a flexible durable plastic shunt tube, a catheter and a valve. One end of the catheter is placed in the central nervous system, usually within a cerebral ventricle, while the other end is placed either in the peritoneal (abdominal) cavity, or the heart for CSF to be absorbed. The purpose of the valve is to maintain and regulate one-way flow of the CSF\textsuperscript{23,39,46}. Although the shunt system is used to treat hydrocephalus it is not a cure. These systems often meet with complications, in fact as many as 50\% of shunt systems fail within the first 2 years of placement\textsuperscript{15}. A properly functioning shunt system should produce intracranial pressure dynamics that emulate the normal physiologic state. When these shunt systems are not functioning the CSF dynamics may become markedly abnormal and remain so until shunt dysfunction is diagnosed and corrected. The cumulative impact of this cycle, particularly if frequently repeated, may be cognitive and physical impairment\textsuperscript{15}.

\textit{Signs and Symptoms of Shunt Failure}

Although there are numerous tests that can be conducted to confirm hydrocephalus (see table 1 below), in most children it is determined by observation over time with documentation of progressive signs and/or symptoms being a key factor in the
Diagnosing hydrocephalus greatly depends on the age-specific signs of increasing intracranial pressure. Infants exhibit signs of shunt failure through head growth that exceeds the normal rate, bulging of the normally flat anterior fontanelle of the skull, and continuous downward gaze of the eyes. In older children complaints of headaches, vision changes, confusion and worsening school performance are all signs associated with shunt failure. Lethargy, irritability, nausea and vomiting are symptoms that can be associated with shunt failure despite the age of the child.

Several studies have been conducted examining the predictive value of signs and symptoms in determining shunt failure. Kirkpatrick found that inappropriately increasing occipitofrontal head circumferences, tense anterior fontanelles, splayed sutures, and distension of the scalp veins were all signs that accurately indicated shunt failure. Kim et al. reviewed patients that presented in the emergency department with a potential shunt malfunction. They found that shunt track swelling and lethargy were significant and highly predictive of shunt failure. Garton, Kestle and Drake reviewed the signs and symptoms of the patients from the Pediatric Shunt Design Trial study and determined predictive values for signs and symptoms frequently noted in the pediatric patient population. They found nausea and vomiting (positive predictive value [PPV] 79%), irritability (PPV 78%), decreased level of consciousness (LOC) (PPV 100%), erythema (PPV 100%), and bulging fontanelle (PPV 92%). Between 9 months and 2 years after shunt insertion (late encounters), only loss of developmental milestones (PPV 83%, LR 36.7) and decreased LOC (PPV 100%) were strongly associated with shunt failure. Combining them in a weighted scoring system improves the ability to predict shunt failure based on clinical findings.
Shunt Survival and Failure

According to a survey of pediatric acute care facilities throughout the United States, CSF shunts are increasingly common neurosurgical procedures with over 40,000 procedures performed annually in the US alone. These systems often meet with complications, with as many as 50% of shunt systems failing within the first 2 years of placement. Shunt failure can take on several different forms: 1) shunt obstruction and mechanical failures, 2) shunt overdrainage or under-drainage, 3) loculated compartments and 4) shunt infections. Many single and multi-institutional studies have evaluated the impact of the types of implants used (valve, catheter, or specific shunt system) surgeon expertise, and environmental factors (operating room temperature, length of time in the OR, types of previous shunt failure, and number of previous shunt failures). Geography and seasonality as potential predictors of shunt failure have been explored. Clinical variables have been reviewed numerous times, including gestational age, age at initial shunt, birth weight, and hydrocephalus etiology. Tuli et al, Kestle et al, and Bergsneider et al conducted several shunt survival studies looking at factors that contribute to shunt survival and their findings were similar. They found shunt survival to range from 60-75% at 1-year with 10-year ranging from less than 30% to 37%. Sainte-Rose reviewed the types of shunt failures and found that within their patient population proximal shunt obstruction and shunt infection were responsible for the majority of their revision procedures at 67% and 19%, respectively. The remaining revisions were due to overdrainage or loculated ventricles. The overwhelming conclusion from these studies is that the majority of shunts do not survive long term.
As seen, many studies have taken on the challenge of understanding the natural history of hydrocephalus, identifying clinical risk factors associated with shunt-related outcomes, and determining the costs associated with hydrocephalus and the treatment of hydrocephalus. However, few studies have approached hydrocephalus from a public health perspective, identifying how sociodemographic predictors affect shunt-related outcomes and assessing patient level financial data when determining the cost associated with managing hydrocephalus.

Sociodemographic Predictors and Chronic Illnesses

Because the literature is limited on studies that evaluated sociodemographic factors and hydrocephalus, we turned our attention to the chronic disease literature to identify the sociodemographic factors previously found to be associated with health care access. Over the last two decades, studies have been published looking at social class, employment, gender, marital status and age, with many studies showing an inverse relationship between SES and morbidity and mortality. Benzeval found that income level was more important than income change when looking at access to care. Additionally this study found that long term income (consistent income over a 5 year period) had a greater impact on access than did current income. Seid in his study looking at barriers to care in a pediatric asthma population found that health insurance was a cause of forgone care. Wang conducted a study at the Hospital of Sick Children in Toronto and found that within his premature patient population, despite universal health care, socioeconomic related inequalities affected hospitalization and ultimately mortality rates. Heck et al tested the hypothesis that among children of lower
socioeconomic status, children of single mothers would have relatively worse access to care than children in two-parent families, but there would be no access difference by family structure among children in higher SES families\textsuperscript{16}. The study examined the relationship between a child’s family structure (e.g. single mother or two-parent family) and health care access and utilization (e.g. having no physician visits in the year prior to the study, no usual source of health care, and having unmet health care needs). When evaluating physician visits attended in the past 12 months, the study found no difference between children of single mothers and those children with two-parent families. Heck’s study found that maternal education level impacted health care access and utilization. Single mothers and two-parent families’ experienced similar health seeking behaviors but when you stratified by levels of maternal education significant differences emerged. Several other studies looked at the direct causality of socioeconomic status and health\textsuperscript{17,49,50,62}. These studies found that lower socioeconomic status was associated with increased health inequalities, psychological and behavioral factors and mortality.

The above mentioned studies have illustrated that sociodemographic variables are influential when determining health-seeking behaviors. These studies are important to our project as they confirmed the need for further consideration of the impact factors such as level of maternal education, and family structure have on health seeking behaviors and the outcomes related to children with chronic illnesses. Our project will examine the impact of these sociodemographic variables on health-seeking behaviors specific to children with hydrocephalus.
The Economics of Hydrocephalus

Previous studies have assessed the treatment of hydrocephalus based on hospital charges, using ICD-9 or CPT (current procedural terminology) codes. Simon et al recently published a cross-sectional study that looked at hospital admissions, total hospital days and total hospital charges of children with hydrocephalus over 3 points in time in comparison to other subpopulations of chronically ill children (e.g. cystic fibrosis, gastrostomy). Her analysis also utilized ICD-9 and CPT codes reported in 2003 to determine the impact of hydrocephalus on admissions, hospital day and hospital charges. Simon found that hydrocephalus accounted for approximately 38,000 admissions, and 400,000 hospital days. Additionally she found that hydrocephalus made up 3.1% of all pediatric acute care hospital charges ($1.4-2.0 billion for the year 2003) compared to cystic fibrosis that accounted for 2.9% of hospital charges. This study concluded that children with hydrocephalus use a disproportionate share of hospital days and healthcare dollars.

Families caring for children with hydrocephalus incur out-of-pocket expenses each time their child has a shunt failure episode. Although not previously examined in the hydrocephalus patient population there are many studies in the literature that evaluated how caring for a chronically ill child affects the family financially. These studies examined wage and labor outcomes, maternal employment status, access to services and resources, transportation costs, and costs associated with the care of siblings. The studies demonstrated that compared to families without a chronically ill child both maternal and paternal employment rates were lower, and parents received lower wages when they worked. Level of severity and the need for increased care for
the child over time led to increased reporting of financial problem \textsuperscript{32}. Also seen was the variation among socioeconomic status. Families with lower socioeconomic status were more likely to report finance-related problems as these families had less resources available \textsuperscript{32}.

As seen in previously conducted research, hydrocephalus had an effect on employment. Other issues such as the overall economic impact to the family have not been assessed. Based on the reported experience with other chronic illnesses we can anticipate that there would be an increased economic burden on the family caring for children with hydrocephalus. It is important to continue to assess the economics surrounding the treatment and management of hydrocephalus in order to identify potential cost-saving measures for the health care community and third party payers. More important is the need to identify ways to alleviate the financial burden felt by the family.

Summary

An important gap in the current literature is the examination in a pediatric patient population of the impact of sociodemographic factors (e.g. family structure, income and access to health care and services to address unmet needs) on the management of the failure of the shunt used for the treatment of hydrocephalus and the economic burden on the family. We propose to examine shunt failure in the cohort of patients followed at a single institution for several reasons: (1) more extensive data collection is feasible than in a multi-center study; (2) the inclusion of only children with ventriculo-peritoneal shunt systems in place as the diagnostic criteria and the initial surgical management are more uniform thereby increasing the power of detecting effects of sociodemographic predictors
in a smaller sample population. The study results may allow us to identify ways to potentially improve the care and ultimately the outcomes of patients with hydrocephalus and reduce the burden on the families.
Specific Aims, Research Questions and Hypotheses

**Aim 1:** To estimate the effect of risk factors (age at initial shunt insertion, weight at initial shunt insertion, gestational age, age at the time of shunt failure, etiology, insurance status, race, and gender) on the shunt survival rate associated with ventricular-peritoneal shunts placed in hydrocephalic patients treated at The Children’s Hospital of Alabama (CHA)

1. What is the 2-year shunt survival rate among the pediatric hydrocephalus population treated at the CHA?
2. What predictors (etiology of hydrocephalus, age at initial shunt failure, age at initial permanent ventriculo-peritoneal shunt insertion, gestational age, weight at initial permanent ventriculo-peritoneal shunt insertion, race, gender, insurance status) are associated with an increase in the risk of shunt failure in the pediatric hydrocephalus population treated at CHA?

2a. Null Hypothesis: Children greater than one year of age at the time of initial shunt insertion are not associated with an increased risk of shunt failure

   Alternative Hypothesis: Children greater than one year of age at the time of initial shunt insertion are associated with increased risk of shunt failure.

2b. Null Hypothesis: Comorbidities (such as prematurity and VLBW) are not associated with an increased risk of shunt failure.

   Alternative Hypothesis: Comorbidities are associated with an increased risk of shunt failure within the first year of initial shunt placement.
**Aim 2:** To examine the sociodemographic factors (maternal age, maternal education, maternal employment, household income, primary caregiver income, insurance status, number of adults living in the primary household, number of siblings living in the primary household, and distance to CHA) that delay seeking medical evaluation after initial onset of symptoms.

3. What symptoms of shunt failure were mothers able to properly identify?

4. Does the age of the mother impact the time to medical evaluation after the initial onset of symptoms?

   **Null Hypothesis:** There is no association between maternal age ranges and the time to medical evaluate after the initial onset of symptoms

   **Alternative Hypothesis:** There is a delay to medical evaluation after the initial onset of symptoms seen in children born to mothers younger than 19 years of age compared to mothers 19 years of age or older.

5. Is the distance from the primary household to Children’s Hospital of Alabama associated with a delay in medical evaluation after the initial onset of symptoms?

   **Null Hypothesis:** Distance from the primary household to CHA is not associated with a delay in medical evaluation after the initial onset of symptoms.

   **Alternative Hypothesis:** Those primary households closer in proximity to CHA do not have a delay in medical evaluation after the initial onset of symptoms.
6. What is the time to medical evaluation after the initial onset of symptoms for mothers with more than one adult in the primary household?

   **Null Hypothesis:** The number of adults in the primary household is not associated with a delay in medical evaluation after the initial onset of symptoms

   **Alternative Hypothesis:** Having only one adult in the primary household is associated with delayed medical evaluation after the initial onset of symptoms.

**Aim 3:** To evaluate the economic burden of a shunt failure episode.

7. What do third party payers reimburse (hospital, physician, and emergency department) associated with a shunt failure episode?

8. What out-of-pocket expenses do caregivers incur during with a shunt failure episode?

9. Do reimbursements and caregiver out-of-pocket expenses associated with shunt failure episode differ across levels of factors (length of stay, type of shunt failure, insurance status, and distance from CHA)?
CHAPTER 3

Factors Associated with Initial Ventriculo-Peritoneal Shunt Failure in Children with Hydrocephalus

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In preparation for The Journal of Neurosurgery Pediatrics
Format adapted for dissertation
Abstract

Introduction Although many researchers have examined predictors of shunt failure in the pediatric patient population, few have focused on social factors that influence shunt failure. The purpose of this study was to identify social, clinical and neonatal factors associated with ventriculo-peritoneal (VP) shunt failure. Methods We conducted a retrospective review of patients, born between the years 2000-2005, initially diagnosed and treated for hydrocephalus at the Children’s Hospital of Alabama. Allowing for 2-years of follow-up we analyzed shunt failure by time intervals (3, 6, 12, 18, and 24 months). Results Patients born less than 37 weeks gestational age had a 61% probability of having a shunt failure within 3-months of the initial shunt placement. Of those patients with acquired hydrocephalus (including intraventricular hemorrhage of prematurity) 58% had shunt failure within 3-months of the initial shunt placement. Weight at initial VP shunt insertion and age at initial VP shunt insertion were inversely associated with an increased risk of failure of their initial ventriculo-peritoneal shunt (p=<.0001). Conclusion Premature birth as well as premature IVH are associated with ventriculo-peritoneal shunt failure and continue to be a significant challenge.

Key Words

Ventriculo-peritoneal shunt, pediatrics, shunt failure, survival analysis
Introduction

Ventriculo-peritoneal shunts continue to be the standard surgical procedure for treating children diagnosed with hydrocephalus, regardless of etiology. According to a survey of pediatric acute care facilities, over 40,000 CSF shunts are placed annually in the US. These implants have an associated failure rate and reasons for shunt failure continue to be a topic of interest from a clinical and public health perspective. There have been many single and multi-institutional studies that evaluated the impact of the types of implants used (valve, catheter, or specific shunt system) surgeon expertise, and environmental factors (operating room temperature, length of time in the OR, types of previous shunt failure, and number of previous shunt failure). Geography and seasonality as potential predictors of shunt failure have been explored. Clinical variables have been reviewed numerous times, including gestational age, age at initial shunt, birth weight, and hydrocephalus etiology. Tuli et al, Kestle et al, and Bergsneider et al conducted several shunt survival studies looking at factors that contribute to shunt survival and their findings were similar. They found shunt survival to range from 60-75% at 1-year with 10-year ranging from less than 30% to 37% (see table 1). Sainte-Rose reviewed the types of shunt failures and found that within their patient population proximal shunt obstruction and shunt infection were responsible for the majority of their revision procedures at 67% and 19%, respectively. The remaining revisions were due to overdrainage or loculated ventricles. The overwhelming conclusion from these studies is that the majority of shunts do not survive long term. However, variability between populations and institutions continues to be a theme throughout this literature. One challenge faced is the on-going discussion regarding
determinants of shunt survival. Are there clinical and social factors that influence shunt survival and ultimately how a patient’s hydrocephalus is treated and managed?

A ventriculo-peritoneal shunt has public health implications as well as clinical consequences. Each time a hydrocephalic child returns to the operating room the consequences not only include the increased risk for future shunt failure including infection, but also affects outcomes that impact the child, the family and society. Such consequences include: 1) the increased risk of developmental and cognitive delays (including loss of IQ points with every additional surgical intervention for shunt failure)\textsuperscript{29,37}, 2) the almost certain lifetime of shunt dependency\textsuperscript{11,15,16,18,31,33,44,46}, 3) the overall quality of life of the child\textsuperscript{25-27} and 4) the small but serious risk of death due to shunt failure\textsuperscript{1,6,45}.

At the Children’s Hospital of Alabama (CHA) approximately 400 shunt procedures are performed annually. An estimated 165 (approximately 40%) of those shunt procedures are new shunt implants. The remaining procedures are related to shunt revisions due to failure. Shunt failure continues to make up a larger portion of the neurosurgical procedures performed at our institution as it does at other high volume pediatric tertiary referral centers. Better understanding of the clinical, neonatal and social factors associated with shunt failure is crucial to effective clinical management of hydrocephalic children. For this reason the goal of this study was to estimate the effect of risk factors (etiology of hydrocephalus, age at initial shunt insertion, weight at initial shunt insertion, gestational age, and demographic factors such as gender, race, and insurance status) on the shunt survival rate associated with ventriculo-peritoneal shunts placed in hydrocephalic patients treated at CHA.
Clinical Materials and Methods

Patient Population

We conducted a retrospective review of all patients, born between the years 2000-2005, initially diagnosed and treated for hydrocephalus at the Children’s Hospital of Alabama. We complemented our review of inpatient medical record data with surgical services data, and admission, discharge and transfer data. Clinical (etiology of hydrocephalus, age at initial shunt failure, number of shunt failures within two years), neonatal (age at initial permanent ventriculo-peritoneal shunt insertion, gestational age, weight at initial permanent ventriculo-peritoneal shunt insertion) and social determinants (race, gender, insurance status) were compiled for review. We allowed for two years of follow up data. Patients were considered eligible for this study if they underwent a permanent ventriculo-peritoneal shunt procedure between 2000 and 2005. Patients were excluded if they were previously treated for hydrocephalus at an outside healthcare facility prior to being followed at CHA.

The University of Alabama at Birmingham Institutional Review Board number X070718006, original approval on July 31st, 2007 (renewal approved July 23\textsuperscript{rd}, 2009), and CHA research confirmation number 0705-753 were obtained. Both a waiver of consent and waiver of HIPAA were approved. Confidentiality and HIPAA agreements were signed and are on file with CHA.
Statistical Analysis

SAS 9.2 was used to analyze the data. Univariate predictors associated with shunt failure were determined. Test statistics, including t-test and chi-square, were used to compare observed vs. expected results of time to event (i.e. time to shunt failure). Kaplan-Meier modeling was used to determine the cumulative probability of a child remaining free from shunt failure up to 2-years after initial ventriculo-peritoneal shunt placement. The Cox Proportional Hazard Model was used to determine the distribution of the independent effects on survival rates among covariates.

Results

We identified a total of 439 patients, born between 2000 and 2005, who underwent surgical intervention for the treatment of hydrocephalus. Of those 338 (76%) met the eligibility criteria and were included in our study cohort. 101 patients were ineligible because they either did not go on to receive a permanent procedure, they underwent their initial shunt procedure at an outside facility, they received a permanent shunt procedure other than a ventriculo-peritoneal shunt or they were lost to follow up. Of the 338 patients included in our study 159 (47%) had one or more shunt failures within the two-year follow up period (only the initial shunt failure was considered in this analysis). The remaining 178 had no shunt failure within two years of their initial VP shunt placement and one patient was censored due to death prior to the end of the two-year follow up period (see figure 1).

A summary comparison was conducted of those patients that were found to have had a shunt failure within two years of the initial VP insertion and those patients that did
not have a failure within two years (Table 3). Both the shunt survival and shunt non-
survival groups were found to be similar when comparing gender, race, insurance status
and etiology (congenital vs. acquired) of hydrocephalus. Patients born preterm were
approximately three times more likely to suffer initial VP shunt failure within two years
than were those patients born full term. Age at initial shunt placement was found to be
significant at p=<.0001. Patients undergoing initial VP shunt insertion prior to three
months of age had a greater failure rate (59%) than those receiving shunts between the
ages of three to six months (44%) or at more than six months (29%). Of the 159 shunts
that failed, 85 (53%) of those failed within the first three months of initial shunt
placement, 80% failed by one year post initial VP insert (see graph 1 and 2).

We used the Spearman’s rank correlation coefficient to measure the association of
clinical and neonatal factors (etiology of hydrocephalus, age at initial VP shunt insertion,
weight at initial shunt insertion, gestational age, and age at shunt failure, 18,20,24,32,35,36)
with shunt failure. Weight at initial shunt insertion and age at initial shunt insertion were
significant (p=<.0001). For every unit increase of weight (in kilograms) at initial shunt
placement, the likelihood of failure decreased (Spearman’s rank coefficient -.336,
p=<.0001). 75% of the children less than 2 kilograms at the time of their initial shunt
insertion experienced a shunt failure compared to 25% of those children greater than 5
kilograms at the time of their initial shunt insertion. For every unit increase of age (in
months) at initial shunt placement, the likelihood of failure decreased (Spearman’s rank
coefficient -.265, p=<.0001). Approximately 60% of children undergoing their initial
shunt insertion prior to three months of age experienced a shunt failure compared to 25%
of those children that underwent their initial shunt insertion after three months of age.
Using the life-table method we estimated the conditional probability of a patient experiencing shunt failure given that the patient had not experienced a shunt failure prior to the start of time $t$. In this case intervals in months (three, six, twelve, eighteen and twenty-four months) was the unit of analysis. Etiology of hydrocephalus ($p=.0412$), weight at initial shunt insertion ($p= <.0001$), and gestational age ($p=.005$) were associated with ventriculo-peritoneal shunt failure during the initial three months. Patients born less than 37 weeks gestational age had a 61% probability of having a shunt failure within three months of the initial shunt placement. Patients that were categorized as having acquired hydrocephalus (including premature intraventricular hemorrhage) had a 58% probability of having a shunt failure within three months of the initial shunt placement.

We calculated the hazard ratio to estimate the risk of failure in response to covariates in the model. The hazard for shunt failure for congenital hydrocephalus patients was 40% of the hazard for acquired hydrocephalus patients. The hazard for shunt failure for males was 109% of the hazard for shunt failures in females. The log-rank test of equality was used to test the null hypothesis that there were no differences in shunt survival times in the groups studied. Weight at initial shunt insertion and insurance status were found to have a difference in survival characteristics among the groupings, with a log-rank $p$ value of .0148 and .0003, respectively.

**Discussion**

Shunts are the current standard of care for the treatment and management of many types of hydrocephalus. This study sought to identify clinical, neonatal, and social factors associated with ventriculo-peritoneal shunt failure.
We analyzed several social factors including race, gender, and insurance status that were found to be significant in other studies of chronic childhood diseases\textsuperscript{2,14,28,34,41}. These factors were not predictive of VP shunt failure. We analyzed clinical and neonatal factors and found that age at initial ventriculo-peritoneal shunt insertion and weight at initial ventriculo-peritoneal shunt insertion was associated with shunt failure. Our findings complemented what has previously been published in the literature\textsuperscript{6,13,32,43}. Premature infants are difficult to manage for several reasons. Nutritional instability that prevents a child from feeding or gaining weight and thin skin that increases the risk of wound breakdown or hardware exposure leading to infection and increased failure risk. In infants with abdominal insufficiency (inability of the peritoneum to absorb CSF) and gastrointestinal disorders such as necrotizing enterocolitis (death of intestinal tissue) adding a foreign body such as a distal catheter may increase the risk of infection or failure\textsuperscript{5}. There is an increased risk for additional bleeds\textsuperscript{12,19,38,40}. Additionally this subpopulation can have increased proteinaceous material in the CSF increasing the risk for ventricular catheter obstructions. Mechanical issues, such as catheter length and valve size are a concern when shunting small infants. Although not found to be statistically significant, valve type and size has been associated with shunt failure in previously conducted studies\textsuperscript{8,24,39,43}. There are several limitations to our findings. As this was a retrospective study we were bound by the data that had previously been collected for clinical purposes and also limited by the accuracy of that data. In order to have a more controlled study population we included only those patients receiving a ventriculo-peritoneal shunt which limited our sample size and may have limited our ability to assess these predictors on our entire shunt
patient population. However we were able to evaluate a large birth cohort within a single institution adding strength to our study. As the majority of shunt failure occurs within the first two years of the initial permanent shunt placement our follow up period was adequate to assess the impact of neonatal factors on our patient population but limited our ability to estimate the impact of social and clinical factors.

**Conclusion**

Our study concluded that the premature patient population diagnosed and treated for hydrocephalus was at higher risk for shunt failure. Research endeavors are currently being conducted at our institution assessing the impact of prematurity on the treatment and management of hydrocephalus. A prospective cohort study would help to identify predictors of initial shunt failure.
Bibliography

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Table 4: Life Table Survival Estimations by Failure Status

Figures and Graphs

Figure 1: Study Patient Flowchart (N=number of patients)
Graph 1: Survival Curve of Patients with Initial Ventriculo-Peritoneal Shunt Failure (Overtime)
Graph 2: Hazard Curve of Patients with Initial Ventriculo-Peritoneal Shunt Failure (Overtime)
<table>
<thead>
<tr>
<th>Years of Shunt Survival</th>
<th>Survival Percentages</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Tuli et al\textsuperscript{43}</td>
</tr>
<tr>
<td>1-Year</td>
<td>60-75%</td>
</tr>
<tr>
<td>2-Year</td>
<td></td>
</tr>
<tr>
<td>3-Year</td>
<td></td>
</tr>
<tr>
<td>4-Year</td>
<td></td>
</tr>
<tr>
<td>10-year</td>
<td>30-37%</td>
</tr>
</tbody>
</table>
Figure 1: Study Patient Flowchart
(N= number of patients)

All Patients Undergoing Surgical Intervention from 2000-2005
N=439

Eligible Patients Based on Birth and Initial Treatment at CHA
N= 338

Failed within 2-years of initial VP insertion
N=159

Ineligible Patients (Initially diagnosed treated at an outside facility)
N=101

No Failure within 2-years of initial VP insertion (1 patient censored due to death)
N=179
Table 2: Fail No Fail Comparison

<table>
<thead>
<tr>
<th></th>
<th>Failed Within 24 Months N=159</th>
<th>Did Not Fail Within 24 Months N=178</th>
<th>P Values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>58 (36%)</td>
<td>68 (38%)</td>
<td>.630</td>
</tr>
<tr>
<td>Male</td>
<td>101 (64%)</td>
<td>111 (62%)</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>91 (57%)</td>
<td>108 (61%)</td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>60 (38%)</td>
<td>57 (32%)</td>
<td>.074</td>
</tr>
<tr>
<td>Hispanic</td>
<td>5 (3%)</td>
<td>14 (8%)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>2 (1%)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>*1 Missing Observation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insurance</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private</td>
<td>66 (42%)</td>
<td>74 (42%)</td>
<td>.559</td>
</tr>
<tr>
<td>Public</td>
<td>89 (56%)</td>
<td>100 (56%)</td>
<td></td>
</tr>
<tr>
<td>Self Pay</td>
<td>4 (3%)</td>
<td>5 (3%)</td>
<td></td>
</tr>
<tr>
<td>Age At Initial Shunt (in months)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-3</td>
<td>101 (64%)</td>
<td>70 (39%)</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>&gt;3 - 6</td>
<td>29 (18%)</td>
<td>37 (21%)</td>
<td></td>
</tr>
<tr>
<td>&gt; 6</td>
<td>29 (18%)</td>
<td>72 (40%)</td>
<td></td>
</tr>
<tr>
<td>Gestational Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 37 Weeks</td>
<td>117 (74%)</td>
<td>139 (78%)</td>
<td>.462</td>
</tr>
<tr>
<td>&gt; 37 Weeks</td>
<td>42 (26%)</td>
<td>40 (22%)</td>
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<tr>
<td>Etiology By Category</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Congenital</td>
<td>75 (47%)</td>
<td>83 (47%)</td>
<td>.564</td>
</tr>
<tr>
<td>Acquired</td>
<td>82 (52%)</td>
<td>91 (51%)</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>2 (1%)</td>
<td>5 (3%)</td>
<td></td>
</tr>
<tr>
<td>Weight at Initial Shunt (in Kg)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-2</td>
<td>30 (19%)</td>
<td>9 (5%)</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>&lt;2-5</td>
<td>78 (49%)</td>
<td>63 (35%)</td>
<td></td>
</tr>
<tr>
<td>&lt;5-10</td>
<td>28 (18%)</td>
<td>49 (28%)</td>
<td></td>
</tr>
<tr>
<td>&lt;10</td>
<td>11 (7%)</td>
<td>41 (23%)</td>
<td></td>
</tr>
</tbody>
</table>
Graph 1: Survival Curve of Patients with Initial Ventriculo-Peritoneal Shunt Failures
(N=159)

53%

80%
Graph 2: Hazard Curve of Patients with Initial Ventriculo-Peritoneal Shunt Failures
(N=159)
Table 3: Life Table Survival Estimations by Failure Status

<table>
<thead>
<tr>
<th>Failure Interval</th>
<th>Intervals (in months)</th>
<th>Conditional Probability of Failure</th>
<th>Hazard Ratio</th>
<th>Total Failed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initial Failure</td>
<td>0-3</td>
<td>.53</td>
<td>.24</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3-6</td>
<td>.24</td>
<td>.09</td>
<td></td>
</tr>
<tr>
<td></td>
<td>6-12</td>
<td>.46</td>
<td>.10</td>
<td></td>
</tr>
<tr>
<td></td>
<td>12-18</td>
<td>.65</td>
<td>.16</td>
<td></td>
</tr>
<tr>
<td></td>
<td>18-24</td>
<td>.91</td>
<td>.28</td>
<td>159</td>
</tr>
</tbody>
</table>
CHAPTER 4

The Impact of Sociodemographic Factors on the Delay of Seeking Medical Evaluation after Initial Onset of Ventriculo-Peritoneal Shunt Failure Symptoms in Children

SHANNON CN, FRANKLIN FA, ACAKPO-SATCHIVI L,
FARGASON C, KILGORE ML, KIRBY RS

In preparation for The Journal of Neurosurgery Pediatrics
Format adapted for dissertation
Abstract

Introduction The purpose of this study was to examine the sociodemographic factors (maternal age, maternal race, maternal education, maternal employment, income (household and primary caregiver), insurance status, household composition (number of adults living in the primary household, number of siblings living in the primary household), and distance to Children’s Hospital of Alabama) as they relate to delay in time of medical evaluation after initial onset of symptoms related to ventriculo-peritoneal shunt failure in the hydrocephalic pediatric patient population. Methods We identified 159 shunted hydrocephalus patients, born between the years 2000-2005, that have experienced at least one shunt failure requiring surgical intervention. We then mailed to each patient’s caregiver a sociodemographic survey along with a self-addressed stamped envelope. Included in the mail-out packet was a shunt failure symptom tracking sheet. The caregivers were asked to recall the symptoms their child experienced during his/her last shunt failure episode. Results Eighty one (50%) out of the 159 surveys were completed and returned giving us a smaller response rate and sample size than we projected at the start of this study. Ninety percent of our surveys were completed by the mother. Eight percent of our mothers were less than 19 years of age with the remaining ninety two percent split between the other three age categories (19-24, 25-30 and over 30). 48% of our mothers listed their employment status as ‘none’ at the time of the survey and reported household income of $20,000 or less. 39% of our mothers reported their education level to be high school/GED or less than high school. We found that primary caregiver income and maternal education level was associated with time to medical evaluation after the onset of shunt failure symptoms (p=.0042 and p=.0167,
respectively). Patients of these caregivers were evaluated for shunt failure either during the 3 to 7 day time interval or the greater than 7 day time interval. **Conclusion** Further research and a larger sample size are needed to determine what sociodemographic factors affect time to medical evaluation when a child is in shunt failure. We need to further examine the barriers associated with income and education level to determine what challenges our caregivers experience when accessing health care.

**Key Words**

Hydrocephalus, Pediatrics, Shunt Failure, Education, Sociodemographic Factors
Introduction

Over the last two decades national surveys, including the National Health Interview Survey, have captured and assessed the relationship between sociodemographic factors and the management of chronic diseases, such as asthma and diabetes, in the pediatric population. Although the literature is limited on studies that examined at sociodemographic factors and hydrocephalus, there have been many studies conducted that examined the impact of sociodemographic factors on the morbidity and mortality of chronic childhood illnesses. Insurance status, socioeconomic status, family unit, household income level, race/ethnicity, gender, and geographic location have been shown to impact available and accessible health care.

Adler et al found that variant levels of health existed not only among levels of socioeconomic status but also within each level. Benzeval found that income level was more important than income change when looking at access to care. Additionally this study found that long term income (consistent income over a 5 year period) had a greater impact on access than did current income. Seid in his study looking at barriers to care in a pediatric asthma population found that health insurance was a cause of forgone care. Wang conducted a study at the Hospital of Sick Children in Toronto and found that within his premature patient population, despite universal health care, socioeconomic related inequalities affected hospitalization and ultimately mortality rates. Heck et al tested the hypothesis that among children of lower socioeconomic status, children of single mothers would have relatively worse access to care than children in two-parent families, but there would be no access difference by family structure among children in higher SES families. The study examined the relationship between a child’s family
structure (e.g. single mother or two-parent family) and health care access and utilization (e.g. having no physician visits in the year prior to the study, no usual source of health care, and having unmet health care needs). The study found that when looking at physician visits in the past 12 months there was no difference between children of single mothers and those children with two-parent families. Heck’s study found that it was the maternal education level that affected health care access and utilization compared to the family structure. Single mothers and two-parent families’ experienced similar health seeking behaviors but when you stratified by levels of maternal education significant differences were identified. Several other studies looked at the direct causality of socioeconomic status and health 8,21-23. These studies found that lower socioeconomic status was associated with increased health inequalities, psychological and behavioral factors and mortality.

Based on our review of the literature we hypothesized that caregiver characteristics, including income level, socioeconomic status, education level, and employment status, significantly impact the time to medical evaluation once the shunt failure symptoms are recognized. We hypothesized that there was a delay in seeking medical attention if a family was of lower socioeconomic status. We also hypothesized that young single mothers, with less income and less education were less likely to recognize the symptoms related to shunt failure and were therefore less likely to seek necessary medical care for her child.
**Clinical Materials and Methods**

*Study Design*

We identified 159 shunted hydrocephalus patients, born between the years 2000-2005, that have experienced at least one shunt failure requiring surgical intervention. We then mailed to each patient’s caregiver a sociodemographic survey along with a self-addressed stamped envelope. Included in the mail-out packet was a shunt failure symptom tracking sheet. The caregivers were asked to recall the symptoms their child experienced during his/her last shunt failure episode.

*Demographic Survey and Symptoms Tracking Sheet*

The demographic survey captured information related to the primary caregiver, the primary household, the patient, and the out-of-pocket expenses incurred by the primary caregiver (see table 1). The symptoms tracking sheet was used for caregivers to identify the symptoms that their child experienced during the last shunt failure episode. Symptoms synonymous with shunt failure were included on the tracking sheet. We also asked caregivers to recall the length of time they noted their child having each of the symptoms listed (see table 2). These surveys were completed and returned on a voluntary basis.

*Analysis*

To describe the characteristics of the study sample, means, proportions, variances, and ranges were calculated for all variables. Two sample t-tests were used to test for mean difference between participants on the continuous variables. To test for association
between caregiver sociodemographic characteristics chi-square tests were conducted on all nominal and ordinal variables and the Fisher’s exact test was used when expected cell sizes were less than 5. We used multiple linear regression models to evaluate the impact of sociodemographic factors on time to medical evaluation after the onset of shunt failure symptoms. All variables that were identified with p values less than or equal to .01 in the previous simple linear regression models were included as possible explanatory variables for selection.

During our data cleaning phase of our study we determined several limitations in our data collection. We originally asked for the estimated household income for the primary household. However household income did not properly represent primary caregiver income. Therefore we added the variable primary caregiver income level and used the Department of Labor statistics as a proxy measurement taking into consideration age and educational level of the caregiver.

The original operational definition of time to delay of medical evaluation allowed us to collect the variable as a continuous variable (time equal to each day up to 7 days and a category for greater than 7 days). However our time categories did not allow for an adequate sample size per category. For this reason we combined our time variable into a categorical variable to include: less than one day, one to three days, three to seven days and greater than seven days.

For consistency we utilized MapQuest, as used in previously published studies, to determine distance from the primary household to CHA. We examined admit, discharge and transfer data to capture the primary residence. We then utilized MapQuest tool to determine the distance in miles from the primary residence to Children’s Hospital.
of Alabama. This allowed us to have a standardized measurement for comparison.

Given that both time and miles were measurements of distance we decided to use miles in our analysis. Once we gathered all the information we categorized distance into 3 categories: 1) 0 to 60 miles from CHA, 2) 60 to 100 miles from CHA, 3) more than 100 miles from CHA

**Results**

We identified a total of 439 patients that underwent surgical intervention for the treatment of hydrocephalus. 101 patients were ineligible because they either did not go on to receive a permanent ventriculo-peritoneal shunt procedure, underwent their initial ventriculo-peritoneal shunt procedure at an outside facility, received a permanent shunt procedure other than a ventriculo-peritoneal shunt or were loss to follow up. The remaining 338 (76%) met the eligibility criteria and were included in our study birth cohort. Of the 338 patients included in our study 159 (47%) had one or more shunt failures within the 2-year follow up period. These caregivers received a survey packet in the mail. Of the 159 surveys mailed out 81 (51%) surveys were completed and returned. The remaining 78 surveys were either not received or not completed (Figure 1).

Univariate analysis was conducted to look at the range of observations by each independent variable. We used chi squares to test the null hypothesis of no association between the sociodemographic factors in our model. Prematurity and gender were binary variables while all other independent variables in the model were categorical.
Caregiver Characteristics

Eighty one surveys were completed and returned giving us a 50% response rate. Although we were unsuccessful in reaching our estimated goal of 70% the surveys returned seemed to provide a representative sample of our patient population (see table 3). Ninety percent of our surveys were completed by the mother. Eight percent of our mothers were less than 19 years of age with the remaining ninety two percent split between the other three age categories (19-24, 25-30 and over 30).

48% of our mothers listed their employment status as ‘none’ at the time of the survey and reported household income of $20,000 or less. 39% of our mothers reported their education level to be high school/GED or less than high school.

For this study insurance status was a categorical variable- self-pay, private (BCBS, military, commercial and HMO) and public (Medicaid, SCHIP, etc.). Private insurance represented 46% of our patients while public insurance made up 51% with self pay patients representing only 3%.

Child Characteristics

Forty percent of the children with completed surveys had their initial ventriculoperitoneal shunt placement prior to the age of 3 with 58% born premature. Seventy percent of the children with completed demographic surveys were Caucasian with the remaining 30% listed as African American or other. The number of males and females in our study was 48 to 33 respectively.
**Time**

We ran a regression analysis and found that lower income and lower education level of the primary caregiver was associated with later time to medical evaluation after the onset of shunt failure symptoms ($p=0.0042$ and $p=0.0167$, respectively). Patients of these caregivers were evaluated for shunt failure either during the 3 to 7 day time interval or the greater than 7 day time interval. No other factors were found to be associated with time to medical evaluation at CHA after the onset of shunt failure symptoms.

**Discussion**

Our analysis concluded that primary caregiver income and maternal education level were associated with time delays in seeking medical evaluation after the onset of shunt failure symptoms. These results are in line with what has previously been found and reported. Income level and ultimately socioeconomic status does seem to influence access to health care in our patient population. What we still are not able to determine is why.

We looked at distance from the primary household to Children’s Hospital of Alabama but found no correlation between income level and miles away from the hospital. However we cannot discuss caregiver income level without giving full consideration to the lack of transportation that many families face on a daily basis, making distance a barrier to health care. A recently published study by looking at emergency department use among Medicaid enrollees concluded that driving time to the hospital did impact utilization \(^{15}\). If a family must rely on public transport, a family member or friend as a means for transportation to a medical facility, time becomes a
factor. Although transportation may be available it may not be easily accessible making distance, however great or small, a much larger barrier to health care. If the primary caregiver is working in an hourly job, he/she may not have access to benefits such as paid time off, and may not have extra disposable income to use for things like co-pays, baby sitters for siblings, bus fair, food, etc.

Maternal education can pose its own set of barriers. Reading and understanding written materials caregivers receive prior to the original hospitalization can be difficult if the materials are not written in such a way that all education levels can comprehend; Heck et al found that even in two-parent families if the mother had a lower education level the child had more unmet health needs compared to those children who had mothers with higher levels of education\(^7\). A lack of understanding of the signs and symptoms of shunt failure may also be a barrier to address. A study looking at child mortality due to shunt failure found that lack of education was the cause for delayed medical evaluation resulting in a child’s death\(^1\). Cultural and language differences may also be a barrier. Several studies have shown that there is an increased need for health-related educational materials and media for households that speak a language other than English as their primary language\(^{16,18}\). These studies showed that if caregivers are educated, appropriately as it relates to their culture, they will seek health care. What we are still unclear on is to what degree these factors delay seeking medical evaluation after the onset of shunt failure symptoms in our patient population. There could be several reasons for our results. We had a limited number of responses to the survey that we sent out giving us a smaller sample size for analysis. Additionally we may have social response bias skewing our results. Although the survey was voluntary (all returned surveys were
completed in their entirety) and the caregiver was instructed to answer only the questions he/she felt comfortable answering, several of the questions were related to sensitive information. For this reason caregivers may not have answered the questions as accurately as we anticipated.

We also asked our caregivers to identify the shunt failure symptoms and length of those symptoms prior to medical evaluation that their child experienced during the last shunt failure. Although we provided a tracking sheet of symptoms we did not categorize symptoms by age and we did not include symptoms unrelated to shunt failure and therefore were unable to appropriately assess knowledge directly related to signs and symptoms of shunt failure. The caregivers did seem to know what symptoms their child had experienced but it is unclear if they understood about shunt failure specifically or if they understood the importance of time when seeking medical evaluation.

Our study was conducted at a single institution with a large patient population. This allowed us to identify a large number of patients that had experienced a shunt failure within the study period of interest. Although we identified a large sample size, we were limited by the number of survey responses which gave us a small sample size to analyze. This may have led to our study being underpowered, which kept us from detecting differences in time to medical evaluation among groups.

This study also allowed us to develop and pilot a survey instrument that can be further defined for future studies. We did not meet the projected response rate of 70% but did finish the study having a return response rate of 50%. This response rate was sufficient for allowing us to begin assessing our hydrocephalic patient population and we
have identified several ways to improve the response rate for future studies including performing the survey during the hospitalization for the episode of shunt failure

**Conclusion**

This study evaluated the impact of sociodemographic factors on time to medical evaluation after the onset of shunt failure symptoms. We found that primary caregiver income and maternal education level were associated with time to medical evaluation. We hypothesize that there were barriers directly related to these factors, such as lack of access to transportation, lack of flexibility in the caregivers job, lack of additional disposable income, lack of culturally appropriate educational materials and the need for improved shunt teaching prior to discharge that influence the time a caregiver seeks medical evaluation for their child. This was our first attempt at identifying knowledge of hydrocephalus and shunt failure and how that knowledge affects health seeking behavior in this patient population. Further research should be conducted to look at this issue.
Bibliography

Tables and Figures

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Table 3: Symptoms Tracking Sheet

Table 4: Responders vs. Non-Responders Characteristics

Table 5: Time to Medical Evaluation after Initial Onset of Recognized Shunt Failure Symptoms by Sociodemographic Factors of the Caregiver

Table 6: Time to Medical Evaluation after Initial Onset of Recognized Shunt Failure Symptoms by Sociodemographic Factors of the Child
Figure 1: Response Rate for Survey Completion
(N= number of patients)

All Patients Undergoing Surgical Intervention from 2000-2005
N=439

Eligible Patients Based on Birth and Initial Treatment at CHA
N= 338

Ineligible Patients (Initially diagnosed treated at an outside facility)
N=101

Had a VP shunt failure and sent a survey packet to complete
N=159

Did not experience a shunt failure
N=179

Surveys and symptoms tracking sheets returned
N=81

Surveys not returned or completed
N=78

Surveys not completed by caregiver
N=65

Survey packets returned due to incorrect address or no forwarding address
N=13
<table>
<thead>
<tr>
<th>Table 1: Caregiver Demographic and Economic Survey</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>DEMOGRAPHIC &amp; ECONOMIC DATA FORM</strong></td>
</tr>
<tr>
<td><em>(To be completed by the caregiver)</em></td>
</tr>
<tr>
<td>Date Survey Completed:</td>
</tr>
<tr>
<td>Name of Patient:</td>
</tr>
<tr>
<td>Age at First Surgery:</td>
</tr>
<tr>
<td>Patient Date of Birth:</td>
</tr>
<tr>
<td>Date of Last Surgery (if known):</td>
</tr>
<tr>
<td>Premature Infant: Y or N</td>
</tr>
<tr>
<td># of Previous Shunt Surgeries:</td>
</tr>
<tr>
<td>Is the Patient Enrolled in Special Education Classes? Y or N</td>
</tr>
<tr>
<td>Name of Person Completing the Survey:</td>
</tr>
<tr>
<td>Relationship to Patient:</td>
</tr>
<tr>
<td>Address of Primary Household (where the child lives most of the time)</td>
</tr>
</tbody>
</table>

**PLEASE CIRCLE OR MARK THE CATEGORY THAT BEST DESCRIBES YOU**

<table>
<thead>
<tr>
<th><strong>Mom’s Age (or Primary Caregiver)</strong></th>
<th>Less than 19</th>
<th>19-24</th>
<th>25-29</th>
<th>30-35</th>
<th>Greater than 35</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mom’s Education (or Primary Caregiver)</strong></td>
<td>Less than High School</td>
<td>High School Diploma or GED</td>
<td>Some College (less than 2 years)</td>
<td>College</td>
<td>Graduate Degree</td>
</tr>
<tr>
<td><strong>Mom’s Employment (or Primary Caregiver)</strong></td>
<td>None</td>
<td>10 to less than 20</td>
<td>20 to less than 35</td>
<td>35-45</td>
<td>More than 45</td>
</tr>
<tr>
<td><strong>Insurance Status</strong></td>
<td>Self Pay</td>
<td>Private (BCBS, etc)</td>
<td>Public (Medicaid, SCHIP)</td>
<td>Government (Military)</td>
<td></td>
</tr>
<tr>
<td><strong>Number of Adults in the Primary Household</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>More than 3</td>
<td></td>
</tr>
<tr>
<td><strong>Number of Siblings in the Primary Residence</strong></td>
<td>None</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>More than 3</td>
</tr>
<tr>
<td><strong>Ages of Siblings</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**PLEASE CIRCLE OR MARK THE CATEGORY THAT BEST DESCRIBES YOU**

<table>
<thead>
<tr>
<th><strong>Estimated Household Income</strong></th>
<th>Less than $10,000</th>
<th>$10,000-$20,000</th>
<th>$20,001-$30,000</th>
<th>$30,001-$45,000</th>
<th>$45,001-$60,000</th>
<th>$60,001-$75,000</th>
<th>Greater than $75,000</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of Days Missed From Work Due to Child’s Shunt Related Illness</strong></td>
<td>0-2 days</td>
<td>2-5 days</td>
<td>5-7 days</td>
<td>7-10 days</td>
<td>More than 10 days</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Did you return to your regular work hours after the child went home from the hospital</strong></td>
<td>Yes, I am working the same hours</td>
<td>No, I am working less hours</td>
<td>How many hours a week do you work now?</td>
<td>No, I am not working at all</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 2: Caregiver Out-of-Pocket Expenses Incurred during the Shunt Failure Episode

<table>
<thead>
<tr>
<th>Did you pay for:</th>
<th>How much did you spend?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transportation &amp; Gas: <strong>Y or N</strong></td>
<td>$</td>
</tr>
<tr>
<td>Lodging and Food: <strong>Y or N</strong></td>
<td>$</td>
</tr>
<tr>
<td>Co-Pays: <strong>Y or N</strong></td>
<td>$</td>
</tr>
<tr>
<td>Additional Childcare for Siblings: <strong>Y or N</strong></td>
<td>$</td>
</tr>
<tr>
<td>How many days before admission did you note:</td>
<td>Did Not Have</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>--------------</td>
</tr>
<tr>
<td>Headache</td>
<td></td>
</tr>
<tr>
<td>Vomiting</td>
<td></td>
</tr>
<tr>
<td>Fussiness</td>
<td></td>
</tr>
<tr>
<td>Sleepiness</td>
<td></td>
</tr>
<tr>
<td>Fever</td>
<td></td>
</tr>
<tr>
<td>Seizure</td>
<td></td>
</tr>
<tr>
<td>CSF Leak At The Incision Site</td>
<td></td>
</tr>
<tr>
<td>Abnormal Eye Movement</td>
<td></td>
</tr>
<tr>
<td>Swelling Along The Shunt Track</td>
<td></td>
</tr>
<tr>
<td>Redness Along The Shunt Track</td>
<td></td>
</tr>
<tr>
<td>Firm Soft Spot</td>
<td></td>
</tr>
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</table>
Table 4: Survey Responder vs. Non-Responder Characteristics

<table>
<thead>
<tr>
<th></th>
<th>Responders N=81 (%)</th>
<th>Non-Responders N=78 (%)</th>
<th>P values</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>45 (56%)</td>
<td>56 (72%)</td>
<td>.001</td>
</tr>
<tr>
<td>Female</td>
<td>36 (44%)</td>
<td>22 (28%)</td>
<td></td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White Non Hispanic</td>
<td>48 (60%)</td>
<td>43 (55%)</td>
<td>.298</td>
</tr>
<tr>
<td>African American</td>
<td>28 (34%)</td>
<td>32 (41%)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>5 (6%)</td>
<td>3 (4%)</td>
<td></td>
</tr>
<tr>
<td><strong>Insurance Status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private</td>
<td>35 (43%)</td>
<td>31 (40%)</td>
<td>.463</td>
</tr>
<tr>
<td>Public</td>
<td>44 (56%)</td>
<td>45 (58%)</td>
<td></td>
</tr>
<tr>
<td>Self</td>
<td>2 (2%)</td>
<td>2 (2%)</td>
<td></td>
</tr>
<tr>
<td><strong>Etiology of Hydrocephalus</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acquired</td>
<td>34 (42%)</td>
<td>41 (54%)</td>
<td>.046</td>
</tr>
<tr>
<td>Congenital</td>
<td>46 (57%)</td>
<td>36 (46%)</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>1 (1%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Average Age of the child at Initial VP Shunt Insert</strong></td>
<td>5 months</td>
<td>4 months</td>
<td></td>
</tr>
</tbody>
</table>
Table 5: Time to Medical Evaluation after Initial Onset of Recognized Shunt Failure Symptoms by Sociodemographic Factors of the Caregiver N=81

<table>
<thead>
<tr>
<th>Time in Days</th>
<th>&lt; 1 day</th>
<th>1- &lt; 3 days</th>
<th>3- &lt; 7 days</th>
<th>Greater than 7 days</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Maternal Age (years)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 19</td>
<td>1</td>
<td>3</td>
<td>3</td>
<td>0</td>
<td>.9342</td>
</tr>
<tr>
<td>19-24</td>
<td>8</td>
<td>7</td>
<td>6</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>25-29</td>
<td>4</td>
<td>8</td>
<td>5</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Greater than 30</td>
<td>6</td>
<td>12</td>
<td>6</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td><strong>Maternal Education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>.017</td>
</tr>
<tr>
<td>High School Diploma or GED</td>
<td>4</td>
<td>4</td>
<td>23</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Some College (less than 2 years)</td>
<td>8</td>
<td>15</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>College or greater</td>
<td>5</td>
<td>2</td>
<td>6</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td><strong>Maternal Employment (hours/week)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>8</td>
<td>15</td>
<td>23</td>
<td>2</td>
<td>.4526</td>
</tr>
<tr>
<td>10 to less than 20</td>
<td>3</td>
<td>5</td>
<td>4</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>20 to less than 35</td>
<td>5</td>
<td>5</td>
<td>2</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Greater than 35</td>
<td>3</td>
<td>5</td>
<td>1</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td><strong>Primary Caregiver Income Level ($)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;17923</td>
<td>4</td>
<td>6</td>
<td>12</td>
<td>2</td>
<td>.0042</td>
</tr>
<tr>
<td>&lt;23521</td>
<td>8</td>
<td>14</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>&lt;34993</td>
<td>5</td>
<td>2</td>
<td>6</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>&lt;44266</td>
<td>1</td>
<td>6</td>
<td>0</td>
<td>3</td>
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</tr>
<tr>
<td><strong>Insurance Status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Self</td>
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<td>1</td>
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<td>0</td>
<td>.1413</td>
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<td>21</td>
<td>9</td>
<td>5</td>
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</tr>
<tr>
<td><strong>Number of Adults Living in the Primary Household</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>3</td>
<td>9</td>
<td>3</td>
<td>2</td>
<td>.6155</td>
</tr>
<tr>
<td>2</td>
<td>12</td>
<td>17</td>
<td>15</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>3 or more</td>
<td>4</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td><strong>Distance from Primary Household to CHA</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 &lt;60 miles</td>
<td>11</td>
<td>10</td>
<td>6</td>
<td>5</td>
<td>.5121</td>
</tr>
<tr>
<td>60 &lt;100 miles</td>
<td>3</td>
<td>11</td>
<td>5</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>&gt;100 miles</td>
<td>5</td>
<td>9</td>
<td>9</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Time in Days</td>
<td>&lt; 1 day</td>
<td>1- &lt; 3 days</td>
<td>3- &lt; 7 days</td>
<td>Greater than 7 Days</td>
<td>P Value</td>
</tr>
<tr>
<td>--------------</td>
<td>---------</td>
<td>-------------</td>
<td>-------------</td>
<td>---------------------</td>
<td>---------</td>
</tr>
<tr>
<td>Child’s Age at Initial VP Shunt Placement</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-3 years</td>
<td>9</td>
<td>6</td>
<td>1</td>
<td>17</td>
<td>.7389</td>
</tr>
<tr>
<td>3-6 years</td>
<td>4</td>
<td>4</td>
<td>1</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>6-12 years</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>&gt; 12 years</td>
<td>4</td>
<td>7</td>
<td>1</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Female</td>
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<td>15</td>
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<td>4</td>
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<tr>
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<td>12</td>
<td>15</td>
<td>14</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Race of the Child</td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>Caucasian</td>
<td>13</td>
<td>19</td>
<td>16</td>
<td>8</td>
<td>.7791</td>
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<tr>
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<td>9</td>
<td>2</td>
<td>2</td>
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</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Born Premature</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>9</td>
<td>21</td>
<td>7</td>
<td>8</td>
<td>.034</td>
</tr>
<tr>
<td>No</td>
<td>10</td>
<td>9</td>
<td>13</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>
CHAPTER 5

The Economic Impact of Ventriculo-Peritoneal Shunt Failure

SHANNON CN, FARGASON C, FRANKLIN FA, KIRBY RS,
ACAKPO-SATCHIVI L, KILGORE ML

In preparation for The Journal of Neurosurgery Pediatrics
Format adapted for dissertation
Abstract

Introduction Understanding medical costs surrounding chronic illnesses, such as hydrocephalus, continues to be a priority among researchers, hospital administrators and third party payers. Equally or potentially more important is the need to understand the short-term and long term costs experienced by the families caring for children with chronic illnesses. As seen in previously conducted research, chronic childhood illnesses increase the financial burden to the family unit. We hypothesize that hydrocephalus is no different than other chronic childhood illnesses. Therefore the purpose of this study was to determine what the third party payer reimbursement rate was for a shunt failure episode and to determine what out-of-pocket expenses families associated with a ventriculo-peritoneal shunt failure episode. Methods We conducted a retrospective review of patients, born between the years 2000-2005, initially diagnosed and treated for hydrocephalus at the Children’s Hospital of Alabama (CHA). Patients were considered eligible for the study if they experienced a shunt failure episode within 2-years following discharge from the hospitalization for the initial ventriculo-peritoneal shunt placement. Institutional reimbursement data from the Children’s Hospital of Alabama incurred during a shunt failure episode were analyzed. Self-reported demographic survey was mailed out and caregivers were asked to report any out of pocket expenses (transportation cost, food and lodging, sibling child care expenses, copayments) they encountered during their child’s shunt failure episode. Results Institution reimbursements and caregiver out-of-pocket expenses were combined to give us the payer cost for a shunt failure episode at our institution. The mean reimbursement total for shunt failure was $17,211. The mean caregiver out-of-pocket expenses incurred during the shunt failure episode was $893.
The mean total cost of a shunt failure episode was $17,668. The mean length of stay for a shunt failure was 6.84 days. When looking at hospital admissions by type of shunt failure the length of stay for a shunt failure episode ranged from 4.86 to 13.9 days (p value=.0088) and third party payer reimbursement totals ranged from $11,187 to $41,514 (p value=.0094). Caregiver out-of-pocket expenses also differed across shunt failure type ranging from $628 to $2780 for a shunt failure episode (p value=.0004). Caregiver out-of-pocket expenses were significant when comparing shunt failure by private versus public insurance. Caregivers with private insurance averaged $1279 for out-of-pocket expenses while caregivers with public insurance averaged $536 for out-of-pocket expenses (p value=.0066). **Conclusion** Ventriculo-peritoneal shunt failures continue to be costly. Additional research is needed to identify ways to improve patient outcomes by reducing required shunt revisions, and by reducing shunt revisions due to shunt infections thereby reducing the length of stay of these patients.

**Key Words**

Ventriculo-peritoneal shunt, pediatrics, shunt failure, cost analysis


**Introduction**

The treatment and management of children with hydrocephalus has contributed to the thirty- four percent increase in utilization and hospitalization length of stay (LOS) in the United States over the last decade \(^1\)\(^,\)\(^17\), accounting for more than an estimated $100 million of national healthcare expenditures annually \(^11\)\(^,\)\(^19\). Previous studies have assessed the treatment of hydrocephalus based on hospital charges, using IDC-9 or CPT (current procedural terminology) codes\(^16\)\(^,\)\(^17\). Simon et al recently published a cross sectional study that looked at hospital admissions, total hospital days and total hospital charges of children with hydrocephalus over 3 points in time in comparison to other subpopulations of chronically ill children (e.g. cystic fibrosis, gastrostomy)\(^20\). Her analysis also utilized 2003 ICD-9 and CPT codes to determine the impact of hydrocephalus on admissions, hospital day and hospital charges. Simon found that hydrocephalus accounted for approximately 38,000 admissions, and 400,000 hospital days. Additionally she found that hydrocephalus made up 3.1% of all pediatric acute care hospital charges ($1.4-2.0 billion for the year 2003) compared to cystic fibrosis that accounted for 2.9% of hospital charges. This study concluded that children with hydrocephalus use a disproportionate share of hospital days and healthcare dollars.

Families caring for children with hydrocephalus incur out-of-pocket expenses each time their child has a shunt failure episode. Although not previously examined in the hydrocephalus patient population there are many studies in the literature that evaluated how caring for a chronically ill child affects the family financially. These studies examined wage and labor outcomes, maternal employment status, access to services and resources, transportation costs, and costs associated with the care of siblings.
They demonstrated that compared to families without a chronically ill child both maternal and paternal employment rates were lower, and parents received lower wages when they worked\textsuperscript{15}. Level of severity and the need for increased care for the child over time led to increased reporting of financial problem \textsuperscript{14}. Also seen was the variation among socioeconomic status. Families with lower socioeconomic status were more likely to report finance-related problems as these families had less resources available \textsuperscript{14}.

As seen in previously conducted research, chronic childhood illnesses increase the financial burden to the family unit. We hypothesize that hydrocephalus is no different than other chronic childhood illnesses. Therefore the purpose of this study was to determine what the third party payer reimbursement rate was for a shunt failure episode and to determine what out-of-pocket expenses families associated with a ventriculo-peritoneal shunt failure episode.

**Clinical Materials and Methods**

*Patient Population*

We conducted a retrospective review of patients, born between the years 2000-2005, initially diagnosed and treated for hydrocephalus at the Children’s Hospital of Alabama (CHA). Patients were considered eligible for the study if they experienced a shunt failure episode within 2-years following discharge from the hospitalization for the initial ventriculo-peritoneal shunt placement (see figure 1). Patients were excluded if they experienced no shunt failure episode within the 2-year follow up period or if they
experienced a shunt failure episode prior to discharge from initial ventriculo-peritoneal shunt placement hospitalization.

Study Design

Institutional reimbursement data from the Children’s Hospital of Alabama incurred during a shunt failure episode were analyzed. Cost variables (hospital, physician and emergency department reimbursements, and length of stay), and demographic variables (race, gender, insurance status, address for primary residence) were collected. We adjusted for inflation over the study period using the Bureau of Labor Statistics Consumer Price Index inflation calculator using 2009 as the comparison year.

Self-reported demographic survey was mailed out to 126 caregivers. In this survey we asked caregivers to also tell us about any out-of-pocket expenses (transportation cost, food and lodging, sibling child care expenses, copayments) they encountered during their child’s shunt failure episode (see table1). 126 patients received the survey. Sixty-five (52%) caregivers returned the survey with noted out-of-pocket expenses. The remaining sixty-one (48%) did not return the survey and therefore out-of-pocket expenses were not captured for these caregivers. We are not able to conclude whether the caregiver was unable to recall this information or if the no out-of-pocket expenses were incurred by the caregiver during the shunt failure episode.

The University of Alabama at Birmingham Institutional Review Board number X070718006, original approval on July 31st, 2007 (renewal approved July 23rd, 2009), and CHA research confirmation number 0705-753 were obtained. Both a waiver of consent and waiver of HIPAA were approved. Confidentiality and HIPAA agreements were signed and are on file with CHA.
Variables

For the purpose of this study, we defined shunt failure as an episode of symptoms that required hospitalization and surgical intervention for shunt failure with replacement of all or part of the ventriculo-peritoneal shunt system. Additionally any visits to the Emergency Department for evaluation of shunt failure (determined by the ICD-9 diagnosis code V45.2 for postsurgical presence of cerebrospinal fluid drainage device), up to 90-days of his/her required hospitalization for shunt failure was included as part of the shunt failure episode.

For consistency we utilized MapQuest (a tool using a geocoding algorithm to estimate the latitude and longitude of the address of interest by US post office data) to estimate the most direct route in miles and time from the primary household to Children’s Hospital of Alabama. To determine mileage cost we multiplied our mileage estimate by $0.55, the current NIH (National Institutes of Health) governmental rate for mileage reimbursement.

Reimbursement total was the total third party payer reimbursements for hospital charges, physician charges and emergency department charges related to the shunt failure episode. Patient total was the self-reported out-of-pocket expenses incurred by the primary caregiver during the last shunt failure episode. The sum of the reimbursement total and the patient total was the total costs of a shunt failure episode. Length of stay was the total number of in-patient hospital days associated with the shunt failure episode. Insurance status was a binary variable listed as Private (BlueCross BlueShield, commercial, military or HMO) or Public (Medicaid, AlKids, SCHIP). For the purposes of this study we utilized primary insurance only and did not give consideration to those
patients that may have a secondary insurance provider. Etiology was a binary variable listed as Acquired (IVH, meningitis, tumor, post traumatic brain injury) or Congenital (spina bifida, genetic, dandy walker, hydranencephel, arachnoid cyst, and aqueductal stenosis). All other variables captured were caregiver and patient demographic variables.

**Results**

*Characteristics of Study Population*

We identified a total of 126 patients that experienced a shunt failure episode. Our study population insurance mix was split with 46% private insurance and 54% public insurance. The average gestational age was 33.6 weeks and the average age at initial ventriculo-peritoneal shunt placement was 5 months. Non Hispanic white (59%) made up the majority of our study population followed by African Americans (36%) with the remaining patients classified as either Hispanic or other. Of the 126 patients included in the study 67 (53%) of them fell into the ‘acquired hydrocephalus’ etiology category, 57 (45%) were listed as congenital and 2 had an etiology of unknown origin. We examined type of shunt failure within our study population and found that the majority of our patients were categorized as either shunt obstruction (65%) or shunt infection (16%) (table 2).

*Cost Characteristics*

We obtained patient level third party payer reimbursement data (hospital, physician and Emergency Department) from Children’s Hospital of Alabama and the Health Services Foundation of the University of Alabama at Birmingham. For our
analysis we used only reimbursements and avoided charges as we did not have access to the itemized list of costs incurred during the hospitalization. The total reimbursement was the sum of the hospital, physician and Emergency Department reimbursements. Emergency Department reimbursements were only included if the emergency department visit was to evaluate the patients’ signs and symptoms related to shunt failure and occurred within 90-days of the hospitalization for shunt failure. The 90-day period is an arbitrary timeframe but one that was decided upon after discussions with experienced neurosurgeons. Reimbursements for direct admission through the Emergency Department were included in the hospital reimbursements data and therefore were not a separate category in our analysis. Caregiver out-of-pocket expenses (transportation, mileage, food and lodging, child care costs for siblings, and co-payments) were estimated from self-report surveys. Institution reimbursements and caregiver out-of-pocket expenses were combined to give us the cost for a shunt failure episode at our institution. The mean reimbursement total for shunt failure was $17,211. The mean caregiver out-of-pocket expenses incurred during the shunt failure episode was $893. The mean total cost of a shunt failure episode was $17,668. The mean length of stay for a shunt failure was 6.84 days. We looked at the reimbursements associated with a shunt failure episode by type of shunt failure (see table 3). The average hospital length of stay for a shunt failure episode ranged from 4.86 to 13.9 days (p value=.0088). Third party payer reimbursement totals ranged from $11,187 to $41,514 (p value=.0094). Caregiver out-of-pocket expenses also differed across shunt failure type ranging from $628 to $2780 for a shunt failure episode (p value=.0004).
We further evaluated shunt failure reimbursements by insurance status at the time of the shunt failure (tables 4). Caregiver out-of-pocket expenses were significant when comparing shunt failure by private versus public insurance. Caregivers with private insurance averaged $1279 for out-of-pocket expenses while caregivers with public insurance averaged $536 for out-of-pocket expenses (p value = .0066). Patients with private insurance were hospitalized an average of 6.34 days while those with public insurance were hospitalized an average of 7.48 days. Private insurance reimbursed at an average of $21,268 per procedure while public insurance reimbursed at an average of $14,382. Neither length of stay nor reimbursement totals was found to be significant.

**Discussion**

Shunted hydrocephalus, as with other childhood chronic illnesses, requires a lifetime of management often requiring multiple surgical interventions to manipulate or replace a child’s implanted shunt system. Previous studies have looked at ICD-9 billing codes to estimate the charges associated with a shunt failure and related shunt revisions. Our study looked further into the financial impact associated with shunt failure by assessing what third party payers reimbursed and what out-of-pocket expenses caregivers incurred during a shunt failure episode.

We found that type of shunt failure was associated with the length of stay, third party payer reimbursement rate and the caregiver out-of-pocket expenses incurred during a shunt failure episode. Although all shunt failure types lead to a surgical intervention requiring new implants for either part or all of the shunt system, these failure types are dissimilar with regards to treatment and management. Shunt obstruction is often treated
with one surgical intervention (revision of the obstructed catheter or valve only) while shunt infections require at least two surgical interventions (removal of the entire existing shunt system and insertion of a new shunt system after three confirmed CSF culture negative results) and a seven day course of antibiotics making this particular type of failure more costly. The increased length of stay required to treat a shunt infection not only puts a patient at higher risk for additional infection, it also increases out-of-pocket expenses incurred by the caregiver.\textsuperscript{10,12,19} Shunt malplacement or malfunctions such as a CSF leak or loculated ventricles are often more difficult to treat often leading to additional procedures and diagnostic scans, and longer hospitalizations. Given the recent push by state governments for hospitals to implement patient safety guidelines and quality improvement programs to improve overall outcomes of patients,\textsuperscript{2-9} it is important to reduce the frequency of shunt failure episodes including shunt infections our patient population experiences.

We also found that insurance status was associated with caregiver out-of-pocket expenses incurred. Those patients with private insurance had a greater amount of out-of-pocket expenses than those with public insurance. There are several reasons that could explain our findings. Within our study population the average distance from the primary household to CHA for those with private insurance was 112.5 miles compared to the 63 miles for those with public insurance. This could impact gas, food and lodging expenses. Secondly, private insurance usually carries with it a co-payment for hospitalization and prescriptions. Additionally, caregivers who receive public insurance usually also qualify for other governmental or public health services such as transportation vouchers, food vouchers, and reduced prescription costs.
This study allowed us to assess the cost of shunt failure in a single institution with a large patient population. To give us a more homogeneous patient population we excluded patients that were previously treated at an outside facility and/or experienced their initial shunt failure prior to discharge from their initial ventriculo-peritoneal shunt hospitalization. We were able to utilize hospital level reimbursement data that allowed us to gain a more accurate picture of the financial impact associated with a shunt failure episode. Additionally we were able to add a patient caregiver component to our analysis, a cost component that has not received a great deal of attention in the literature. One limitation of this study was the lack of detail about the caregiver’s indirect costs associated with a shunt failure episode. Capturing information regarding type of employment (salary vs. hourly), time off from work due to their child’s shunt failure episode, and lost wages, would allow us to understand the financial burden on the family unit and the potential barrier to health care access these caregivers face.

**Conclusion**

The purpose of this study was to determine the third party payer reimbursement rate for a shunt failure episode and to determine the out-of-pocket expenses families incurred during a ventriculo-peritoneal shunt failure episode. We found that reimbursement totals, length of stay and caregiver out-of-pocket expenses were associated with type of shunt failure and with insurance status. A case control study looking at those patients treated for a shunt failure compared to patients that did not experience a shunt failure is needed to further estimate the financial impact of a shunt failure episode.
Bibliography

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7. New York Hospital Infection Disclosure Act, in S7766, Section 2805-q, 2004
8. Tennessee Senate Bill, in SB1855, Title 68, Chapter 11, Section 201 (27), 2005
Tables and Figures

Figure 1: Patient and Survey Response Breakdown (N=number of participants)

Table 1: Study Population Characteristics

Table 2: Descriptive Characteristics of Survey Responders vs. Non-responders

Table 3: Mean Cost of a Shunt Failure Episode by Type of Failure

Table 4: Mean Cost of a Shunt Failure Episode by Insurance Status (Private vs. Public)
Figure 1: Patient and Survey Response Breakdown
(N=number of participants)

Total number of patients with shunt failure episodes
N=159

- Total number of patients with shunt failure post discharge
  N=126 (79%)
- Total number of patients excluded due to shunt failure episodes prior to discharge
  N=30 (19%)
- Total number of patients excluded due to self-pay status
  N=3 (2%)

- Total number of patients with caregiver out-of-pocket expense data
  N=65 (52%)
- Total number of patients without caregiver out-of-pocket expense data
  N=61 (48%)
Table 1: Descriptive Characteristics of Survey Responders vs. Non-responders

<table>
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<tr>
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<th>Responders N=65 (%)</th>
<th>Non Responders N=61 (%)</th>
<th>P values</th>
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<td></td>
<td></td>
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<td>25 (39)</td>
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<tr>
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<td>38 (61)</td>
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<td></td>
<td></td>
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<td>34 (54)</td>
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<td>African American</td>
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<td>Hispanic</td>
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<td>2 (3)</td>
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<tr>
<td>Other</td>
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<td>1 (2)</td>
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<td>Malplacement</td>
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<td>Malfunction</td>
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<td>6 months</td>
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Table 2: Study Population Characteristics  
N=126

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</tr>
<tr>
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<tr>
<td><strong>Average Gestational Age of Patients</strong></td>
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<td></td>
</tr>
<tr>
<td></td>
<td>33.6 weeks</td>
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<tr>
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<td>Malplacement</td>
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<td>Malfunction</td>
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Table 3: Mean Cost of a Shunt Failure Episode
By Insurance Status (Private vs. Public)

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Table 4: Mean Cost of a Shunt Failure Episode by Type of Failure

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CHAPTER 6
CONCLUSION

Ventriculo-peritoneal shunts continue to be the standard surgical procedure for treating children diagnosed with hydrocephalus, regardless of etiology. A properly functioning shunt system should produce intracranial pressure dynamics that emulates the normal physiologic state. Although the shunt system is used to treat hydrocephalus it is not a cure. These systems often meet with complications, with as many as 50% of shunt systems failing within the first 2 years of placement $^{67,75}$. At such times the CSF dynamics may become markedly abnormal and remain so until shunt dysfunction is diagnosed and corrected.

There have been many single and multi-institutional studies that evaluated the impact of the types of implants used, surgeon expertise, and environmental factors on shunt survival. One challenge faced is the on-going discussion regarding determinants of shunt survival in the higher risk populations.

High Risk Population

This project evaluated shunt survival in a single pediatric institution and found premature infants to be a higher risk population when looking at shunt failure after the initial ventriculo-peritoneal shunt placement. The underlying severity of their illness and
additional comorbidities often prevent these infants from tolerating a shunt system. Nutritional instability that prevents a child from feeding or gaining weight and thin skin that increases the risk of wound breakdown or hardware exposure leads to infection and increased failure risk. In infants with abdominal insufficiency (inability of the peritoneum to absorb CSF) and gastrointestinal disorders such as necrotizing enterocolitis (death of intestinal tissue) adding a foreign body such as a distal catheter may also increase the risk of infection or failure. There is an increased risk for additional intracranial bleeds in this population leading to an increased risk of failure due to clots obstruction the ventricular catheter. Mechanical issues, such as catheter length and valve size are a concern when shunting small infants.

Our study confirmed the need to address shunt survival in the premature patient population. Research endeavors are currently being conducted at our institution assessing the impact of prematurity on the treatment and management of hydrocephalus. A prospective case control study would allow for further analysis of the premature patient population as a predictor of shunt failure.

Caregiver Characteristics and Knowledge

Although there are clinical factors and diagnostic tests that can be conducted to determine shunt failure, in most children it is determined by observation over time with documentation of age-specific progressive signs and/or symptoms being a key factor in the diagnosis. The second aim of this project evaluated caregiver characteristics and knowledge to determine what impact there was on time to medical evaluation. Our analysis concluded that primary caregiver income level and maternal education were
associated with time delays in seeking medical evaluation after the onset of shunt failure symptoms. These results are in line with what has previously been found and reported. Income level and ultimately socioeconomic status does seem to influence access to health care in our patient population. What we still are not able to determine is why.

We looked at distance from the primary household to Children’s Hospital of Alabama but found no correlation between income level and miles away from the hospital. However we must give full consideration to the potential lack of transportation that many families face on a daily basis. If a family must rely on public transport, a family member or friend as a means for transportation to a medical facility, time becomes a factor they cannot control. Although transportation may be available it may not be easily accessible making distance, however great or small, a much larger barrier to health care.

Maternal education can pose its own set of barriers. There may be a lack of medical sophistication that comes with lower education levels. Cultural differences including language may be a barrier associated with under-educated caregivers. A lack of understanding of the signs and symptoms of shunt failure may also be a barrier to address. We asked our caregivers to identify the shunt failure symptoms and length of those symptoms prior to medical evaluation experienced by their child during the last shunt failure. The caregivers did seem to know what symptoms their child had experienced but it is unclear if they understood about shunt failure specifically or if they understood the importance of time when seeking medical evaluation.

Improving shunt teaching prior to discharge from the initial ventriculo-peritoneal shunt insertion hospitalization could potentially improve the knowledge base of our
caregivers. A longitudinal study would allow us to properly assess knowledge and health seeking behaviors over time to determine what additional opportunities for teaching there are within our patient population.

Economic Impact

Shunted hydrocephalus, as with other childhood chronic illnesses, requires a lifetime of management often requiring multiple surgical interventions to manipulate or replace a child’s implanted shunt system. Families caring for children with hydrocephalus incur out-of-pocket expenses each time their child has a shunt failure episode. Although not previously examined in the hydrocephalus patient population there are many studies in the literature that evaluated how caring for a chronically ill child affects the family financially.

The purpose of aim three of this project was to determine the third party payer reimbursement rate for a shunt failure episode and to determine the out-of-pocket expenses families incurred during a ventriculo-peritoneal shunt failure episode. We found that type of shunt failure was associated with the increased length of stay. We also found that the third party payer reimbursement rate and the caregiver out-of-pocket expenses incurred during a shunt failure episode differed significantly depending on the type of shunt failure diagnosed. We found that insurance status was associated with caregiver out-of-pocket expenses incurred. Those patients with private insurance had a greater amount of out-of-pocket expenses than those with public insurance.
A prospective cohort study looking at those patients treated for a shunt failure compared to patients that did not experience a shunt failure is needed to further estimate the financial impact of a shunt failure episode.

Public Health Importance

Hydrocephalus has public health implications as well as clinical consequences. The increased rate of survival of very low birth weight infants has increased the rate of surviving hydrocephalic children\(^\text{20}\). As previously mentioned, hydrocephalus affects 1 in every 500 children with nearly half of these children born premature\(^\text{1}\). Each time a child with hydrocephalus returns to the operating room the consequences not only include the increased risk for future shunt failure including infection, but also effects outcomes that impact the child, and the family. Such consequences include: 1) the increased risk of developmental and cognitive delays (including loss of IQ points with every additional surgical intervention for shunt failure)\(^\text{51,64}\), 2) the almost certain lifetime of shunt dependency\(^\text{19,23,26,33,54,55,76,82}\), 3) the overall quality of life of the child\(^\text{45-47}\) and 4) the small but serious risk of death due to shunt failure\(^\text{2,9,77}\).

Policy Implications

The results of this project showed that there are opportunities to improve the standard of care surrounding the treatment and management of hydrocephalic patients. Families of higher risk patients could benefit from a better understanding of the importance of earlier recognition of signs and symptoms. This type of education can potentially reduce ER visits, reduce the number of emergent shunt revisions, reduce the
number and duration of hospitalizations and ultimately reduce costs associated with treating children with hydrocephalus.

By further evaluating the use of ventricular peritoneal shunts in the treatment of hydrocephalus, healthcare providers can gain a better understanding of the technical challenges of our higher risk patients and assess alternatives to shunting these patients as premature infants.
LIST OF REFERENCES


40. NIH: Hydrocephalus, in Medline Plus Medical Encyclopedia, 2006
Form 4: IRB Approval Form
Identification and Certification of Research Projects Involving Human Subjects

UAB's Institutional Review Boards for Human Use (IRBs) have an approved Federalwide Assurance with the Office for Human Research Protections (OHRP). The Assurance number is FWA00005960 and it expires on January 23, 2012. The UAB IRBs are also in compliance with 21 CFR Parts 50 and 56 and ICH GCP Guidelines.

Principal Investigator: SHANNON, CHEVIS NACOLE
Co-Investigator(s):
Protocol Number: X070718006
Protocol Title: Shunt Failure in Children with Hydrocephalus: Impact of Sociodemographic Predictors on Time to Medical Evaluation for Shunt Failure and the Economic Burden Associated with Shunt Failure

The IRB reviewed and approved the above named project on 7-23-09. The review was conducted in accordance with UAB’s Assurance of Compliance approved by the Department of Health and Human Services. This Project will be subject to Annual continuing review as provided in that Assurance.

This project received EXPEDITED review.
IRB Approval Date: 7-23-09
Date IRB Approval Issued: 7-23-09
HIPAA Waiver Approved?: Yes

Marilyn Doss, M.A.
Vice Chair of the Institutional Review Board for Human Use (IRB)

Investigators please note:

The IRB approved consent form used in the study must contain the IRB approval date and expiration date.

IRB approval is given for one year unless otherwise noted. For projects subject to annual review research activities may not continue past the one year anniversary of the IRB approval date.

Any modifications in the study methodology, protocol and/or consent form must be submitted for review and approval to the IRB prior to implementation.

Adverse Events and/or unanticipated risks to subjects or others at UAB or other participating institutions must be reported promptly to the IRB.
UAB IRB Approval of Waiver of Informed Consent and/or Waiver of Patient Authorization

✓ Approval of Waiver of Informed Consent to Participate in Research. The IRB reviewed the proposed research and granted the request for waiver of informed consent to participate in research, based on the following findings:

1. The research involves no more than minimal risk to the subjects.
2. The research cannot practicably be carried out without the waiver.
3. The waiver will not adversely affect the rights and welfare of the subjects.
4. When appropriate, the subjects will be provided with additional pertinent information after participation.

Check one:  ✔ Waiver of Authorization (below)
☐ or Waiver of Authorization (below)
☐ Waiver of Authorization not applicable

✓ Approval of Waiver of Patient Authorization to Use PHI in Research. The IRB reviewed the proposed research and granted the request for waiver of patient authorization to use PHI in research, based on the following findings:

1. The use/disclosure of PHI involves no more than minimal risk to the privacy of individuals
   i. There is an adequate plan to protect the identifiers from improper use and disclosure.
   ii. There is an adequate plan to destroy the identifiers at the earliest opportunity consistent with conduct of the research, unless there is a health or research justification for retaining the identifiers or such retention that is otherwise required by law.
   iii. There is an assurance that the PHI will not be reused or disclosed to any other person or entity, except as required by law, for authorized oversight of the research study, or for other research for which the use or disclosure of PHI would be permitted.
2. The research cannot practicably be conducted without the waiver or alteration.
3. The research cannot practicably be conducted without access to and use of the PHI.

—OR—

☐ Full Review
The IRB reviewed the proposed research at a convened meeting at which a majority of the IRB was present, including one member who is not affiliated with any entity conducting or sponsoring the research, and not related to any person who is affiliated with any of such entities. The waiver of authorization was approved by the majority of the IRB members present at the meeting.

Date of Meeting

Signature of Chair, Vice-Chair or Designee

Date

☐ Expedited Review
The IRB used an expedited review procedure because the research involves no more than minimal risk to the privacy of the individuals who are the subject of the PHI for which use or disclosure is being sought. The review and approval of the waiver of authorization were carried out by the Chair of the IRB, or by one of the Vice-Chairs of the IRB as designated by the Chair of the IRB.

7-23-09
Date of Expedited Review

Signature of Chair, Vice-Chair or Designee

Date 7-23-09