Parents of Children Who Had Hypoxic-Ischemic Encephalopathy: A Mixed-Methods, Exploratory Study

Natalene Kramer

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PARENTS OF CHILDREN WHO HAD HYPOXIC-ISCHEMIC ENCEPHALOPATHY:
A MIXED-METHODS, EXPLORATORY STUDY

A Dissertation
Submitted to the School of Nursing

Duquesne University

In partial fulfillment of the requirements for
the degree of Doctor of Philosophy

By

Natalene P. Kramer

December 2017
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2017
PARENTS OF CHILDREN WHO HAD HYPOXIC-ISCHEMIC ENCEPHALOPATHY: A MIXED METHODS EXPLORATORY STUDY

By

Natalene P. Kramer

Approved November 14, 2017

L. Kathleen Sekula, PhD, PMHCNS-BC, FAAN
Professor of Nursing
(Committee Chair)

Rebecca Kronk, PhD, MSN, CRNP
Associate Professor of Nursing
(Committee Member)

Richard Zoucha, PhD, PMHCNS-BC, CTN-A, FAAN
Professor of Nursing
(Committee Member)

Shelley Peacock, RN, BSC, PhD
Associate Professor of Nursing
University of Saskatchewan
(Committee Member)

Mary Ellen Glasgow, PhD, ANEF, FAAN
Dean, School of Nursing
Professor of Nursing
ABSTRACT

PARENTS OF CHILDREN WHO HAD HYPOXIC-ISCHEMIC ENCEPHALOPATHY:
A MIXED-METHODS, EXPLORATORY STUDY

By
Natalene P. Kramer
December 2017

Dissertation supervised by L. Kathleen Sekula, PhD, CRNP-BC, FAAN

Background

Hypoxic-ischemic encephalopathy (HIE) affects one to eight of 1000 births (Zanelli, 2012). As there is scant literature addressing this population, only inferences may be made as to parental challenges based upon reports for parents dealing with other childhood disabilities.

Purpose

This purpose of this study was to uncover the lived experiences of parents of children who had HIE, as well as evaluate issues of stress, depression, coping, and impact of childhood neurologic disability of parents of children to had HIE from a mixed-methods perspective, in order to better care for them and thus, their families.
Methods

A parallel convergent mixed methods design was used to explore experiences, perceptions and feelings of parents who have a child who had HIE. The quantitative strand addressed 4 research questions which addressed the above stated purpose. The qualitative and quantitative strands were then explored seeking areas of convergence and divergence. Interviews were conducted of nine parents of children who had HIE, guided by a single research question. Quantitative surveys were completed by these parents plus 42 on-line participants. Surveys addressed impact on family, parenting stress, depression, and coping. These data sets were then merged.

Results

Qualitative results yielded six themes: unmet expectations, the source of my strength, life in the negative, outside of reality, lemonade from lemons, and the desires of parents. Parents expressed unmet expectations from the time of their labor and delivery experience through present challenges. Family, God and professionals were identified by parents as providing strength. While few parents identified positive aspects of the experience, almost all voiced clear desires regarding the care they received. Quantitatively, the total impact of disability and the parentally perceived degree of disability (PPDD), were positively correlated ($r_s = .348$, $n = 50$, $p = .013$). Parents exhibited significant stress with 31.4% participants scoring above the 99th percentile for parent child-dysfunction. Of the 43 women in the sample, 16.3% exhibited scores consistent with major depression. The use of emotion and problem-focused coping mechanisms was divided along gender lines and parental perception of disability. Areas of divergence indicated that neither the quantitative surveys nor open ended interviews
were adequate to capture issues, such as communication between parents and health care providers, which was qualitatively revealed, but was not addressed on surveys.

**Implications for Practice**

Health care providers have a significant role in aiding parents in managing the challenges of parenting a child who has had HIE.

**Implications for Research**

Further research aimed at parental needs throughout the caring process may provide clinicians with methods by which more supportive care may be provided.

**Key Words:**

Hypoxic-Ischemic Encephalopathy, Parents, Disability, Stress, Family, Coping, Depression, Mixed Methods, Heidegger
DEDICATION

This dissertation is dedicated to the families of children who had hypoxic-ischemic encephalopathy, who are doing their best to parent and to the nurses, physicians, practitioners, residents, and therapists who do their best in caring for these families. Most of all, I dedicate this dissertation to my family for supporting and encouraging me as I’ve strived to achieve my goals and make a difference. To my husband, Mark, who believed in me, especially when I wasn’t sure I could believe in myself. To my daughter, Stephanie, who proved to me that my dreams can come true and to my son, Andrew, for both his belief in me and technical support. To the memories of my Aunt Martha and mother-in-law Sylvia, who walked this walk with strength and grace and my mother, Adele, who’s compassion remains an inspiration. May they rest in peace.
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To my family for their patience and understanding. We will finally be able to use the dining room table again.

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LIST OF ABBREVIATIONS

aEEG..........................Amplitude Integrated Electroencephalogram
CP..............................Cerebral Palsy
CT..............................Computerized Tomography
CUH............................Cooper University Hospital
DYFS-------------------------New Jersey Department of Youth and Family Services
EEG............................Electroencephalogram
GMFCS........................Gross Motor Function Classification System
HIE.............................Hypoxic-Ischemic Encephalopathy
ICNDS------------------------Impact of Childhood Neurologic Disability Scale
IRB.............................Institutional Review Board
MDI............................Mental Development Index
MRI.............................Magnetic Resonance Imaging
NAA............................N-Acetyl Aspartate
NICHD------------------------National Institute of Child Health and Development
PHQ-2..........................Patient Health Questionnaire II
PPHN-------------------------Persistent Pulmonary Hypertension of the Newborn
PSI............................Parental Stress Index
PTSD-------------------------Posttraumatic Stress Disorder
WCQ............................Ways of Coping Questionnaire
WIC............................Women Infant Children (government nutritional support)
CHAPTER ONE
INTRODUCTION

1.1 Background of the Study

“The act of birth does occasionally imprint upon the nervous and muscular systems of the nascent infantile organism very serious and peculiar evils” (Little, 1861, 234). This was one of the first references to connect issues of labor and delivery with cerebral palsy (CP). The author further describes the saving of moribund infants who later develop seizures, spastic rigidity, hemiplegia, and “idiocy.” Today hypoxic-ischemic encephalopathy (HIE) affects between one and eight out of 1000 births in the United States (Zanelli, 2012). Neonatal HIE is caused by hypoxia and/or a lack of perfusion to neural tissue, often secondary to a significant perinatal event. Birth asphyxia is the antecedent of HIE, which refers to the neurologic sequelae of this insult and is believed to be responsible for 23% of world-wide neonatal deaths. Children who survive may have no discernible disability, be neurologically devastated, or anywhere in between. Children may be left with seizure disorders, cognitive deficits, sensory deficits, or CP. Even in survivors who appear to be typically developing on early developmental evaluation, learning, memory, and/or fine motor dexterity may be found to be lacking (K. Lindstrom, Lagerroos, Gillberg, & Fernell, 2006; Maneru, Junque, Botet, Tallada, & Guardia, 2001; Robertson & Finer, 1988; Robertson, Finer, & Grace, 1989).

The circular process of HIE is due to a series of repeated insults. In essence cell death propagates further cell death due the release of intracellular components which are toxic to surrounding neural tissue (Allen & Brandon, 2011; Blomgren, Leist, & Groe, 2007; F. J. Northington, Chavez-Valdez, & Martin, 2011). Two stages of neuronal
energy failure are interspersed with a latent period, where some recovery occurs, allowing an opportunity to therapeutically minimize damage. The duration of this period of potential recovery is inversely proportional to the severity of the initial insult (Allen & Brandon, 2011; Iwata & Iwata, 2011; Jacobs & Tarrow-Mordi, 2010).

A myriad of stressors and long term medical issues create a variety of challenges for the parents of these children. As there is no literature addressing the experiences or needs of this unique population, only inferences may be made as to their experiences based upon those reported for families dealing with other childhood disabilities. However, in many respects the realities of life for these parents are incomparable to those of parents of children with other disabilities. This is primarily due to the pre-labor belief that a healthy child will soon be joining the family, but then that belief is suddenly threatened. Delivery of a child who develops HIE may be considered traumatic as it is usually occurring following an emergent cesarean delivery or emergent, possibly instrumented vaginal delivery. If the mother is awake and/or the father is present, they witness the resuscitation of their child.

Posttraumatic stress disorder (PTSD) has been well described in association with traumatic, emergent deliveries (Ayers, 2007; Ayers, Eagle, & Waring, 2006; Beck, 2004b, 2006a, 2006b; Creedy, Shochet, & Horsfall, 2000; Moyzakitis, 2004; Nicholls & Ayers, 2007; Ryding, Wijma, & Wijma, 1998). Similarly, posttraumatic stress has been identified within the neonatal intensive care unit (Kersting et al., 2004; Pierrehumbert, Nicole, Muller-Nix, Forcada-Guex, & Ansermet, 2003; Shaw et al., 2009; Vanderbilt, Bushley, Young, & Frank, 2009). Chronic sorrow, grief, depression, and ill health, believed to be secondary to the emotional stresses of caring for a child with a disability,
have been described (Ahmadi et al., 2011; Arndt, Smith, & Tausk, 2008; Benson & Karlof, 2009; Breslau, Staruch, & Mortimer, 1982; Burke, 1989; Case-Smith, 2004; Collings, 2008; Copley & Bodensteiner, 1987; Cramm & Nieboer, 2011; Eakes, 1995; Forinder & Norberg, 2010; Fraley, 1986; Glasscoe, Lancaster, Smyth, & Hill, 2007; Gu, Tang, & Yang, 2012; Hobdell, 1993; Keller & Honig, 2004; Kuroki et al., 2011; Lohf, 2010; Phillips, 1991; Saloviita, Italinna, & Leinonen, 2003; T. B. Smith, Oliver, & Innocenti, 2001; Suarez, Mayer, Ehlert, & Nater, 2010). Provision of optimal care to these families depends upon understanding the factors within this phenomenon.

1.2 Purpose of Study

This study sought to uncover the lived experience, stressors and symptoms consistent with parental stress in parents of children who had neonatal HIE. Evidence was sought to determine the presence of depression. In addition, parental coping was evaluated in terms of its effects on daily life. Furthermore, this information was analyzed based upon the parentally perceived degree of child disability. The parentally perceived degree of disability is important because one may only accurately assess parental perceptions from parents. Parental perceptions of a child’s disabilities may differ from the measured degree of disability, and as parents are the focus of this study, their perceptions are vital in the exploration of their issues.

1.3 Theoretical Framework

The Resiliency Model of Family Stress, Adjustment, and Adaptation is believed to provide an appropriate lens through which one may begin to view and understand the issues of parents of children who had HIE. Family Stress Theory was originally developed in 1949 by Reuben Hill (Friedman, Bowden, & Jones, 2003; Robinson, 1997).
illness. When such stressors are accumulated, they, in and of themselves, can potentiate a crisis within the family, including domestic violence, substance abuse, illness, and others (Adams, 1988). A second variable was identified as family strengths or resources, such as finances or social support. A third variable addresses how families define the seriousness of the stressor event. These three variables interact to determine the family’s ability to cope with, or prevent change based upon the stressor. Change is viewed as a crisis or the degree of disruption to the family unit.

This original model underwent several adaptations over the years. Two of the most commonly cited are the original ABCX Model and the Double ABCX model. The Double ABCX model adds in the effects of cumulative stress, and additional variables that affect the adaptation of the family (Friedman et al., 2003; Robinson, 1997). Coping was viewed as contributory to variable levels of adaptation. Subsequently, the family adjustment and adaptation response model was developed which emphasized potential positive outcomes to a crisis.

The most recent version, known as the Resiliency Model of Family Stress, Adjustment, and Adaptation begins with family stressors which create a crisis in the family, as shown in figure 1. The left-hand side of the figure depicts a crisis upon a family. The center six interconnected hexagons represent family strengths (or weaknesses) which not only interact, but also determine the ultimate outcome of bon-adaptation, adaptation, or mal-adaptation. Each family, as its own entity, has specific characteristics which may include, various family resources, social support, problem
Figure 1.1. Resiliency Model of Stress, Adjustment and Adaptation


solving and coping abilities, and family typology, (i.e. how the family normally functions), and family appraisal of their situation. Emphasis is placed on family strength and resiliency, focusing more on adaptation rather than adjustment, and may be thought of as the various resources within the family which may be of assistance in the family’s ability to maintain function during times of crisis. These are influenced by available resources such as financial, spiritual, or experiential.

Strength and resiliency are also influenced by social supports, such as friends or family; inherent coping abilities; and how the situation is viewed in terms of the impact upon the family. Family typology addresses how the family normally functions. This might include routines or roles, and is closely related to family appraisal. Family
appraisal is how the family views itself and its members. Adjustment may be thought of as the initial responses of the family geared to maintaining its self-defined “normal.” The concept of coping was expanded, now including the ability to problem solve, presumably by using cognitive appraisal. Coping may be thought of as the use of resources to achieve equilibrium in times of crisis (Friedman et al., 2003; Robinson, 1997).

Adaptation may be thought of as the result of coping mechanisms and may include such concepts as a re-defined ‘normal’ or permanent or semi-permanent restructuring of roles within the family. Bon-adaptation may be thought of as positive, successful adaptation, wherein the family is not only stabilized, but actually viewed as having had a positive improvement in various aspects of family functioning. Statements, such as “I see myself as a better person now,” mark bon-adaptation. Adaptation itself may be considered as successful, in that the family is stabilized. It is marked by being able to achieve congruency and a sense of coherence in the face of crisis. Mal-adaptation however, is considered to be unsuccessful coping. The family reacts within a state of chaos which leads to an inability for family members to achieve personal growth and development and may even lead to personal regression. The severity of the crisis or stressor is determined by the degree to which the family unit is threatened by the stressor or the demands it creates (M. McCubbin & McCubbin, 1993). Due to a multiplicity of abstract concepts, this framework may be considered a conceptual model and is based upon four assumptions:

- Families face hardships and changes that are both natural and predictable.
Families develop various strengths and abilities which cultivate the growth and development of both individual members and the family unit, as a whole. These abilities shield the family from disruption during times of transition and change.

These strengths and abilities protect the family from both anticipated and unanticipated stressors and serve to augment adaption to change.

Families both contribute to and benefit from community relationships and resources, most specifically during periods of stress.

1.3.1 Framework Phases

As introduced above, adjustment precedes adaptation in the family dealing with a crisis. The adjustment phase occurs either at the onset of a significant stressor or during a minor stressful experience. During this phase, families tend to maintain their roles and routines. Maintenance of the family is achieved via the hardiness or strength of the family as a unit. This is opposed to family vulnerability, which refers to biologic, economic, social or psychological factors which place the family at greater risk for a maladaptive response. Events such as family celebrations and the maintenance of routine family activities have been found to aid in the sustainment of the family unit during the adjustment phase (H. McCubbin, McCubbin, Thompson, Han, & Allen, 1997).

Major or prolonged crises, such as serious or chronic illness, force the family to move beyond the adjustment phase into an adaptation phase. At this time two factors come into play: family protective and family recovery factors, which help the family to recover and survive as a unit, while “coping” with the crisis (H. McCubbin et al., 1997). Protective factors primarily reside within individual family members, such as problem-solving skills and recognition of support from other family members, the community,
religious programs, and work. The success of these factors is, in large part, influenced by the multiplicity of stressors and demands. For example, if a family is trying to adjust and adapt to a child’s disability and is beginning to find their way when the father loses his job, a new crisis is added which increases the burden upon the family unit, threatening its intact survival. If however, that same family has a variety of protective factors, such as a strong savings account, familial, or community resources the burden is in essence diluted.

Recovery factors might be viewed as a family’s typology which may involve past experiences and cultural mores, in addition to the factors involved in protection. Recovery refers to the use of these skills and supports once a crisis has occurred in order to reestablish familial equilibrium. Critical family recovery and resiliency factors include: 1) self-reliance and equality, which includes specific familial efforts to change patterns; 2) family advocacy, which refers to familial efforts to be involved in supporting not only themselves, but others in similar situations; 3) family meanings, which refer to placing a positive spin on a negative situation in order to promote stability, harmony, and balance; and 4) family schema, or the individual family belief systems which are used to guide the family in managing their behavioral responses and adaptation (H. McCubbin & McCubbin, 1988; H. McCubbin et al., 1997).

1.3.2 Family Typologies

One of the less transparent concepts within this model is family typology. In order to provide individualized care of the family in a state of crisis, it is beneficial to be aware of the various family typologies which health care professionals may encounter. McCubbin and McCubbin (1988) identify several types. The first addresses the degree of familial balance with subtypes of balanced, midrange, and extreme. Balanced families
are generally considered to be the most durable, while extreme are the most dysfunctional and non-viable.

A second typology addresses family rhythmicity: unpatterned, intentional, structuralized, and rhythmic. Unpatterned families place neither value nor emphasis on schedules or routines. Intentional families value routines, but seem unable or undesirous of maintaining or committing to these. Structuralized families do carry out strict routines, but they neither value nor desire them. Rhythmic families desire, value, and maintain strict routines and therefore tend to be highly predictable. It is interesting to note that while some families may begin as rhythmic while children are young, these strict patterns fall to the wayside as children grow and more unpatterned family typologies are appreciated by the time children reach adolescence (H. McCubbin & McCubbin, 1988).

A third typology addresses regenerative families. This typology addresses both family hardiness and family coherence and is classified as either high or low. Family coherence addresses the familial emphasis on acceptance, loyalty, pride, faith, trust, respect, and the sharing of values when tension and strain enter the family unit. It exemplifies how parents see themselves within their worlds, is related to hardiness in terms of its indication of personal strength, and is viewed as a stable personality trait (Antonovsky & Sagy, 1986; H. McCubbin & McCubbin, 1988).

Margalit and Kleitman (2006) evaluated 70 mothers of children with developmental delays who were enrolled in an early intervention program, finding that those mothers who felt more positively and exhibited decreased stress following the intervention were also those mothers who had a greater sense of coherence (p < 0.01).
Hardiness refers to the degree of familial internal strengths and durability combined with the degree of sensed control over life events. It may also include a sense of meaningfulness in life, involvement in external activities, and a willingness to take on new challenges.

Within the regenerative model there are four subtypes: 1) vulnerable families respond to problems by displaying upset, blame, and a lack of care, understanding, pride, loyalty and acceptance of other family members; 2) secure families differ from vulnerable families only in their hardiness, indicating a sense of purpose and an ability to plan; 3) durable families have a positive view of their ability to cope, but at the same time exhibit a lower sense of purpose and meaningfulness in life. They feel unappreciated and out of control in terms of how life’s events affect the family. They identify with a sense of family coherence and compensate for a lack of internal strength by having a wide repertoire of coping mechanisms; 4) Families typified as regenerative cope with problems by maintaining stability through a calm affect, respect, and cultivation of trust. They tend to exhibit faith, accept life’s challenges, and work as a team to address problems. They feel in control of their lives and situations; and are generally more tolerant of hardship.

1.3.3 Resiliency

Family resiliency is influenced by the factors within the model and is a result of family typology and appraisal, situational appraisal, social support, family resources, and inherent coping abilities. In essence, it may be considered the subtotal of these factors which brings the family to variables degrees of success in adaptation. Much of the earlier research on family resiliency was conducted in military families (H. McCubbin, 1988; H. McCubbin, Dahl, & Hunter, 1976; H. McCubbin & Lavee, 1986; H. McCubbin &
McCubbin, 1988). They identify that both individual and family strengths, as well as community support systems are of great importance in the lives of resilient military families. They further found that the various factors provided different levels of support during crisis based upon cultural background.

**Cultural influences.**

Cultural influence may be thought of as a factor within family resources that impacts upon resiliency. Its importance is based upon the individual family’s view of its importance and therefore cannot be ignored. Cultural influence is also a key contributor in non-military families (H. McCubbin, Thompson, Thompson, McCubbin, & Kaston, 1993). This group compared classic Anglo-American families with Native American Indian and Hawaiian families, finding vast differences between Anglo-American and native cultures. Primarily Anglo families are nuclear, individually oriented, and future oriented. Land and nature are viewed as inanimate and for the use of humans and God was viewed as other-worldly. The Native American groups (Aboriginal cluster) hold very different beliefs. Family includes extended family, tribal culture and social networks. Group orientation and needs are more important than individual needs. Spirits are a part of, and in every aspect of life. The Native American Hawaiians specifically believe that the individual should be one with the “cosmos.” The environment in all of its forms should be respected and nurtured. Time is the present and relative.

With these obvious differences in general belief systems, it is understandable that views and coping with chronic childhood illness are also vastly different. Whereas the Anglo-American family may view chronically ill or disabled family members as “different” and stigmatized, both Native American cultures view these individuals as
valued, functioning community members for whatever contribution they may make. The source of illness is due to imbalance or punishment for misconduct and is managed by the community, as opposed to due to an outside, scientific cause which requires outside professional treatment in the Anglo belief. The native cultures viewed illness as normal and interestingly, had no vocabulary to describe or classify a person with a disability, as opposed to the cornucopia of words in the Anglo-American culture. This illustration serves to inform the health care professional that in terms of resiliency, culture must be not only assessed, but respected as appropriate. Another example of these differences was found in a Heideggerian hermeneutical study of Taiwanese mothers of children with cerebral palsy. Huang, Kellett and St. John (2011) found that their participants reported losing face and feeling marginalized by their families as opposed to families in a Swedish study which found that families actually became closer, seeing the target child as a basis for that closeness.

Professional support of a family in crisis will be different based upon socio-cultural belief systems and supports and progressively more complex adaptations of the original stress theory may be applied in order to assess and precisely and respectfully intervene with families in crisis (Tomlinson, 1986). Furthermore, knowing that health care providers make up one culture and parents of children with disabilities make up another, it is understandable that challenges may occur (Roscigno & Swanson, 2011).

1.3.4 Selected Studies Using the Resiliency Model of Stress, Adjustment, and Adaptation

This framework has been expanded to a variety of family stress situations, most particularly families dealing with both acute and chronic illness. Using this model,
McCubbin, Balling, Possin, Frierdich, and Byrne (2002) evaluated resiliency in the face of childhood cancer. They identified six internal family strengths at play in this situation that included:

- Rapid mobilization and reorganization, which addressed the ability to quickly mobilize when the diagnosis was made and the ability to tolerate living as a split family. This referred to one parent being at the hospital and another caring for siblings.
- Support from the health care team was identified by 88% of families as helpful.
- Support from extended family;
- Support from the community;
- Support from the workplace; and
- Changes in family appraisal during treatment were found in terms of recovery. Parents identified common threads that held the family together and seeing the total picture in terms of both positive and negative aspects, then just doing what needed to be done.

The resiliency model was recently used by Chen and Clark (2010) in a correlational study of families of children with muscular dystrophy. They found a positive association between family hardiness and support and parental health. Tak and McCubbin (2002) utilized the resiliency model in their study of families of children with congenital heart disease, finding that perceived social support was predictive of family coping, influencing the resiliency of these families. Brody and Simmons (2007) qualitatively studied resiliency in fathers dealing with childhood cancer, finding four themes: 1) changes and adjustment in family life which created additional strain; 2)
communication patterns, specifically between parent and child and between health care providers and parents noting specifically that fathers tended to be left out; that communication was often targeted to the mother; 3) social support from a multitude of sources, noting that extended family support was particularly valued; and 4) effects of the cancer experience, which included multiple emotions related to adjustments, personal workloads, feeling overloaded, fear, uncertainty, and struggling to remain positive. Fathers often reported positive personality changes in terms of being more supportive, patient and understanding. Despite reported emphasis on support from family, one study found no difference in family hardiness based upon the presence of a spouse or second parent within the home of a special needs child (McNurlen, 1996).

Hall and colleagues (2012) evaluated parental stress in the face of a genetic disorder under the lens of the resiliency model of stress, adjustment, and adaptation using a triangulated methodology. Twenty-two parents were classified as either stressed or not stressed based upon scores from the Parenting Stress Index. Of the parents identified as stressed, vulnerability in terms of ostracism of the child within the community was the single described factor. Unstressed parents did not identify any areas of vulnerability. Family cohesiveness was positively described in both stressed and non-stressed parents in terms of support. Appraisal of the stressor and its severity identified both positive and negative views. Stressed parents voiced frustration, whereas non-stressed parents placed a positive spin on the existence of a delay. Non-stressed parents also identified both benefits, such as a sibling defending a brother or sister, and challenges, such as embarrassment to siblings. Stressed families identified a feeling of lack of support from both family and community. Non-stressed parents verbalized when they were and were
not being supported. Interestingly, the stressed parents did not identify any themes associated with problem solving or coping, as compared with the non-stressed parents who identified educating family members and planning for the future. The differences between stressed and non-stressed parents of children with disabilities were so distinct that a need for further evaluation with a larger cohort was clearly indicated.

This framework has further been applied to families dealing with adult illness, such as congestive heart failure (Yeh & Bull, 2011) and economic hardship (Vandsburger & Biggerstaff, 2004). Its use has also been recommended for use by rehabilitation counselors in order to assess family strengths and resiliency so that the individual with a disability may be further supported (Frain et al., 2007).

**1.4 Research Questions**

In order to begin to understand the challenges and needs of this unique population, the following research questions are posed:

1. What is the lived experience of parents of children who had HIE?
2. What is the relationship between the parentally perceived degree of disability, and the impact of childhood neurologic disability as measured by the Impact of Childhood Neurologic Disability Scale (ICNDS)?
3. Do parents of children who had HIE exhibit more stress than parents of children who do not have disabilities as measured by the Parental Stress Index (PSI-SF)?
4. Do parents of children who had HIE meet criteria for depression as measured by the Patient Health Questionnaire II (PHQ-2)?
5. What coping mechanisms are used by parents of children who had HIE, as measured by the Ways of Coping Questionnaire (WCQ)

1.5 Definitions of Terms

**Asphyxia.** Asphyxia is a situation of impaired exchange of oxygen and carbon dioxide secondary to a loss of blood flow and/or oxygen to the fetus, persisting to the point of creating a significant metabolic acidosis.

**Cerebral Palsy.** Cerebral palsy is a static affliction which affects both movement and posture, which inhibits activity. It is secondary to an abnormality in the developing fetal or infant brain. Affected individuals may also be subject to disturbances of sensation, cognition, communication, perception, behavior, and/or seizures.

**Chronic Sorrow.** Chronic sorrow refers to the ongoing disparity resulting from a loss. Symptoms of grief recur periodically and are potentially progressive. It is characterized by both pervasiveness and permanence.

**Coping.** Coping is a method of reducing stress by variable thoughts or actions used to solve problems (Lazarus & Folkman, 1984). Coping may lie on a continuum between effective or ineffective based upon the degree to which such actions are taken.

**Depression.** Depression is a psychological disorder associated with a saddened mood, loss of interest or an inability to experience pleasure. It may be associated with feelings of guilt or low self-esteem; or disturbances in sleep, eating, or concentration. The affected individual generally feels as if they have low energy and may be severe enough to inhibit the ability to accomplish even routine tasks.

**Hypoxic-ischemic Encephalopathy.** Hypoxic-ischemic encephalopathy is an alteration in neurologic function secondary to a lack of oxygen and/or blood flow to neural tissue.
**Neural Plasticity.** Neural plasticity refers to the adaptability of the brain, which enables it to grow, develop, and acclimate to structural neural injury.

**Parental Grief.** Parental grief refers to suffering or distress over the loss of the idealized child. It is dynamic and may change over time in characteristic and presentation. It is pervasive and may affect all aspects of life for the affected individual. It is a universal experience, although it is personally experienced and adaptations are individually determined. Furthermore, it is experienced and expressed based upon sociocultural, spiritual, and religious norms.

**Posttraumatic Stress Disorder.** Posttraumatic stress disorder is a psychological disorder resulting from being confronted with an event that involves actual or threatened death or serious injury to oneself or others. It includes intrusive thoughts, physical symptoms upon cues that remind the individual of that event, avoidance of reminders, and hyper-arousal. These symptoms last longer than one month.

**Stress.** Stress may be thought of as any disturbance to the physical, emotional, or psychological homeostasis of an organism, creating a discord. The stress response is the organism’s reaction to that stressor.

**Traumatic Birth.** Traumatic birth may be thought of as any birth experience in which the mother undergoes a particularly frightening birth experience. This may include an emergency cesarean section, a rapidly instrumented delivery, the witnessing of resuscitative efforts for the child, a perceived threat to the mother’s well-being, or even insensitive communication by the delivery’s attendants.

### 1.6 Assumptions

In order to conduct this study, the following assumptions were made:
• Participants in the qualitative portion of this study would be willing to honestly express and discuss their life experiences of being a parent of a child who has had HIE.

• The experiences of each parent of a child who has had HIE is unique.

• The experience of being a parent of a child who has had HIE may be, or may have been a stressor to that parent.

• Participants who completed the internet survey are the actual parents of children who had HIE during the neonatal period.

• The constructs of depression, posttraumatic stress, and coping may be both measured and described.

• The construct of chronic sorrow may be qualitatively identified.

1.7 Limitations

• The qualitative portion of this study was dependent upon the ability of the participants to clearly and thoroughly articulate their experiences, feelings, and emotions.

• While quantitative data was obtained from nationally distributed surveys, both qualitative and quantitative data were obtained from in-person participants in northeastern United States, which may have impacted upon the types of responses received.

• The surveys completed from on line participants may have had different responses from in-person participants for several reasons. On-line participants may have different qualities than in-person participants who may or may not have computer access to the internet; participants recruited from on line sites may be
anticipated to come from areas other than Northeastern United States, thus their responses may have differed; or participants who were interviewed from a distance may reveal with a different level of disclosure from in-person participants. Finally, in-person participants completed surveys after their interviews, which may have had an effect on their survey responses

- Participants may have had difficulty with recollection of experiences during the perinatal and early infant period.
- While qualitative data was collected from in-person participants, quantitative data will be obtained from both on-line and in-person participants, which may have impacted the degree of disclosure by in-person participants on the surveys.

1.8 Significance to Nursing

Psychological and physical stress, as well as lack of sleep has been linked to diminished physical health and emotional well-being (Ahmadi et al., 2011; Kuroki et al., 2011; Kuster & Merkle, 2004; Larzelere & Jones, 2008; Suarez et al., 2010; Vere, Streba, Streba, Ionescu, & Sima, 2009) as well as compromised immune functioning (Arndt et al., 2008; Fang et al., 2010; Gu et al., 2012; Stojanovich, 2010). The information gained by investigating the experiences of these parents from the time of birth and diagnosis, will help to educate nurses and other health care professionals in areas never before investigated. By knowing the stress and emotional distress in these parents, more targeted interventions may come forth to reduce emotional and thereby physical maladies. If parents have fewer physical and emotional consequences to their situations, both target children and other family members may suffer from fewer physical and emotional consequences, leading to a potential decrease in their health care
expenditures. Being able to show an improvement in health by providing appropriate emotional, financial, and actual physical support with potential decreased expenditures for a growing fragile population enables nurses and policy makers to lobby for increased financial support for this group.
CHAPTER TWO

REVIEW OF THE LITERATURE

This review contains a detailed description of the literature to date regarding hypoxic-ischemic encephalopathy (HIE) in the newborn. It includes physiology, pathophysiology, clinical findings, neurodevelopmental sequelae, and current therapies. Various aspects of parenting children with disabilities will be put forth. Many studies have evaluated parental perceptions, coping, and various psycho-emotional challenges such as chronic sorrow, stress, posttraumatic stress and depression. These studies will lay the groundwork for future sections addressing issues of parenting a survivor of this often-devastating neonatal diagnosis, which heretofore has not been examined.

2.1 Hypoxic-Ischemic Encephalopathy

“The act of birth does occasionally imprint upon the nervous and muscular systems of the nascent infantile organism very serious and peculiar evils” (Little, 1861, p.234). This was one of the first references to connect issues of labor and delivery with CP. The author describes the saving of moribund infants who later develop seizures, spastic rigidity, hemiplegia, and “idiocy.” He marvels at how infants born in a state of “suspended animation” are saved by midwives and survive without sequelae. Today, understanding the transition from fetal to infantile life continues to progress. While not all cases of CP, seizure disorders, and cognitive delays may be attributed to difficulties in parturition, it may be said that labor and delivery are a high-risk period for the about-to-be-born fetus, which may be laden with peril. It is important to differentiate between the terms birth asphyxia and hypoxic-ischemic encephalopathy. According to Yudkin, Johnson, Clover, and Murphy (1994) asphyxia is a continuous process of hypoxia and
hypercarbia which lead to a mixed respiratory and metabolic acidosis in the fetus, while HIE addresses the physical signs of encephalopathy observed within the newborn. Prior to birth, the fetus lives in a state of relative hypoxemia. Gas exchange and organ perfusion are accomplished by means of the placenta. Organ perfusion is as vital to organ growth and survival as oxygenation. Oxygen delivery to developing organs is based upon the amount of hemoglobin available, cardiac output, and the degree of oxygen saturation (P. J. Murphy, 2005). When cerebral blood flow is reduced beyond a critical threshold, the brain becomes vulnerable to the effects of both hypoxic and ischemic injury (Johnston, Ishida, Nakajima, & Trescher, 2002).

The fetus may be placed at risk for such injury from a variety of etiologies. Prenatal etiologies may be based upon issues which create a state of placental insufficiency, which increase the risk for perinatal complications. Volpe (2008) states that 20% of all cases of HIE may be related to maternal issues. Fetal factors which may place the fetus at risk for perinatal complications include macrosomia, anemia, and polycythemia with resultant hyperviscosity, fetal arrhythmias, and fetal infection. The most significant mechanism of hypoxic injury is asphyxia secondary to circulatory issues such as placental abruption, clotting of placental arteries, cord accidents, or inflammatory processes, and may account for 35% of cases (Locatelli et al., 2008). The perinatal period is a time of great stress to the fetus. Uterine contractions intermittently decrease placental perfusion. The umbilical cord may prolapse into the vaginal canal if the head is not engaged in the pelvis, leading to cord compression with a resultant lack of blood flow to the fetus. A difficult extraction may similarly compress the cord, as may be seen in a breech or transverse presentation, or with an excessively large fetus (Berger & Garnier,
2000; Calvert & Zhang, 2005). Each of these factors, either in combination or isolation places the fetus at risk for neural injury in the period surrounding birth.

In summary, the perinatal period is a time of great stress to the fetus with potential for life long effects upon the child and his family, as well as society. Appropriate physical and psychosocial care is paramount to the neurodevelopmental outcome of the child, the psychosocial and emotional outcomes of both the child and his family, and societal outcomes in terms of health care expenditures.

2.1.1 Neural Development

Embryologic development of the brain involves a complex intertwining of cell divisions, migrations, and differentiations. A structure needed at an early stage of embryonic life may not be required later. Through programmed cell death, also known as apoptosis, differentiation removes that which is no longer needed. As this process is so important and active in the developing brain, it is more likely to be “accidentally” activated in the case of an hypoxic-ischemic insult (Blomgren et al., 2007). During the third trimester there is a 400% increase in gray matter volume (Hill, 2010) making injury at this time particularly significant. These newer areas of the brain are more vulnerable to hypoxic-ischemic injury because neither electrical circuitry nor autoregulation of cerebral blood flow has adequately developed (Badr & Purdy, 2006).

Structural development of the brain continues after birth, with susceptible areas remaining open to insult. This development includes continued weeding of excessive synapses, no longer needed. Some connections are strengthened, and others, which are no longer used, atrophy (Badr & Purdy, 2006).
As neurodevelopment occurs in a specific order based upon gestational age, so may vulnerability to injury be influenced. Lesions associated with hypoxic-ischemic injury in term infants will primarily be appreciated in the thalamus, basal ganglia, brainstem, and cortical areas. This principle also affects the responsiveness to various interventions. For example, the greatest window of opportunity for the effectiveness of intervention is between 28 weeks gestation and 15 months post-term and is often thought of as the plasticity of the newborn brain (Cioni, Acunto, & Guzzetta, 2011).

2.1.2 Pathophysiology of Hypoxic-Ischemic Encephalopathy

Hypoxic-ischemic encephalopathy (HIE) may be thought of as a series of repeated, evolving insults. Cell death associated with the initial hypoxic-ischemic insult sets the stage for repeated chemical and molecular events which cause additional cell death and further damage to the brain (Allen & Brandon, 2011; Blomgren et al., 2007; Fatemi, Wilson, & Johnston, 2009; F. J. Northington et al., 2011). Two primary types of cell death contribute to the ultimate neurologic outcome of affected infants. Necrosis refers to actual lysis of either a single cell or group of cells following cytoplasmic swelling and nuclear dissolution. In apoptosis cells are dismantled and then consumed by surrounding cells. This process takes a significant role during neurodevelopment as well as within pathologic processes.

**Primary and secondary energy failure.**

Two stages have been delineated in the pathophysiology of HIE, primary and secondary energy failure. During the initial reduction of cerebral blood flow, a decrease in oxygen and glucose leads to diminished energy, forcing the cell into anaerobic metabolism, thus increasing the production and release of lactate (Delivoria-
Hanrahan et al. (1996) demonstrated an accumulation of lactate in 15 of 16 neonates suspected of having HIE, as opposed to 4 of 10 controls ($p < .05$) at 18 hours post injury. There is a question as to why the 18-hour mark was used for this study, because at this point infants may well already be within the processes of secondary energy failure. The researchers view this as an area from which gradated values would be more useful than merely noting presence or absence of lactate.

In the unaffected cell, calcium and other ions are balanced within a narrow range, primarily due to energy-driven cellular transport systems (Calvert & Zhang, 2005). Anaerobic metabolism causes failure of these mechanisms, causing sodium ions to invade the cell’s cytoplasm leading to depolarization of neurons with the subsequent release of glutamate, a prominent excitatory neurotransmitter. The glutamate binds to receptors, which leads to a further influx of sodium and potassium, thus pulling additional water into the cell, which further accentuates calcium influx (Blomgren et al., 2007; Delivoria-Papadopoulos & Marro, 2010). This rise in intracellular calcium is accompanied by a fall in ionized calcium, particularly in those who have an adverse outcome (Yoneda et al., 2005). This leads to cerebral edema, ischemia, and microvascular damage which cause further necrosis and apoptosis (Allen & Brandon, 2011).

A reduction of cerebral perfusion is often associated with systemic hypotension and may lead to damage in the parasagittal areas of the cortex, also known as the arterial watershed areas of the neonatal brain (Cioni et al., 2011). As the asphyxial insult worsens, so may the areas of cortical and subcortical damage. When neuronal cells necrose, the contents of those cells are released, accentuating inflammation, which triggers the release of cytokines, which in turn, stimulate the release of oxygen free
radicals and neutrophils (Blomgren et al., 2007; Delivoria-Papadopoulos & Marro, 2010). This causes the release additional inflammatory mediators. Those mediators corrupt the brain’s white matter leading to the development of scar tissue. In the case of a less severe insult, some of these cells may recover, while others will become apoptotic. This cyclic process may occur days after the initial insult (Allen & Brandon, 2011).

Following the latent period, secondary energy failure occurs, usually between six and 48 hours after the initial insult (Allen & Brandon, 2011). Reperfusion and re-oxygenation induce a cascade of events similar to that which occur during primary energy failure. Free radicals damage the cell membrane and lead to additional necrosis and apoptosis. This has been demonstrated in mice following exposure to hyperoxia following hypoxic-ischemic injury (J. D. Koch, Miles, Gilley, Yang, & Kernie, 2008). Free radicals are produced due to a reduction of components within the electron transport system (Delivoria-Papadopoulos & Marro, 2010). Due to high concentrations of unsaturated fatty acids and low concentrations of antioxidants in the neonatal brain, and high oxygen consumption during the transition from fetal to neonatal circulation, neonates are particularly susceptible to oxidative stress (Allen & Brandon, 2011; Chang & Huang, 2006; Delivoria-Papadopoulos & Marro, 2010). This is accentuated during a hypoxic-ischemic state. Subsequent reactions create additional free radicals. Further release of excitatory neurotransmitters over-stimulates receptors. As in primary energy failure, over-stimulation permits further influx of sodium and calcium into the cells. Intracellular ion concentrations, pH, protein phosphorylation and energy metabolism all change, all further the process of cell degradation (F. J. Northington et al., 2011).

Markers of oxidative stress were evaluated by Mondal, Bhat, Banupria, and Koner
in 40 term infants with perinatal asphyxia and were found to be markedly elevated compared with controls. As the stage of HIE worsened or as seizures occurred so did one of the markers, malondialdehyde. A similar study, conducted by Kumar, Mittal, Khanna, and Basu (2008) additionally sought to assess blood brain barrier permeability. While their findings in regards to malondialdehyde were consistent with those of Mondal et al. (2010) they also found that spinal fluid albumin levels and blood brain barrier permeability were significantly higher in infants with HIE ($p < .001$). There was a significant correlation between the blood brain barrier permeability and both plasma malondialdehyde ($p < .001$) and plasma nitrate/nitrite levels ($p < .001$), indicating that an increase in blood brain barrier permeability was associated with an increase in oxidative markers. Given time constraints in regards to the initiation of therapeutic hypothermia, the lack of potential alteration of clinical management based upon the results of spinal fluid analysis, and the requirement to promptly work toward clinical stability, most centers do not perform lumbar punctures on neonates in this situation.

While these studies provide evidence of oxidative stress and changes in blood brain barrier permeability, they provide only inferred evidence of oxidative stress within the brain. Toet, Lemmers, van Schelven, and van Bel (2006) used near infrared spectroscopy to assess regional cerebral oxygen saturation and cerebral tissue oxygen extraction following an asphyxial insult in 18 infants. They found that regional cerebral oxygen saturation remained within normal limits and stable in the infants who had a normal outcome, as opposed to those who had an adverse outcome where levels rose after 24 hours and remained elevated. These differences were significant at 30, 36, and 48 hours ($p < .05$; $< .001$; and $< .001$, respectively. Fractional regional tissue oxygen
extraction in asphyxiated infants was markedly lower than in infants with normal outcomes. The researchers proposed that increased regional cerebral oxygen saturation and decreased tissue oxygen extraction in those who had adverse outcomes were possibly due to neuronal cell death, which lead to a decrease in oxygen uptake by the brain, due to fewer oxygen consuming cells. Evidence of oxidative stress in this population supports the probable role of oxygen free radicals in the evolution of neural injury.

2.1.3 Clinical Symptomatology

Clinical management and outcome prediction for neonates with HIE are largely based upon clinical findings. Physical and neurologic symptomatology develops over time. The standardization of these findings is beneficial to health care providers to guide care, level of support, and provide appropriate parental advisement.

Sarnat and Sarnat (1976) describe a staging process which addresses the severity of neonatal encephalopathy at the time of presentation. It is important to differentiate “neonatal encephalopathy” from “hypoxic-ischemic encephalopathy,” which is a specific type of neonatal encephalopathy. Etiologies of neonatal encephalopathy may include intracranial pathologies, infectious disease, metabolic disorders, and toxic disorders, as well as HIE. A modification of Sarnat’s original staging is used clinically today (S. P. Miller et al., 2004). Stage I includes infants who may be thought of as having mild encephalopathy and is marked by an infant who is hyperalert, but otherwise tending to exhibit normal muscle tone, at times hyper-reflexic, but with a weak suck. Protective reflexes such as cough, gag, and corneal will be intact. No seizures will be present. These findings are notable in the first 24 hours of life and then gradually subside. If the infant progresses to or presents with Stage II signs, one will observe lethargy or mild
tonal abnormalities at rest. He may be generally obtunded, but may also exhibit hypertonia when stimulated as well as possible seizures. The examination tends to remain abnormal for 48 to 72 hours, and sometimes longer, prior to improvement in most cases. However as cerebral edema increases, the examination may also worsen. In Stage III, or severe encephalopathy, the infant will be flaccid and comatose, non-responsive. He may exhibit decerebrate posturing, which consists of an extension of the legs and arms, back arching, and outward turning of the wrists. Seizures may be absent or frequent and of short duration. Symptoms tend to worsen over the first 72 hours. An increase in intracranial pressure with loss of pupillary responses, and brain stem reflexes, such as cough, gag, or corneal reflexes, along with a tense fontanel is considered to be ominous (Levene & Sinha, 2002). Similar criteria have been used for all studies evaluated involving HIE and are consistent with the clinical findings delineated by Sarnat and Sarnat (1976). They include various combinations of: 1) Apgar score of $\leq 4$ or 5 at five minutes; 2) metabolic acidosis, with either cord arterial or first postnatal base deficit of $\geq 16$ or pH $< 7.1$; 3) delayed onset of respiration for at least five minutes; 4) need for mechanical ventilation immediately after birth; 5) evidence of moderate to severe encephalopathy; 6) multisystem involvement; and 7) $\geq 35-37$ weeks post-conceptual age. 

Hypoxic-ischemic encephalopathy is not usually seen in isolation from hypoxic-ischemic injury to other body systems. The brain is usually protected and experiences injury only after injury has occurred in other organ systems. Dysfunction in the renal, gastrointestinal, metabolic, hepatic, hematologic, respiratory, and cardiac systems may often be seen; thus, resulting in a culmination of multiple system supports and complex medical interventions, all of which are witnessed by parents.
Aberrations in glucose metabolism and utilization are preceded only by the asphyxial insult in the progression of HIE. In this process glucose is rapidly metabolized anaerobically to maintain cellular energy, leading to a decrease in serum glucose (Volpe, 2008). Salhab, Wyckoff, Laptook, and Perlman (2004) retrospectively evaluated hypoglycemia in HIE, finding that 15/27 (56%) infants with a blood sugar of ≤ 40 as opposed to 26/158 (16%) with a blood sugar of > 40 had an abnormal neurologic outcome ($p = .00003$). Of those with low blood sugars and abnormal outcomes, four additional factors were associated: lower pH ($6.86 \pm 0.07$ vs. $6.92 \pm 0.04$; $p = .004$), greater need for CPR and/or intubation ($12 \ [75\%] \ vs. \ 4 \ [36\%]; \ p = .04$,) lower 5 minute Apgar score ($11 \ [73\%] \ vs. \ 1 \ [8\%]; \ p = .04,$) and lower mean arterial blood pressure ($34 \pm 10 \ vs. \ 42 \pm 10; \ p = .006$). Similar findings were obtained by Nadeem and colleagues (2011) who found that early hypoglycemia was significantly correlated with severe HIE ($p = .012$), but that mean blood glucoses over 72 hours were not correlated with outcome. This may be due to the ongoing management of glycemic status by clinicians with fluids being adjusted to maintain euglycemia. It may be more beneficial to look at glucose infusion requirements in regards to outcome.

Renal dysfunction is a common finding in the infant with HIE. It consists of oliguria or anuria, elevated serum potassium, and elevated creatinine. Hepatic dysfunction may be noted by elevated transaminases. Coagulopathies may occur and are believed secondary to bone marrow insult in some cases (Pasternak & Gorey, 1998).

A not uncommon complication of perinatal asphyxia and HIE is myocardial dysfunction. Using electrocardiography (EKG,) Kanik et al. (2009) found that 13/34 (38.2%) of infants with HIE, also had findings consistent with myocardial dysfunction.
EKG changes were significantly associated with both death and poor outcome \( (p < .001, p = .02, \) respectively). In addition, they found that troponins obtained on day of life three were markedly elevated in non-survivors. Kluckow (2011) recommended adequate monitoring and appropriate treatment and support, including both volume and pressor support, as these are essential in minimizing the effects of myocardial damage, ventricular dysfunction, abnormal transition to extrauterine circulation, and impaired autoregulation, which may contribute to neuronal damage from HIE.

Perhaps the most difficult to manage associated diagnosis with HIE is persistent pulmonary hypertension of the newborn (PPHN). In-utero, pulmonary vascular pressure is high due to the fact that the only blood flow required by the lungs is for nutrition, as the placenta provides perfusion and oxygenation to the systemic circulation. At birth, the fetal shunts close as pulmonary vascular pressures drop (Abman, 2004; Liu & Feng, 2009). The infant cannot survive without maintaining pulmonary vasodilatation. The pulmonary vascular bed, as with all vascular beds, is muscularized. When a fetus has been stressed in-utero over a period of time, that musculature may hypertrophy or “remodel.” In the face of an asphyxial insult, that musculature becomes reactive to low oxygen tension and acidosis. When this occurs, the endovascular musculature constricts, reducing blood flow to the lungs and creating a right to left shunt across the ductus arteriosus or the foramen ovale, hence creating a state of PPHN. This process is also influenced by the same chemical mediators that are active in the pathophysiology of the HIE, itself. Despite understanding the physiology of PPHN, it remains a puzzle as to why some stressed neonates develop PPHN and others do not. However, the same
stressors and insults which lead to HIE also lead to PPHN, such that both may occur in concert.

2.1.4 Neural Plasticity

Despite a lack in full understanding, improvement and even resolution of neural injury has been described for years. One of the earliest descriptions of this improvement was made by Sigmund Freud (1897). Perhaps one of the most developmentally active periods of the brain occurs between two and three months prior to term through six to eight months post term. At this time myelination is occurring and apoptosis is rapid due to continued differentiation (Cioni et al., 2011). It is believed that developmental changes may be reflective of neural plasticity and not merely continued growth and development. Furthermore, it is possible that the rapid growth and development in early childhood, as a factor within neural plasticity, may be able to permit a tailored growth and development which aids in the recovery from neurologic insult. Nelson and Ellenberg (1982) described 229 children who were diagnosed with CP at one year of age. By age 7, over half displayed no motor disabilities, leading to a question of recovery. Resolution of findings of CP occurred most often in children with mild CP and less in moderately or severely affected children. These researchers found that the children who recovered from CP had more visual and visuo-motor abnormalities and cognitive delays. Hyperactivity was common, with 50% of these children being affected. Additional associated findings in children who ‘outgrew’ CP included more frequent seizures, abnormal speech, emotional immaturity, and learning disabilities that were not associated with cognitive delay. The question of ‘recovery’ from CP is contrary to established understandings of this entity and therefore requires further investigation. It is possible
that some of the improvements appreciated may be more due to maturational changes than a change in the characteristics of the disability.

The intricacies of neural plasticity intrigue the neonatal and pediatric practitioner. Prognoses cannot be cut and dry, as recovery is influenced by a wide variety of factors. The discernment of these components is still in its embryonic stage. Quairiaux, Stzonenko, Megevand, Michel, and Kiss (2010) evaluated functional deficit and recovery in sensorimotor networks in HIE in the rat. By 21 days after the insult, functional recovery in the sensorimotor network was evident. Failor and colleagues (2010) also used rats to evaluate changes in the visual cortex following an hypoxic-ischemic insult. They found that mild to moderate damage did not prevent the development of normal visual cortical responses. Mice were used by Fagel et al. (2009) to more fully understand the molecular mechanisms involved in neuroplasticity. They found diminished markers of vital inhibitory neurons, and a disruption in the receptors for fibroblast growth factor, with an increase in excitatory neurotransmitters. It is possible that such expression of a variety of neurotransmitters may impede recovery. It is therefore further possible that understanding of these processes may lead to therapies which may stimulate a more rapid recovery, improve functional neuroplasticity and thereby recovery.

While recovery may occur during infancy and early childhood, when changes of plasticity are rapidly occurring, Ballantyne, Spilkin, Hesselink, and Trauner (2008) sought to determine if recovery in intellect and language may be maintained. They conducted longitudinal testing of 29 pre-school and school age children who had suffered a perinatally acquired, unilateral ischemic stroke. Their findings indicated that continued plasticity following early focal damage accounted for stability in all and improvement in
some, in terms of cognitive function over time. The caveat to this is that the existence of seizures limited that plasticity with lower results on intellectual and language testing, as well as cognitive abilities. This finding supports the statement by the American Academy of Pediatrics Neurology Group on Neonatal Seizures (Clancy, 2006) that seizures are a significant risk factor for neurologic disability.

As cortical visual impairment is commonly secondary to perinatal asphyxia (Flodmark, Jan, & Wong, 1990). Pallagrosi (1993) advises that the first year of life is the most likely period for children to respond to therapies geared to promoting visual development. While plasticity is most often thought of in terms of a younger child, Walther and colleagues (2009) found movement therapy beneficial in seven children and young adults between the ages of 10 and 30, who had a prenatal or perinatal unilateral cortico-subcortical infarction of the middle cerebral artery. The researchers concluded that constraint-induced movement therapy induced neuroplastic changes in the primary motor cortex. Certainly, this possibility provides hope for continued improvement over the long term for individuals with disabilities.

In summary, the prediction of recovery is challenging. Factors that impact upon that neonate’s neural plasticity are not yet well defined. It behooves the health care professional to be aware of potential recovery, albeit often incomplete, in terms of leaving that window open for hope. In addition, much is still to be learned in terms of how to maximize the potential of each child, most particularly while the brain has the greatest ability to take advantage of supportive therapies.
2.1.5 Magnetic Resonance Imaging

As the prediction of neurodevelopmental outcome is important to parents and health care providers in terms of planning appropriate support, structural damage is most accurately assessed by magnetic resonance imaging (MRI). Cowan and colleagues (2003) showed that most injuries occurred perinatally. This study which included both MRI data and postmortem examination, when applicable, looked at 351 term and post-term infants with encephalopathy and/or early seizures. They found that infants with encephalopathy had basal ganglia, thalamic, cortical or white matter lesions, with a few having focal infarction as opposed to infants who presented only with early seizures.

With this as a base, Miller et al. (2005) sought to determine if a relationship existed between the various patterns of brain injury seen in neonatal encephalopathy and a variety of prenatal and perinatal factors. They evaluated 163 newborns with neonatal encephalopathy or perinatal respiratory or neurologic depression. MRI findings of acute or subacute injury were common with 63 (52%) and 15 (29%) infants in the first and second cohorts with watershed predominant injuries, 25 (22%) and 18 (35%) respectively with basal ganglia and thalamic injuries and 32 (37%) and 19 (37%) with normal MRIs. The watershed area of the brain is particularly susceptible to injury as it refers to an area of overlap of the anterior and middle cerebral arteries. When circulation to this area is compromised, the surrounding area becomes ischemic. Predominant injury patterns were often accompanied by injuries in other areas. Most notably, total brain injury was observed in 45% of those with basal ganglia/thalamic injury. Emergent Caesarian delivery was associated with infants who had basal ganglia/thalamic injury. Newborns with basal ganglia/thalamic injury showed more severe neurologic signs in the immediate
neonatal period, consistent with a late severe insult, which may or may not have been preceded by an earlier and/or less intense insult. Intensity of resuscitation was correlated with the basal ganglia/thalamus score \( (p < .0001) \), the severity of encephalopathy \( (p < .0001) \) and seizure severity \( (p < .0001) \) and was more consistent with a late, severe insult.

Ferrari and colleagues (2011) sought to correlate MRI findings with clinical outcomes. The most significant finding was that of the 21 of 34 infants with basal ganglia and thalamic injury, 16 had CP, one had mild motor impairment, and four infants had normal outcome at two years. The caveat to this finding is that the five infants who did not develop CP had very early MRI studies. Given this, basal ganglia and thalamic injury were determined to be the best predictor for CP \( (p < .001) \). While the ultimate extent of injury is still in a process of evolution, MRIs may not be particularly beneficial for parental advisement of outcome if obtained too early.

Twomey and colleagues (2010) evaluated early (by 10 days of age) and late MRI findings at two years of age, in 26 term infants with HIE. They found that the patterns of ischemia on early MRI, as well as the combined scores of basal ganglia, basal ganglia/watershed, and summation of images were significant predictors of two-year outcome \( (p < .0001) \). Late MRI findings of a thin corpus callosum were associated with unfavorable outcomes \( (p = .02) \). Similar findings were obtained by van Kooij et al. (2010) who followed children to 10 years of age, finding that the degree of encephalopathy, early and late MRI findings, and neurodevelopmental outcome were correlated.

A retrospective study of 48 infants born at \( \geq \) 36 weeks gestation, had evidence of a perinatal sentinel event, an abnormal neurologic exam and an MRI within six weeks of
life was conducted by Okereafor et al. (2008). The researchers found that when compared with 229 low risk term infants, maternal hypertension was significantly more common in case infants ($p = .03$) and more case infants were of African descent ($p = .0065$). This indicates a need for further evaluation of variables such as socioeconomic status, access to care, or physiologic differences between the groups.

The corpus callosum has been described as a target area in HIE. Takenouchi, Heier, Engle, and Perlman (2010) evaluated 34 such infants at $8 \pm 2$ days of life, finding that 29% infants had restricted diffusion in this area. Of these, 90% had poor outcomes including death, with 40% exhibiting bilateral basal ganglia and extensive white matter involvement. These findings are consistent findings of Twomey et al. (2010).

Hippocampal atrophy has been described in children who suffered from perinatal asphyxia and is believed to be associated with memory issues in adolescence (Maneru et al., 2003). Glass and colleagues (2009) correlated MRI findings with seizures in 103 children with HIE, finding that basal nuclei predominant patterns were most common in those with severe seizures (54.6 %;) while watershed predominant injuries were common with mild or moderate seizures (50%) and no seizures (55.8%). When the patterns of injury were compared between severe seizures and mild/moderate or no seizures, the difference was significant ($p < .0001$). Because the severity of MRI injury is highly correlated with outcome and seizure severity is highly correlated with MRI findings, the researchers deduced that the severity of seizures may also be correlated with outcome.

One of the features assessed on MRI is diffusion-weighted imaging. Hunt, Neil, Coleman, Kean, and Inder (2004) evaluated 28 term infants with HIE as soon as feasible after birth (mean = 5.6 days) with outcome evaluated in 12/16 survivors. They found that
lower diffusion coefficients were associated with greater neuromotor deficits and were associated with Sarnat staging ($p = .003$).

Magnetic resonance spectroscopy has been used to evaluate various metabolites following HIE. Ancora et al. (2010) used this method, along with aEEG in 31 infants with HIE, finding that N-acetyl aspartate (NAA), NAA/creatinine, NAA/choline in the basal ganglia were significantly correlated with the development of CP at two years of age, ($p = .000, .000,$ and $ .002,$ respectively). Consistent with the findings of Hanrahan and colleagues (1996) the correlation with lactate was not significant. It is possible that the timing was not correct to capture the value. While significance is clear, it is possible that the expense of this type of study may outweigh the benefits.

While magnetic resonance techniques provide useful information, they are valueless without clinical correlates. Mercuri et al. (1999) studied 58 infants with HIE. Of the six infants who had a normal MRI, four (66.7%) had an abnormal initial neurological exam. Nineteen infants had minimal white matter or basal ganglia lesions with 14 having abnormal neurologic exams. Thirteen of these infants were reassessed after ten days, with five remaining abnormal. Only four were reevaluated at the end of the first month of life, with all having a normal neurologic examination. Seven children had diffuse white matter changes, with three having a significant hemorrhagic component. All had abnormal exams in the first two weeks, which consisted of hypotonia, poor suck, seizures, and poor visual responsiveness. These abnormalities improved in those who had only ischemic lesions. This may be due to neural plasticity. The 15 infants who had significant involvement of the basal ganglia, thalami, and white matter had persistent, marked abnormalities on examination consisting of marked
hypotonia, fisting of both hands and fists, inability to suck, poor swallow, poor alertness, and poor auditory and visual responsiveness. After two weeks, ten infants remained unchanged, while 5/15 infants displayed differential tonal abnormalities with decreased lower extremity and increased upper extremity tone. Tremors and multiple abnormal movement types could be appreciated. The researchers suggest that in the absence of neuroimaging, the neurological examination is both useful and specific in terms of prognosis. At this time however, specifically with the use of therapeutic hypothermia, this suggestion must be taken with an element of caution as the initial neurologic examinations may be less predictive of outcomes. Nonetheless, MRI has become an invaluable adjunct to the care of neonates and children who had HIE.

2.1.6 Electroencephalogram

The clinical picture of the infant with HIE may be correlated with electroencephalogram (EEG) findings. Stupor, coma, and seizures are common in moderate and severe encephalopathy. In general, the neurologic examination of a newborn is vastly different from an adult or child due to incomplete myelination of the axons. For this reason, seizure activity, in particular, does not always clinically appear as obviously as in an adult. When seizures are perceived clinically, most signs are subtle and some forms are more common in preterm than term infants, although all of them from simply facial, eye, oral, or tongue movements to multifocal tonic or clonic seizure activity may be appreciated in both groups.

Murray, Boylan, Ryan, and Connelly (2006) used a case study to follow video EEG findings with clinical correlates and MRI. Clinically, the infant was believed to be having seizures and was treated, however upon evaluation of the EEG, no seizure activity
was detected. Upon review of the video, these episodes were believed to be hypertonia with clonus. Whether this indicates a need for staff education in neurological assessment, as clonus is distinguishable from seizure activity or whether this indicates a type of “seizure” occurring in a portion of the brain inaccessible to EEG evaluation and therefore somewhat elusive is unclear. This is particularly important because as parents may frequently be at the bedside when a clinical diagnosis of seizures is made, it may impact their emotional responses and thereby coping.

Pasternak and Gorey (1998) studied MRI and EEG in 11 neonates with seizures. Four of these demonstrated a severe encephalopathy accompanied by severe background abnormalities on EEG. In the 7 infants with moderate encephalopathy, the EEGs tended to show no abnormal background activity, but did show ictal activity.

Two types of EEGs may be performed in neonates with HIE. The first is a full EEG using multiple leads, as discussed above. The second is an amplitude integrated EEG (aEEG,) which has been found useful in this population as it uses only two leads, thereby allowing it to be placed quickly and monitored by non-neurologists. Its sensitivity and ease of use make it beneficial in the detection of neonatal seizure activity (Frenkel et al., 2011). It has been found useful for early prognostic evaluation and in some situations for choosing newborns that would benefit from cooling therapies.

In the intensive care setting, it may be stated that if an infant clinically appears significantly affected by the hypoxic-ischemic event or if a marked metabolic acidosis is present, one need only to be patient, the seizures will appear. However, according to Murray et al. (2006) despite statistical significance of some selected clinical markers as
correlates with seizure activity, none of them were adequate predictors of electrographic seizure activity.

Perhaps one of the more vexing issues in caring for infants with HIE and their families is prognostication. To that end aEEG has becoming useful. Ancora et al. (2010) used aEEG and magnetic resonance spectroscopy to evaluate 32 infants with HIE. Correlation with outcome was achieved using aEEG recordings from 6, 12, and 24 hours of life. They found that all newborns that had normal background activity at six hours also had normal development at two years. A severely abnormal aEEG background was seen in two infants; one of whom died and one of whom developed CP. The prognostic value of the aEEG in infants with a moderately abnormal background was aided by follow-up evaluations. The two who had deteriorating patterns at 12 hours developed CP. The three who had an unchanged pattern at 12, but improved by 24 hours had normal development at two years. While statistical significance was achieved in evaluating the prognostic ability of a severely abnormal aEEG, with only two patients in this group, it is difficult to draw inferences for future use.

In a follow-up study, Murray et al. (2008) used developmental follow-up at two years of age in conjunction with neonatal EEGs in 44 infants with HIE. They found that a normal or only mildly abnormal EEG at six hours was associated with a normal two-year neurodevelopmental outcome. In terms of abnormal neurodevelopmental outcome, absent sleep-wake cycling, burst suppression, and low amplitude were all significantly correlated ($p < .001$) for both burst suppression and low voltage at six hours of life; and at 48 hours of life for continued loss of sleep wake cycling ($p = .005$). Unfortunately, neurodevelopmental outcomes were not reported.
Similar findings were obtained by Nash et al. (2011) who combined EEG with video monitoring in 41 infants with HIE treated with hypothermia. EEG background improved in 19, remained unchanged in 15, and worsened in 5. In contrast with previous studies, of the 14 infants who displayed burst suppression or extremely low voltage at the beginning of cooling, only nine (64%) had maximal injury on MRI, while five had either mild injury or a normal MRI, possibly due to therapeutic hypothermia. After 72 hours of cooling, moderate to severe injury was present in 1/12 (8%) infants with a normal EEG background, while five infants showed burst suppression or extremely low voltage, all of whom had moderate to severe injury on MRI. Identification of electrographic seizures occurred in 14 (34%) infants with onset at various points in time. Of note, 43% did not exhibit a clinical correlate, including three who were in status epilepticus. This is consistent with the findings of Connell, Oozeer, de Vries, Dubowitz, and Dubowitz (1989) who found that 42% of neonates had no clinical signs associated with electrographic seizure activity. The use of the video in conjunction with EEG by Nash et al. (2011) illustrated a high percentage of subclinical seizures in this population; an important finding, as there are continued discussions in the literature as to the significance of subclinical seizures (Clancy, 2006; Scher, 2003; Wusthoff et al., 2011).

Despite studies which discuss alterations in neuronal cell processes during seizure activity, a question remains as to whether seizures are due to, or cause further brain injury (Scher, 2003) or whether purely electrographic seizures should be treated. According to Clancy (2006) for the Neurology Group on Neonatal Seizures, neonatal seizures are the important sign of acute encephalopathy, are a significant risk factor for death or neurologic disability, and may themselves contribute to neurologic disability.
Other researchers believe that seizures are not associated with outcome. Kwon et al. (2010) performed a secondary analysis of data from the Neonatal Research Network whole body hypothermia trial. Of 208 infants, 127 were reported as having clinical seizure activity. The researchers found that when these 127 infants were compared with the 81 who did not have clinical seizures, more were born to African American mothers, were born at an outlying institution and transported in, had lower ten-minute Apgar scores, required continued resuscitation at ten minutes, had greater levels of acidosis and were classified as having severe encephalopathy. Given the difficulty in clinical seizure recognition, as well as missed electrographic seizures in this population, further evaluation is warranted. In addition, a seizure should be contrasted with multiple or difficult to control seizures. With this in mind, potential significance could have been diluted.

2.1.7 Current Management

Initial clinical management.

The initial management of a neonate with HIE is geared toward therapies that are both lifesaving and life maintaining. Delivery room management is based upon the guidelines set forth by the American Academy of Pediatrics, Neonatal Resuscitation Program (Zaichkin, Weiner, & Major, 2011). The infant is dried and stimulated. If respirations are depressed the infant will be given positive pressure ventilation by either endotracheal tube or by resuscitation bag and mask. If the infant’s heart rate is inadequate, chest compressions will be initiated. If there is an inadequate response, epinephrine will be given. If indicated, fluid resuscitation with normal saline via an umbilical venous line may be used. Once the infant has a stable heart rate, it is vital to
bring the infant to the mother, if only for a moment. If a team member is able to stay with the parent(s) for a time to explain what has happened and briefly what is to happen, it may be anticipated to be helpful. Even this brief period may be considered beneficial in terms of long-term maternal child interaction and has been referred to as the “Early maternal sensitive period.” While imprinting, a concept often thought of in terms of young animal behavior is often not thought of in terms of human kind, it has been shown that a similar process may be a factor within the human animal, as well (Bystrovoa et al., 2009; Goldberg, 1983; Klaus, 2009; Mehler et al., 2011). This separation between mother and infant is magnified when the infant must be transferred to a tertiary center and the mother remains hospitalized.

**Initial intensive care management.**

The initial management within the neonatal intensive care unit is geared toward stabilization of body systems. If a cooling therapy is anticipated, the radiant warmer under which the infant lies may be turned off. Alternatively, it may be turned off after vascular access is obtained, as this becomes a more difficult task in a cool infant. Initial ventilator settings will be determined. Umbilical venous and arterial access lines will be placed. When the lines are placed, a blood gas, in addition to a complete blood count, and possibly blood culture will be obtained. If the infant is hypotensive, a combination of fluid and pressors may be used. Metabolic derangements, such as hypo- or hyperglycemia or hypocalcemia will be corrected. Hypoglycemia must be corrected and gluoses must be maintained within a normal range, although that range has not been defined in this population (Salhab et al., 2004; Volpe, 2008). If clinical seizure activity is present, it should be treated immediately, with phenobarbital being the most common, initial
therapy. While, the mother will not yet be able to be at the bedside, some intensive care
units may allow the father some access to the area during sterile procedures.

**Subsequent intensive care management.**

Nutritionally, infants with HIE are customarily not fed, particularly if they are
being cooled. Total parenteral nutrition is utilized in order to maintain a positive nitrogen
balance. When metabolic acidosis is a continuing issue, acetate rather than chloride may
be used to minimize acidosis and its complications. The addition of potassium is based
upon renal function and evaluation of serum electrolytes. When enteral feeds are
ultimately initiated, breast milk is appropriate, when available.

Respiratory management is based upon blood gases and supportive needs.
Conventional ventilation, high frequency jet, or oscillatory ventilation may be required.
Exogenous surfactant administration has been found to be beneficial when secondary
surfactant deficiency exists (Lista, Bianchi, Castoldi, Fontana, & Cavidioli, 26AD; Rey-
Santano et al., 2012). When HIE is significant enough to depress either respiratory effort
and/or protective reflexes such as cough or gag, then despite inherently normal lungs, it
may be impossible to extubate the infant. In situations such as this, it may be appropriate
to entertain discussions of limitation of aggressive management.

Persistent pulmonary hypertension (PPHN) may be a significant issue in the child
with HIE. Management may include ventilation styles which maintain higher PaO₂ and
lower PCO₂ levels, although not at the extreme levels used in the past. Hypocarbia,
particularly in levels less than 20 is associated with decreased cerebral blood flow and is
associated with poor neurologic outcomes. Hypoxia and hyperoxia are associated with
impaired neurologic outcome. While being hypoxic fails to provide the necessary
substrate for cellular recovery, hyperoxia may incite cerebral vascular dilatation, which may predispose the infant to intracranial hemorrhage (Klinger, Beyene, Shah, & Perlman, 2005).

Inhaled nitric oxide is a commonly used pharmacologic method used to decrease pulmonary vascular resistance (Top, Ince, Schouwenberg, & Tibboel, 2011). It is easily administered via the ventilator circuit as a continuous gas, has rapid onset of action, a short half-life, and minimal side effects. While extracorporeal membrane oxygenation may be used when nitric oxide fails to adequately improve oxygenation, one may ask if its use is appropriate in light of a significant neurologic insult.

Cardiovascularly, tricuspid regurgitation and hypotension may be clinically evident. Troponins may be elevated and may be followed. Hypotension may be secondary to diminished intravascular fluid volume, diminished contractility, and/or decreased systemic vascular tone. Maintenance of hemodynamic stability is vital in order to maintain both adequate cerebral perfusion pressure and adequate organ perfusion. This may be managed with fluid administration and/or vasopressive support.

Hematologically, infants who have HIE may also exhibit bone marrow depression. All cell lines may be affected and care is supportive in nature with transfusion of products as clinically indicated. Hepatic dysfunction may be evidenced by elevation of transaminases and diminished clotting factors. It is also possible that infants may develop disseminated intravascular coagulation. Care is again, supportive in nature.

Disturbed renal function is not uncommon. Infants may develop oliguria or anuria. When urine is available for testing, a simple urinalysis may display hematuria and/or proteinuria. Serum metabolic panels may display an elevated urea nitrogen or
creatinine. Care may involve limitation of protein intake, limitation or elimination of potassium, and/or fluid restriction. Cardiac issues, such as hypotension must be addressed in order to provide adequate renal perfusion

**Therapeutic hypothermia.**

In recent years, standard of care dictates that HIE be treated with hypothermic therapy, either by whole-body hypothermia or selective head cooling in order to minimize potential neurologic sequelae. Hippocrates was the first who reported the benefits of hypothermia and had actually packed soldiers’ wounds with snow. These techniques faded from use and resurfaced in the 1960s, for cardiac surgery, using as a backdrop reports of intact survivorship from cold water drowning (Dance, 2011).

As stated previously, the latent period may be of variable duration, based upon the severity of the insult. It is believed that this may be the most effective time period for hypothermic strategies to be effective (Allen & Brandon, 2011; Iwata & Iwata, 2011). With this in mind, cooling must be initiated within six hours of life. Therefore, in addition to achieving vascular access and working toward stabilization, the medical and nursing teams must also be evaluating the infant for the appropriateness of this therapy and be prepared to initiate it quickly. The National Institute of Child Health and Human Development (Higgins et al., 2006) produced an executive summary which detailed the criteria for whole body cooling (Table 2.1).
**Table 2.1**

<table>
<thead>
<tr>
<th>Screening Criteria</th>
<th>Inclusion Criteria</th>
<th>Exclusion Criteria</th>
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<tr>
<td>Postmenstrual age ≥ 36 weeks</td>
<td>Seizure activity</td>
<td>Major congenital anomaly</td>
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<tr>
<td>Diagnosis of encephalopathy</td>
<td>Moderate or severe Encephalopathy</td>
<td>Severe intrauterine growth restriction with birthweight ≤ 1.8 Kg</td>
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<tr>
<td>≤ 6 hours of life</td>
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<td>Consent refused</td>
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<tr>
<td>pH ≤ 7.0 or base deficit ≥ 16 mmol/L within the first hour of life</td>
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<td>Inability to initiate cooling by 6 hours of life</td>
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<tr>
<td>pH 7.01 – 7.15 and base deficit of 10-15.9 mmol/L or if blood gas is not available</td>
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<tr>
<td>Acute perinatal event, or 10 Minute Apgar score ≤ 5, or assisted ventilation initiated at birth and continued for at least 10 minutes</td>
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Early animal studies have demonstrated the efficacy of hypothermia for the treatment of ischemic injury in terms of an overall decrease in neuronal loss (Coimbra & Wieloch, 1994; Gunn, Gunn, de Haan, Williams, & Gluckman, 1997; Hickey et al., 2000; Ko et al., 2001). In preparation for a pilot study of hypothermia in asphyxiated newborns, Shankaran et al. (2002) used miniature pigs. The second arm of this study, supported by the National Institute of Child Health and Development (NICHD) Neonatal Research Network, sought to determine feasibility and safety in 19 infants with moderate and severe HIE. The researchers found that heart rates decreased in the hypothermic group, but that this was not clinically significant. No adverse events were
reported during the cooling period. Two adverse events occurred in the normothermic group; one infant had a persistent acidosis and one died after withdrawal of support.

Three subsequent randomized, controlled trials have provided the basis for therapeutic hypothermia in the United States and Europe. All were cooled to 33.5 degrees centigrade for 72 hours, beginning within the first 6 hours of life. The NICHD group studied 208 infants (Shankaran et al., 2005). Infants who were moribund, had mild encephalopathy, congenital abnormalities, severe growth restriction or an inability to begin therapy by six hours of age were excluded. Death occurred in 23.5% of infants in the hypothermia group as opposed to 35.8% of infants in the control group. Rates of disabling CP were 19% and 30%, blindness 7% and 14%, and hearing impairment 4% and 6%, respectively for hypothermia and control groups. Despite an apparent difference, statistical significance was not achieved. Notwithstanding, the researchers concluded that whole body cooling is both safe and effective in the reduction of death or disability in infants with moderate or severe encephalopathy.

The second major hypothermia trial took place in the United Kingdom. The TOBY trial enrolled 325 infants. The researchers found that cooled infants had improved survival without neurologic abnormality \( (p = .003) \). The risk of CP was decreased (relative risk, 0.67; 95%; CI, 0.47 to 0.96; \( p = .03 \)). Neurodevelopmental evaluation revealed improved scores for mental, psychomotor and gross motor development in the cooled group \( (p = .03; .03; \) and \( .01, \) respectively).

The third of the three major randomized controlled trials was also conducted in Europe, using methodology consistent with the previous trials (Simbruner, Mittal, Rohlmann, Muche, & neon.nEUROnetwork Trial Participants, 2010). Death or severe
disability occurred in 51% of infants treated with hypothermia, as opposed to 83% of normothermic infants ($p = .001$). The researchers cite a neuroprotective effect in those who had severe HIE ($n=77; p = .005$). Subsequent studies have all had similar findings.

A retrospective review of ten cooled and 11 non-cooled infants was conducted by Compagnoni et al. (2002) who found a significant reduction of major neurologic abnormalities and abnormal MRI findings in the hypothermia group ($p < .05$). Similar results have been obtained in other studies (Artzi et al., 2011). Secondary analyses of the NICHD data was undertaken by Gunn et al. (2008), who found that while hypothermia did not affect the severity of encephalopathy at day of life four, infants with moderate encephalopathy had higher rates of favorable outcomes ($p = .006$).

Selective head cooling, either with or without mild systemic hypothermia has similarly been determined to be safe and effective (Gunn, Gluckman, & Gunn, 1998; Lin et al., 2006). Wyatt, et al. (2007) conducted a multicenter study of 218 term infants with moderate to severe encephalopathy and abnormal aEEG findings randomized to selective head cooling and mild systemic hypothermia or routine care. As with total body cooling studies, selective head cooling was found to be significantly associated with a decreased risk of adverse outcomes (28/62 [45%] of cooled infants as opposed to 39/69 [57%] of controls) for moderate encephalopathy and (28/40 [70%] of cooled infants as opposed to 32/35 [91%] of controls) for severe encephalopathy.

While hypothermia has been shown to be beneficial, hyperthermia has been associated with a greater risk for adverse neurologic outcomes (Laptook et al., 2008; Wyatt et al., 2007). Laptook et al (2008) suggest that this may be due to: brain injury
raises body temperature, an elevated temperature causes brain injury, or elevated
temperature is a marker for an underlying process which includes encephalopathy.

Multiple evaluations of the effects of therapeutic hypothermia on various bodily
functions have been conducted. Gebauer, Knuepfer, Tillig, Pulzer, and Vogtmann (2006)
evaluated hemodynamic changes. In addition to lower heart rates, the researchers found
that cardiac output was reduced during cooling, but returned to normal levels after
rewarming. Sleep-wake cycling, as assessed by aEEG in cooled neonates and
neurodevelopmental outcome at 18 months was evaluated by Takenouchi et al. (2011).
Achievement of sleep-wake cycling in 14/22 infants within the first five days of life was
associated with a normal outcome. The seven infants who never developed a sleep-wake
cycle either died or had severe impairments (p = .006). Osredkar et al. (2005) found that
delays in the onset of sleep-wake cycling were positively correlated with the severity of
HIE. Particularly in infants with grade II HIE, infants who had a good outcome generally
achieved sleep-wake cycling by 29 hours of life, as opposed to those with a poor outcome
at 48 hours of life (p < .001). The difference in time to achieve sleep-wake cycling in
cooled versus non-cooled infants is interesting and worthy of further study.

Therapeutic hypothermia, in conjunction with appropriate neonatal critical care is
becoming a useful adjunct, if not a mainstay, in the treatment of neonates with HIE.
While cost analyses have not been done, one may anticipate that reducing the degree of
disability in a child will have an effect on health care costs. Much research is still needed
in this area. It is too soon since the advent of this therapy for long term follow-up. In
addition, the effects of this therapy on parents have not been reported to date. The infants
are cold and pale; parents may not touch them skin to skin. They are usually intubated and sedated. This cannot be without effect on the parent.

2.1.8 Developmental Follow-up

Numerous studies have evaluated the outcomes of children and adults who experienced neonatal HIE, both prior to and since the advent of cooling therapies with much energy spent upon prediction of outcome. With this in mind, it is important to look at outcomes based upon children’s ages.

**Early outcomes.**

Two neurodevelopmental scales tend to be used by researchers and clinicians in the evaluation of young children. The *Griffiths Scale* tends to be utilized throughout Europe, whereas the *Bayley Scales of Infant Development*, tend to be utilized within the United States. The scales are interchangeable in terms of measurement indices and reliability. However, the physical and mental development scores are significantly higher on the Griffiths ($p < .001$). Thus, while the scales are exchangeable in terms of items and reliability, the results are not (Ramsay & Fitzhardinge, 1977). The explanations for these differences include: 1) the socioeconomic statuses between groups used for normative data differed, 2) the Griffiths Scale weights all skills equally; whereas there is a difference is the weights of various skills based on age within the Bayley; 3) the Griffiths may use maternal report of skills as opposed to the Bayley, where all skills are measured. Even with these differences, the scores obtained from each instrument are highly correlated (.96 for physical scales and 0.85 to 0.83 for mental development).

Yudkin, Johnson, Clover, and Murphy (1994) addressed markers of asphyxia and neurodevelopmental outcome in 159 infants who were assigned a one minute Apgar score
of three or less. However, it is well known that the one minute Apgar is a poor predictor of neonatal well-being. Neurodevelopmental assessment at five years of age was carried out using the *Griffiths Developmental Scales* and the *Rutter Behavior Screening Questionnaire*. There were no differences between acidotic and non-acidotic infants. The researchers concluded that serious fetal compromise was not related to long term outcome. The degree of academia and fetal heart rate reported, however were not clear.

Haataja et al. (2001) utilized the *Hammersmith Infant Neurological Examination* in conjunction with MRI findings in 53 term infants with HIE. Twenty-nine children were neurologically normal. Of the remaining 24, three had movement disorders (ataxia, tremor, athetoid,) one each had hemiplegia and diplegia, 11 had quadriplegia, and eight had both quadriplegia and dystonia, with results not being reported for two. Ten children were unable to sit independently at two or four years of age. Eight were able to sit, but not walk at age 2, with only one able to walk independently by four. Neurologic evaluations were within normal limits in all children who had either a normal MRI or only moderate white matter lesions. Severe basal ganglia and white matter lesions were associated with suboptimal neurologic scores. Overall, 40% of infants had suboptimal scores which were correlated with MRI lesions. Steinman et al. (2009) evaluated watershed and basal ganglia injury with verbal intelligence quotients in 64 four year olds with a history of neonatal encephalopathy without motor deficits. Lower verbal and performance intelligence scores were correlated with increased watershed and basal ganglia injury ($p \leq .05$ on all subscales). After separation of the two primary injury types, the association between watershed injury and diminished verbal intelligence remained significant ($p = .01$). This is consistent with other studies which cite language
as the primary identified cognitive problem. The researchers hypothesize that performance scores may be related to an interaction between the two injury patterns.

Ferrari et al. (2011) sought to correlate both the severity and location of brain damage with general movements during infancy and two-year outcome in 34 infants. The most significant finding was that cramped-synchronized movements were associated with the development of CP (specificity, 100%; sensitivity, 68.7%; PPV, 100%; NPV 78.3%).

A retrospective analysis was conducted in term infants treated with whole body hypothermia, who also had MRI data available by Massaro et al. (2010). Of these 30 infants, thirteen had unfavorable outcomes (one of whom was lost to follow-up at nine months). These outcomes consisted of spastic quadriplegia in 10, spastic diplegia in 1, death in 1, and in the infant not evaluated at nine months, severe tonal abnormalities with absent suck and visual fixation. Eight of these 12 children required gastrostomy tubes. Interestingly 4/10 with spastic quadriplegia appeared normal at the time of hospital discharge. MRI findings revealed that both basal ganglia and thalamic scores were independently associated with unfavorable outcomes ($p = .035$, each). While these findings are consistent with existent data, both the retrospective nature of the study and the numbers of participants lost to follow-up make it difficult to interpret the findings.

Miller et al. (2004) looked at encephalopathy scores and clinical seizure activity to predict outcome based upon the Bayley Scales of Infant Development II. The cohort consisted of 68 children with varying degrees of encephalopathy. By 30 months 12% had died and were included in the abnormal outcome group (32% of the cohort). The remaining infants had varying degrees of motor and cognitive delays. There was a high
predictive value for the maximum encephalopathy score and the presence of clinical seizures for an abnormal outcome. For each point of increase in the encephalopathy score over the first three days of life, there was a 370% increase in the risk of an abnormal outcome ($p < .00001$). The effect of clinical seizures was associated with a 411% increase in risk ($p < .00001$). The combination of the encephalopathy score and clinical seizures on the first day of life revealed a sensitivity of 72%, specificity of 94%, PPV of 84%, and NPV of 88% in the prediction of an abnormal outcome at 30 months, making them strong predictors. Another study from this center evaluated socioeconomic factors to predict outcome (S. P. Miller et al., 2002). They found that 40% of infants could be classified as normal, 30% as abnormal, and 30% as deteriorated. Deteriorated infants were found to have a decrease in MDI between 12 and 30 months, but no deterioration in neuromuscular scores. What is of note is that none of the infants who deteriorated were receiving rehabilitative therapy. The researchers caution that this is a high-risk group that needs to receive appropriate developmental services.

**Later outcomes.**

While early developmental outcome is important, additional cortical functions are required as children mature. Robertson and Finer (1988) evaluated preschool age children with a history of mild to moderate neonatal encephalopathy secondary to perinatal asphyxia, but without a specified disability. Using established school readiness tests, they compared 127 healthy controls with 71 children with a history of moderate encephalopathy and 56 with mild encephalopathy. They found that children without disabilities with a history of moderate encephalopathy showed significantly lower scores than controls for quantitative language ($p < .01$), auditory memory ($p < .05$) and letter
recognition ($p < .01$). Of the 71 children with moderate encephalopathy, ten had more than a 12-month delay on expressive language and 13 on receptive language compared with either the mild encephalopathy or control groups.

Once children begin school, intellectual disabilities become more obvious. Robertson et al. (1989) evaluated 145 eight year olds with a history of HIE along with a control group of 155 healthy children. According to classroom teachers, 20% of controls, 11% of the mild, 38% of moderate, and 100% of children in the severe encephalopathy group were receiving some type of in-school assistance from resource room help or special classes. Psycho-educational test scores for children in the moderate and severe encephalopathy groups were significantly lower than the controls ($p < .001$).

A study conducted in Australia (Dixon et al., 2002) sought to determine the developmental outcomes of children up to eight years of age with a history of moderate or severe neonatal encephalopathy. Out of 242 cases and 563 controls, they found that general intelligence quotients were more than two standard deviations below the mean in 23.3% of cases as opposed to 2.5% in controls ($p < .001$) with the greatest deficits being in speech and hearing. CP developed in 11.6% of cases and no controls. After controlling for CP, the data continued to show a difference between cases and controls ($p < .001$). After controlling for cases with identifiable syndromes, the difference remained significant ($p < .001$). In addition, they found that 25% of those with moderate encephalopathy had poor outcomes, as opposed to 63% who presented with severe encephalopathy. Furthermore, they found that children who had had seizures were more than three times more likely to develop CP than those who were seizure free ($p = .04$).
Even children with no apparent disability have been found to have challenges. Maneru et al. (2001) evaluated 28 adolescents who had a history of perinatal asphyxia with a “good” neurologic outcome, including normal intelligence, along with 28 healthy matched controls. Memory was the first area where youths with antecedents of HIE could be appreciated; both in remembrance of a sum of words and delayed recall ($p = .03$ and .02, respectively). The *Weschler Intelligence Scale* revealed deficits with dexterity and fine motor coordination ($p = .01$). Lindstrom et al. (2006) conducted telephone interviews of parents of 28 teenage survivors of moderate encephalopathy without major neurologic impairments. The minor complications in this group consisted of hearing impairment, brachial plexus palsy, equinovarus malformation, and benign epilepsy. Four (14%) had an intelligence quotient of < 70, two of whom attended a specialized school. Borderline intelligence with intelligence quotients between 71 and 85 was present in 28.6%. Interfering problems in short term memory were reported in 64%, as compared with 13% of sibling controls ($p < .002$). Time perception and orientation difficulties were reported for 14 cases and eight siblings ($p < .005$). While methodologies and samples in these two studies were vastly different, both identified memory issues as problematic.

Parent questionnaires were used by Moster, Lie, and Markestad (2002) to examine the relationship of a low five minute Apgar score, clinical symptoms of neonatal encephalopathy, and minor school impairments in 727 school age children, who were stratified by Apgar score into three groups. After children who had major neurological impairments were excluded, the researchers found that children who had a five-minute Apgar score between zero and three had a greater risk of later minor motor impairments and attention deficit/hyperactivity disorder by a factor of 13 and 14-fold, respectively, as
well as a seven-fold increased risk of an epileptic disorder. This group was also reported to perform below average in reading, writing, spelling, and mathematics. Of note, in the absence of clinical encephalopathy, the low Apgar score had no effect on these variables.

Clearly, young people who have a history of HIE are at risk for physical and neurodevelopmental challenges, some of which are not apparent until later childhood. At this point in time, there are no published studies which address the long-term development of children who have been treated with therapeutic hypothermia. As its use becomes more widespread, these follow-up studies will become available.

**Cerebral palsy.**

Perhaps one of the most commonly recognized, severe long-term neurologic problems associated with HIE is cerebral palsy (Perlman, 2006) with the most recent lifetime costs as high as 1.2 million euros (Kruse et al., 2008). It is noted that the diagnosis of CP is clinically descriptive and not etiologic (Bax et al., 2005). The most recent definition states that CP is:

> A group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behavior, and/or by a seizure disorder (Bax et al., 2005, p. 572).

In addition, the authors note that while a definitive diagnosis cannot be made until 18 months of age, neonatal difficulties in both gross motor function and feeding are often described in infancy. This is consistent with the findings of previously described studies (Dixon et al., 2002; Haataja et al., 2001; S. P. Miller et al., 2004). An association between poor suck and significant tiring with feeds has been associated with severe
impairment of both upper and lower limbs at four years of age as well as inadequate growth at eight years of age (Motion, Northstone, Emond, Stucke, & Golding, 2002).

Physical challenges may have an effect on quality and duration of life for afflicted individuals and their families. Little has been published in regards to life expectancy of children with this disability. Hutton, Cooke, and Pharoah (1994) evaluated the status of 1251 children born over an 18-year period in the United Kingdom. They looked at 20-year survival finding that the degree of functionality was germane in terms of long term survival. While those with minimal deficits had a 20-year survival of 99%, those who were severely affected only had a 20-year survival of 50%. As it may be anticipated that many severely affected children may die in their early years, Strauss and Shavelle (1998) evaluated life expectancy in adults with CP, finding that individuals in the lowest functioning group had greatly reduced life expectancy, with only 50% surviving an additional 7.8 years. Individuals who were able to roll, sit, and feed themselves had a 12-year lower life expectancy than the general population, while highly functioning individuals had a five-year lower life expectancy. In 2008, this issue was readdressed (Strauss, Brooks, Rosenbloom, & Shavelle) with little additional change; rather the authors recommend that life expectancy estimates be extended by eight years.

Scope of the problem.

Given the pervasive, all-encompassing nature of CP, it is important to understand the reach of its tentacles. Individuals may suffer from muscle spasms and involuntary movement which may limit ambulation, speech, and the ability to sit unaided or orally feed. There may be disturbances in sensation, communication, or perception, cognitive delays, and behavioral or seizure disorders. Physical abilities are most commonly
assessed by means of the Gross Motor Function Classification System (GMFCS). This system grades abilities between I and V. Children in level I can perform all activities of health children of their age, although they may be slower, or have difficulty with balance and coordination. Children in level V have varying degrees of difficulty in head and trunk control, as well as difficulty in controlling voluntary movement (Beckung & Hagberg, 2002; Erkin, Culha, Ozel, & Kirbiyik, 2010) (See Table 2.2).

**Table 2.2**

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<th>Gross Motor Function Classification System (Beckung &amp; Hagberg, 2002)</th>
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As the hallmark of CP, motor impairments are significant to life quality. Ostensjo, Carlberg, and Vollestad (2004) purport that the total is greater than the sum of the parts. Using multivariate analysis to assess a variety of factors and their impact on daily life, they found that it is not merely gross motor or fine motor function, spasticity, cognitive challenges, or feeding dysfunction, but rather the intertwining of those deficits which create the larger impact. It may be thought of as losing compensatory mechanisms. If a child has spasticity or hemiplegia, but maintains cognitive abilities that child may thrive. However, if feeding disabilities are added and nutrition is compromised, the child loses the ability to fully maintain appropriate neurodevelopment.
Spasticity.

One particular physical challenge which impacts upon quality of life is spasticity. The general belief is that spasticity must be relieved. However, relief of spasticity may be replaced with hypotonia, which may actually decrease functionality of the affected limb(s). Reasons to treat spasticity might include reducing muscle spasm and pain, augmenting use of bracing equipment, minimizing deformity and postural abnormalities, or improving ease of care (Delgado et al., 2010). Gorter, Verschuren, Van Riel, and Ketelaar (2009) studied the physical limitations imposed by spasticity, finding that the initial degree of spasticity had a significant impact upon gross motor development in a young child ($p < .05$). Consistent with the work of Ostensjo et al. (2004), the researchers further found that spasticity, in and of itself, was a minimal factor in functional development. They purport that additional factors, such as family and environment are significant and needed for optimal gross motor development.

Unfortunately, spasticity affects more than gross motor capabilities. Ersoz, Selcuk, Gunduz, Jurtaran, and Akyuz (2006) found that school age children with spastic CP have restricted chest wall movement, predisposing them to respiratory complications, and therefore recommend early pulmonary rehabilitation.

Motor function.

Recognizing the significance of quality of life in children with CP, Chen et al. (2011) sought to determine the effect of motor function on life quality. The researchers studied 39 ambulatory children between the ages of five and twelve with CP, classified as level I ($N = 25$) or II ($N = 14$) using the GMFCS. In addition to testing motor proficiency, they used the CP Quality of Life questionnaire. They found that parents of
level II children viewed access to service and overall family health as more important, in terms of the child’s quality of life, than parents of children classified as level I GMFCS ($p = .01; p = .016$, respectively). Pain and impact of disability were viewed as affecting quality of life more in level II ($p = .012$). They found that the composite of fine motor skills was positively correlated to functioning ($r = 0.39, p = .014,$) as well as self-esteem and the general emotional well-being ($r = 0.40, p = .011$). Visual-motor control was positively correlated with almost every subscale of quality of life ($r = 0.39-0.43, p < .05,$) except pain, impact of disability, and access to service. Dexterity and upper limb speed were positively correlated with general functioning, participation and physical health, emotional well-being, and self-esteem ($r = 0.32-0.45, p < .05$). The coordination of upper limb activity was positively correlated with social and emotional well-being, acceptance, and function. These measures revealed that in terms of parentally perceived child quality of life that vision and fine motor abilities were more important than gross motor abilities. Because both of these allow more social interaction than gross motor abilities and humans are social creatures, the skills which may be used in social interaction may be viewed as more important.

*Fatigue.*

Another factor which may impact upon socialization in the child with CP is fatigue. In addition to an association of pain with fatigue, energy expenditures in CP are significant. Bell and Davies (2010) studied 16 children with mild CP (level I and II by GMFCS) and 16 typically developing children. They found that while children with CP had a less physical activity, their energy expenditures were greater. Ambulation, while a gross motor ability and a less significant factor in socialization, according to Chen et al.
(2011) may also be viewed as necessary in socialization as well as of import in carrying out activities of daily living. Chong, Mackey, Broadbent, Stott (2011) evaluated measured walking abilities in comparison with parentally perceived walking abilities in children with levels I-II CP. They found that for children categorized as level II, parentally perceived walking abilities were in concert with measured abilities. In children with level I disabilities, the correlation was weak. This may be due to the addition of escalators, narrow spaces, and carrying, which were not a part of the laboratory analysis. The researchers caution that walk tests are not well correlated with walking in the community because the community is less controlled and therefore, less safe. In addition, they discriminate between walking ability and walking activity. In other words, what the child is able to do as opposed to what that child actually does.

Growth and nutrition.

Activity, in children with CP, is generally associated with nutritional state. Poor growth has been described in children with CP and is believed to be due, in part, to undernutrition (Stallings, Charney, Davies, & Cronk, 1993a, 1993b). Difficulty with mastication, swallowing, gastroesophageal reflux, emesis, chronic aspiration, and constipation, as well as access to food due to physical limitations and/or difficulty in expressing needs impact upon growth and development, quality of life, socialization, and life expectancy (Erkin et al., 2010). This group studied 120 children between two and 18 years of age with CP (71 mildly to moderately, and 26 severely affected). Feeding dysfunction was present in 4% of children in the mild to moderate group and 22% in the severe group ($p < .001$). Rates of epilepsy, lack of functional communication, and lack of hand use, which contribute to gastrointestinal problems, were significantly higher in the
severe group ($p < .05; p < .001; p < .001$, respectively). One profound issue in the children with feeding dysfunction was the inability to bite off food (57.7%) in this group. Mealtime duration was longer for those with feeding dysfunction by almost 2 hours per day ($p < .001$) to as long as 3 hours, as opposed to parents of healthy children with a mean of 0.8 hours. The reasons found for feeding difficulties were: lack of appetite (38.3%), excessive drooling (30.8%), and constipation (25%). The researchers stated that reflux with aspiration and pneumonia may be contributors due to the use of medications which reduce lower esophageal sphincter tone. In addition to the physical challenges, trunk braces increase intra-abdominal pressure and thereby reflux. Fung and colleagues (2002) in their cohort of 230 children with moderate to severe CP similarly found that the degree of gross motor dysfunction was correlated with the degree of feeding difficulty ($p < .001$). Children with severe feeding impairment had more general illness ($p = .042$) and more days missed from school and spent in bed.

Visual assessments of feeding were conducted in 100 children with CP between the ages of 1 and 9 years (Gangil, Patwari, Aneja, Ahuja, & Anand, 2001). The mean developmental age was 7.6 months (1-36 months). Hypotonia was associated with poor feeding skills ($p < .001$). Additional issues including swallowing problems, coughing, choking, emesis, recurrent pneumonia, and drooling. These issues were most frequently in children who had seizure disorders ($p < .001$). All of these children were undernourished, with 35% being classified as having severe malnutrition. Caloric intake was significantly lower than in healthy controls ($p < 0.01$), as were all anthropometric measurements. Both the frequency and severity of feeding issues were greater in this study than others. This may be due to several reasons. This cohort was more severely
impaired than what has been described in other studies. The researchers state that there was a lack of parental awareness in regards to CP and associated problems, with a resultant lack of recognition of a feeding problem. In addition, access to nutritional supportive services may be limited in India, compared with the United States and Europe. The researchers did show that nutritional rehabilitation was effective in some of these children.

A similar sample assessed the prevalence and nature of feeding difficulties, and oral motor dysfunction in 49 children between one and three years of age with CP (Reilly, Skuse, & Poblete, 1996). Oral motor dysfunction was prevalent in 91.5% of studied children. In addition to poor skills which required at least partial tube feedings, 40% of mothers reported that oral feeding attempts were difficult due to back arching and an inability to make the child comfortable. Hewetson and Singh (2009) evaluated this challenge qualitatively from the mothers’ perspectives, finding that emotional and practical challenges, feelings of incompetence, and loss of social contact took significant tolls. One mother described “making herself hard,” just so that she could get through it. It is impossible to look at the physical issues of feeding problems in children with CP without also evaluating the significant effect upon the parents.

Children with CP tend to be thin, stunted, display low protein levels and have decreased bone mineralization. (Arrowsmith et al., 2010; Bell & Davies, 2010). Few tend to be overweight. Stallings et al. (1993a) found obesity in 8% in their sample of children with hemiplegia or diplegia. Many of these children actually had increased muscle development, believed to be compensatory and aiding in ambulation. Arrowsmith and colleagues (2010) studied 21 children with spastic quadriplegia who
required gastrostomy tube feedings along with age-matched healthy controls. While body fat and protein improved with gastrostomy feeds, there was no improvement in bone mineralization. It is possible that the non-weight bearing status of this cohort may be related to decreased bone mineralization. It may also be anticipated that inadequate bone mineralization may be responsible for some of the pain reported in both children and adults with CP. Of note, however, there is no consensus in the literature regarding skeletal maturation in this population, with a variety of studies noting increased and decreased maturation for age (Gilbert, Gilbert, & Henderson, 2004; Gollapudi, Feeley, & Otsuka, 2007; Henderson, Gilbert, Abbas, Worley, & Stevenson, 2005). More research is needed in this area, specifically with a larger cohort.

Environment.

Given the physical challenges of CP, the environment of these individuals must be considered in both self-management and assisted care. Dickenson and Colver (2011) along with other members of the European Sparcle group developed the European Child Environment Questionnaire to assess the availability of environmental needs and supports for children with CP. The study included 818 affected families. They found that 75% of families required an adequate vehicle and smooth pavements; 50% of children needed wheelchairs and wide doorways. Few additional needs were cited for children without ambulation limitations. Social support needs were great with only one third of families who needed support groups having access. While only 40% needed assistance at home, almost all required specialized therapy and financial information. Time for tasks was critical, both at home and school, with over 80% of children needing this support. It would be helpful to assess this information and test this instrument in the
United States and various socioeconomic groups. Differences may be anticipated with subsequent implications for interventions. Furthermore, as a newer instrument, validating research needs to be completed and correlated with objective assessments of the environment.

Pain.

Pain is subjective and pervasive in both children and adults with CP with 48-84% being affected (Hirsh, Gallegos, Gertz, Engel, & Jensen, 2010; Russo et al., 2008; Schwartz & Engel, 1999; Turk, Geremski, Rosenbaum, & Weber, 1997). Pain levels can be significant with 23% of 83 adult subjects categorizing their pain as level 7 or higher on a 10 point scale (Hirsh et al., 2010). Communication challenges may make it difficult to express that experience. Hadden and von Baeyer (2002) found a wide range of pain behaviors in both verbal and nonverbal children with CP. These included some expected behaviors, such as crying and others were idiosyncratic, such as laughing or self-abuse. Parents reported that the activity which created the greatest pain in their children was assisted stretching, a vital therapy to maintain mobility and independence.

In contrast to this study which found no difference in the degree or frequency of pain based upon degree of motor impairment. Ramstad, Jahnsen, Skjeldal and Diseth (2011) found that musculo-skeletal pain was greater in children with more motor impairment. To better understand of this phenomenon, Castle, Imms, and Howie (2007) conducted a phenomenological study of six adolescents and young adults with CP and chronic pain. Unavoidable suffering, described as a part of the individual and unimaginable to those without this experience was common. Emotional distress, frustration, and desperation were expressed. Significant energy was spent on trying to
improve their situations from relaxation to repeated attempts at obtaining professional assistance. The pain was described as all-encompassing, creating social isolation and academic failure due to a loss of concentration and stress. In concert with these findings, Russo et al. (2008) using the Pediatric Quality of Life Inventory, found that quality of life was significantly lower for hemiplegic children with pain than without ($p < .01$). They note that children often relied on rest, sleep, and massage to gain some relief.

*Sensory deficits.*

A wide variety of sensory deficits in children with CP have been described. Hohman Baker and Reed (1958) found that 72% of their sample of 47 children had some form of sensory deficit including an inability to sense form, impaired two-point discrimination, and loss of position sense. They also found challenges with temperature, wet-dry, and light touch.

Visual and auditory impairment are a risk for all critically ill neonates. This may be related to effects of their various illnesses, nephrotoxic drugs, noise, and injury to the auditory and visual cortices. Shortly after the advent of auditory brainstem evoked responses in the assessment of neonatal hearing, Anand (1991) studied 24 infants with HIE and compared them with 20 healthy newborns. They found that four neonates failed this evaluation entirely with deficits in 75% of children with stage III and 10% of children with stage II encephalopathy. Visual evoked potentials were used in the early neonatal period for 36 term infants with HIE and correlated with overall outcome (Muttitt, Taylor, Kobayashi, MacMillan, & Whyte, 1991). There were 14 neurologically intact survivors who had results within the normal range. Abnormal visual evoked
potentials were present in all 11 infants who died and the 11 who had significant disabilities at 18 months.

Mercuri and colleagues (2004) assessed visual function in 32 school age children who had had HIE. Of these, 24 (75%) had normal visual testing, with an additional two wearing glasses, and six with uncorrected abnormalities. Visual fields were narrow in six (19%) children. When correlated with neonatal MRI findings, 100% (6/6) children with severe basal ganglia and white matter lesions were classified as cortically blind; 11/39 (28%) had abnormal optic radiations and/or abnormalities in the visual cortex with abnormal visual function; 28 children had no abnormalities in these areas, five (23%) had abnormal vision. The researchers recommend further research in other areas of visual processing. These findings are consistent with those of Venkateswaren and Shevel (2008) who found 20.5% of children with spastic quadriplegia to be blind, due most often to cortical visual blindness and optic atrophy. They found no correlation between the severity of impairment by GMFCS and the loss of vision.

When the individual with a history of HIE develops CP, communication may be compromised by both auditory and motor dysfunctions. Venkateswaren and Shevel (2008) found that 40.2% of children in their cohort of 86 had hearing loss with 5.8% being deaf. However, this cohort had a variety of etiologies for CP. There was not a specific correlation between hearing loss and perinatal asphyxia.

Children with CP may also display tactile dysfunction. This is often overlooked due to the impact of motor deficits. Tactile dysfunction interrupts a child’s ability to accurately and appropriately interact with his environment due to altered perceptions. Children with CP who have dystonia, diplegia, or hemiplegia have been found to have
difficulty with tactile sensory discrimination (Cooper, Majnemer, Rosenblatt, & Birnbaum, 1995; Sanger & Kukke, 2007). Specifically, two-point discrimination, proprioception, and stereognosis may place the child at risk for injury due to an inability to accurately assess their environment. This is vital in terms of control of motor function. Minimal work has been done in this area, however due to the impact on daily functioning; its contribution to the overall picture cannot be overlooked.

Moving to adulthood.

It must be remembered that CP is a lifelong challenge. With improved medical care, more children reach into adulthood and new issues surface. Medical maladies comparable to the same aged population develop; in addition, however, urinary tract infections are greater. This is believed to be secondary to hygiene issues and/or the need for urinary catheters (K. P. Murphy, Molnar, & Lankasky, 1995). This group found a general lack of preventative care with over 90% not being medically evaluated.

Adult rehabilitation centers do not have the experience needed for adults with CP, which is still thought of as a childhood illness. Hilberink, Roebroeck, Nieuwstraten, Jalink, Verheijden and Stam (2007) used physical examination and interviews to assess issues in 54 such adults. In addition, an impairment questionnaire was completed by 48 rehabilitation physicians. Participants with CP cited pain as the most problematic condition (59%). In addition, joint deformities were present in 57%, speech and swallowing difficulties in 20%, visual problems in 22% and auditory impairments in 7%, with a mean of more than three impairments per participant. The physician survey revealed that the most significant issues observed were pain (88%), joint deformities (85%), fatigue (75%), epilepsy (50%), as well as swallowing difficulties, impaired bowel
and bladder function, and visual impairments (30%). Notably, 21% of physicians reported functional deterioration. Hirsh and colleagues (2010) report issues of fatigue (64%) imbalance (55%) weakness (52%) numbness (33%) shortness of breath (29%) and memory loss in 23% of their cohort of 83 adults with CP. Fatigue was most highly correlated with shortness of breath, weakness, and pain (r = 0.52, r = 0.46, and r = 0.40, respectively). Both scoliosis and wheelchair use are associated with respiratory issues. In addition, decreased chest wall excursion is common in children with spasticity (Ersoz et al., 2006). Gastrointestinal reflux is common in individuals with CP, thus predisposing them to respiratory issues and providing a fertile area for future research.

Physical challenges, pain, and social isolation challenge the individual with CP, as well as his/her parent. This introduction allows one to begin to appreciate the potential challenges of parenting not only a child with CP, but also a child with other disabilities.

### 2.2 Parental Response to the Child with a Disability

The studies presented thus far have underscored a variety of challenges that may affect the parent of a child with a disability. The following studies will show that there are multiple responses to both the birth and life course of a child with a disability. Grief, guilt, chronic sorrow, anxiety, depression, and stress may impede the ability of parents to parent to the best of their ability or desire, to enjoy a happy life, or even to maintain the best health for themselves. The successfulness of individual coping skills helps to determine parental outcomes. This portion of the literature will address each of these issues, providing the base for further investigation of parents of children with HIE.

#### 2.2.1 Parental Grief

The literature frequently refers to parental grief in regards to the death of a child
(Arnold & Gemma, 2008; Barr & Cacciatore, 2008; McCarthy et al., 2010; Riley, LaMontagne, Hepworth, & Murphy, 2007). It may also follow the loss of the idealized or healthy child and may be of greater significance for some parents than the death of that child due to lifelong challenges (Chiambretto, Moroni, Guarnerio, Bertolotti, & Rigerson, 2010; Collings, 2008; George, Vickers, & Wilkes, 2007; Godress, Ozgul, Owen, & Foley-Evans, 2005; Worthington, 1989). It describes the mental suffering or distress over an affliction or loss and may be envisioned as a deep, at times heartbreaking distress caused as if the individual was bereaved. When a child dies, that loss is often described as lifelong and more painful than the loss due to the death of an elderly or even an adult person. The constancy of caregiving with lack of adequate respite combined with the emotional pain for that child are believed to contribute to this. Disabilities lead to an individual being placed in a disadvantageous situation in terms of socialization, school, work, or simply independent living (Fotheringham & Creal, 1974). The World Health Organization describes these individuals as having a physical, sensory, intellectual or mental health impairment (Violence against disabled children: UN Secretary Generals report on violence against children (Summary Report), 2005). It is these challenges in a child which may be thought of as producing a grief situation for the parent. When a family experiences a traumatic upset to their envisioned life with a new child, such that that child requires long term care, it is possible that anticipatory grief for that child’s life may occur, which may affect their future interactions with that child, if that child survives.
History of parental grief.

The first elucidation of parental grief occurs in Genesis 4:25, “Adam knew his wife again, and she bore a son and named him, Seth, meaning ‘God has provided me with another offspring in place of Abel.’ For Cain had killed him” (*Tanakh: A new Translation of the Holy Scriptures According to the Traditional Hebrew Text*, 1985). Although vague, this passage does indicate a remembrance of Abel with inferred evidence of his being missed.

In 1633 medical literature warned that excessive grief would dry the brain and bone marrow, hinder digestion, interrupt rest and lead to diseases (Pender, 2010). It is assumed that this grief refers to the reaction following the death of an individual, but it may also refer to the loss of the idealized child. That child is *dead* and has been replaced with a child quite different from the anticipated healthy, joyful, offspring. Infanticide of infants with disabilities was proposed by Ernst Haeckel in 1870 in his book, *The Natural History of Creation* (Weikert, 2004). This became the fuel for the development of eugenics and Hitler’s atrocities in Europe.

At this same time, popular fiction characterized parents of children with intellectual challenges as dedicated, loving and spiritually improved due to these challenges (P. L. Richards, 2004). Shortly after this time however, state schools appeared, the term, “idiot,” was commonplace, and such individuals were listed in the newspapers along with criminals. Darwin’s theories were becoming known. A child with a disability was a problem within the family and the result of sinful, diseased parents. It is understandable that families in the 19th and 20th centuries passed these stigmatizing responses on to future generations.
At the dawn of the twentieth century being “normal” became increasingly important. Imperfections were not part of a divine plan, but rather something to be fixed or discarded. Orphanages held high populations of “unadoptable” children. An authority in the Canadian Department of Health in the 1920s was believed to have said that it was worse for parents to have to raise a child with an intellectual deficit than for that child to have died. While familial emotions regarding their children were rarely mentioned, it was also recognized that the burden was so great that it could lead to the break-down of the family unit due to stress (Strong-Boag, 2007).

In 1950, parental grief in relation to disability was first described in the medical literature. Boyd (Fotheringham & Creal, 1974) addressed this issue in a paper presented to the Bergen-Passaic Unit, New Jersey Parents’ Group for Retarded Children,” where he described the grief work of these parents. The first stage identified was denial of a problem. This is in concert with the Kubler-Ross first stage of grief (Kubler-Ross, 1969). The parents are then said to move into a state of self-pity, followed by feeling pity for their child. If all goes well, these issues are resolved by an “accommodation with the situation.” The prevalent paradigm at the time, however, was that helping the parent was for the purpose of helping the child with little regard for the parents’ psychological and emotional well-being (Richmond, 1957). Olshansky (1962) is the first to refer to chronic sorrow in such parents, emphasizing that this is not an inherent problem in the parents.

Characteristics.

Grief, particularly in response to a child with a disability has not been adequately defined in the literature. Cowles and Rodgers (1991) and Jacob (1993) published concept analyses of grief, however ambiguity continued. This ambiguity was in the following ill-
defined descriptors of grief: normal, abnormal, healthy, unhealthy, resolved, unresolved, acute, early, complicated, dysfunctional, pathological, chronic, morbid, delayed, prolonged, disenfranchised, exaggerated, abbreviated, and inhibited. Grief has been described as holding the attributes of a dynamic, pervasive, individualized normative process, specifically within cultural limitations.

Despite this, it is considered to be dynamic, as the processes, behaviors, emotions, and thoughts related to grief constantly fluctuate (Cowles, 1996; Rodgers & Cowles, 1991). This is in contrast to previous literature which discusses phases or stages of grief. Despite vacillation between stages, one would ultimately resolve the situation. The grief work described in such defined processes assumes that one moves from a grieved state to a state of recovery or resolution (Archer, 2001). This is not the case. In her study on cultural perspectives of grief, Cowles (1996), a parent, expressed that although it was less difficult as time went on, resurfaced memories associated with the deceased person spurred pain and deep sadness. Changes in feelings can, and do occur. One may feel fine until a reminder brings back sad feelings, often with a vengeance. This is in concert with a concept analysis of chronic sorrow, which may therefore also be viewed as a type of grief. One feels “normal” until a trigger event brings back feelings of pervasive sadness (Teel, 1991). Grief is pervasive, affecting all aspects of life.

Grieving individuals experience fatigue, loneliness, anxiety, somatization, guilt, anger, fear, and denial (Barr & Cacciatore, 2008; Cowles, 1996; Jacob, 1993). Lindemann (1944) identified preoccupation with the image of the lost person, hostility, and changes in behavior and social conduct. Grief encompasses physical, emotional,
spiritual, and social dimensions. Descriptions have included “a sense of something missing,” hopelessness, helplessness, and a desire to withdraw from social contact.

Grief is normative and is consistent between both individuals and cultures. Cowles and Rodgers (1991) pointed out that the normative characteristic of grief is embedded within cultural norms and death related rituals with religious and spiritual influences and customs taking on great significance. Socioculturally, norms and rules for the public expression of grief have been based upon these institutionalized values. Benoliel (1985) stated that the patterns of psychological defense in these situations reflect common social and cultural values that have been learned through the family. In relationship to this, Kissane, Bloch, and McKenzie (1997) stated that loss affects the entire family and its relationships; and may be beneficial or detrimental.

Grief is an individual experience. Cowles (1996) described study participants who identified multiple factors which they believed influenced their grief, such as their relationship with the lost individual, how the loss occurred, the level of support, and previous experience with loss. This was influenced by individual combinations of emotional, psychological, spiritual, social and physical factors including age and length of illness (Jacob, 1993; Kissane et al., 1997). Lindstrom (2002) looked at individual grief responses from the perspective of relationships with the deceased. In concert with this, Granek, (2010) stated that there are laws which apply to all individuals experiencing grief: 1) the origin and evolution of the loss, 2) the mechanism by which the grief process occurs and generates its emotional, behavioral and cognitive sequelae, and 3) the mechanism by which these components may, over time, lead to some form of resolution. Benoliel (1985) views human interaction and interdependence as a root of complex
feelings, highlighting the connections between past present and future. In accordance with these precepts, and looking at this concept through the eyes of pediatrics, many developmentalists view grief in terms of adaptation, using previous experiences of loss, along with environmental and psychological influences. While these opinions come from an older psychoanalytic perspective, their logic and relevance is clear and in harmony with current thinking in regards to influences of life experiences on behavior.

Grief is a process (Cowles, 1996; Cowles & Rodgers, 1991; Jacob, 1993; Reed, 2003). Multiple descriptors, such as delayed, chronic, morbid, and others might have one believe that grief may not be normative. These descriptors illustrate differences in the specifics of the grief, but do not detract from the norm that grief is a response to loss. It would therefore be proposed that the term, “universal” may be more correct. Individuals who experience loss, grieve. Cowles and Rodgers (1991) stated that for some, grief may not be a process, but a state of being, unlimited by time with certain events serving as reminders, bringing the individual back to a “renewed grief.” These authors pointed out that due to the highly-individualized nature of grief, that the phenomenon and its symptoms are also highly variable. This is congruent with the work of Reed (2003) who described the perinatal loss of a child as interpersonal through loss of the pregnancy, intrapersonal through loss of identity, or extra-personal through possible loss of one’s position within the family. This may also be viewed, although not stated, as the loss of the healthy child from a perinatal event, such as birth asphyxia with resultant HIE.

Parental grief refers to suffering or distress over an affliction or loss of the idealized child. It is dynamic and changes over time in characteristic and presentation. It is pervasive and may affect all aspects of life for the affected individual. It is a universal,
yet personal experience and adaptations to it are individually determined. Furthermore, it may be affected by others who are also grieving the same loss. Lastly, grief is both experienced and expressed based upon sociocultural, spiritual and religious norms.

There is a paucity of literature addressing grief responses of parents of children who are ill or disabled. McCarthy and colleagues (2010) investigated grief and depression in 58 parents of children who died 2.4 to 9.8 years prior from cancer. They found prolonged grief disorder or complicated grief, which they defined as an elevated level of grief which lasted more than six months. However, there is no supporting data for this time limit. They described separation distress which consisted of intrusive thoughts and yearning for the deceased child as well as traumatic distress which included a loss of identity, avoidance of reminders, anger, and feelings of meaningless in life. Although not studied, one of the factors they believed to have impacted parental adaptation was the burden of a prolonged illness. They found negative correlations between the time since death and separation distress, traumatic distress, and total grief score (all $p < .001$). There was no association between time since death and depression. They identified several predictive factors which of depression and prolonged grief which included economic hardship, perceptions of the oncologists’ care, the child’s quality of life, and the parental preparedness for death. These factors may impact upon parents of children who have been critically ill or have long term disabilities or medical issues. Prigerson et al. (1995) advised that complicated grief and depression must be differentiated as treatment for depression is not beneficial in individuals suffering from grief. Further study is warranted in regards to further differentiation between grief and depression as well as these constructs in parents of ill and disabled children.
Anticipatory grief.

Anticipatory grief was initially described by Lindemann (1944) in regards to a broken marriage following the return of a soldier from World War II. He concluded that the woman’s fear of loss was so great that she had effectively mourned her husband and dissolved her emotional connection. There is a paucity of literature in regards to parental anticipatory grief. Rini and Loriz (2007) used semi-structured in-depth interviews with 11 parents of children who died, uncovering six themes. Giving information to parents was the first theme. The informants reported a lack of adequate information regarding the impending death of their children, giving them inadequate preparatory time to have support systems available. While this is a plausible theme for a variety of situations, anecdotally, some parents report that they do not want any further information; that they do not want to be “beaten over the head” with the critical nature of their child’s illness. The second theme addressed the impact of attitudes and actions of healthcare professionals. It included both positive and negative memories of their children’s deaths based upon the level of supportiveness of the staff. The third theme addressed the importance of the ability to be with their children, even during resuscitation, and participate in care. A need for a private space for mourning was the fourth theme. Policies, procedures and rules were problematic, such as not being able to eat in the child’s room, and were identified as the fifth theme. The final theme was a need for support through the anticipatory mourning process. A question remains in regards to anticipatory mourning in the face of the survival of that child and long-term effects upon the family unit.
Life effects of parental grief.

No matter the descriptions, norms, social mores, or processes, parental grief is not without long term effects. Arnold, Gemma, and Cushman (2005) designed an instrument to study the lifelong effects of a child’s death on their parents which contained both qualitative and quantitative components. One of the most important findings was that 6/43 (14%) of respondents believed that their personal health had worsened following their children’s deaths; five of whom had responded that their grief had not ended. This is in concert with previous findings of somatic pain two years following a child’s death, as well as physical feelings of weakness, numbness or tingling found by Gillis, Moore and Martinson (1997), as well as an increased risk of malignancy (Li, Johansen, Hansen, & Olsen, 2002). Further investigation of this phenomenon is warranted.

Arnold et al (2005) found that 59% of those whose children had died at less than one year of age reported that their grief had ended as opposed to 15% of those whose children died between one and 21 years of age and 26% of those whose children died during adult years. A lack of statistical significance was most likely secondary to a small sample size. This is worthy of further investigation as depressed feelings, anger, and hopelessness were significantly greater in those whose grief had not ended ($p = .005$, .005, and .021 respectively). The qualitative portion of this study (Arnold & Gema, 2008) sought to explore the depth and breadth of long term effects. Only 24 to 52 of the original 74 participants responded to the various open-ended questions within this study. Relationships with other children were affected by parental anxiety, over-protection, or heightened sense of love and attachment. Relationships were often changed with both positive and negative results such as marital strain, communication issues, divorce,
feelings of incompetence, and loss of control; as opposed to feelings of improved inner strength, greater sensitivity, or renewed faith. Some respondents reported being transformed with resultant career changes, volunteerism, and greater compassion. Family, friends, and faith were described as sources of support. Memories, such as the scent of a dying son’s hair, songs, and hymns brought both comfort and renewed pain. These researchers also reported that parents had a strong desire to replace the lost child through a variety of means. While important data were obtained, it is likely that the sample was somewhat skewed as respondents were recruited from the alumni of a school of nursing, therefore investigations using a more heterogeneous sample are warranted.

Psycho-emotional consequences have been reported following the loss of a child. Barr and Cacciatore (2008) studied 612 women who had lost a child due to miscarriage, stillbirth, neonatal, or pediatric death. They found a significant relationship between maternal grief and fear of death in terms of fear of the dying process and premature death ($p < .05$), fear of conscious death ($p < .01$), and fear of the unknown ($p < .01$). While fear for the body after death appeared important, it did not reach statistical significance. These findings relate to the work of Arnold and Gemma (2008), who found long term sequelae such as overprotection of surviving siblings. Barr and Cacciatore (2008) purport that their findings of fears within the confines of maternal grief reflect an existential fear of personal extinction in relationship to surviving children and may be identified as a motivator in a common post bereavement undertaking of trying to be a better person.

A large sample of 449 parents who lost their children to cancer was surveyed four to nine years following their children’s deaths (Lannen, Wolfe, Prigerson, Onelov, & Kreicbergs, 2008). Twenty-six percent reported that they had not entirely worked
through their grief, and 3% reported that they had not worked through any of their grief. There was no difference between mothers and fathers, nor did the number of mothers with unresolved grief diminish over time, although more time may have been required to appreciate this aspect. Fathers, however, showed a significant decrease in unresolved grief over time ($p < .02$). Inability to work through grief was associated with anxiety, depression, and poor quality of life. Fathers were more likely to suffer poor physical and mental health. These findings are consistent with the qualitative data reported by Arnold and Gemma (2008) and the findings of Al-Gamal and Long (2010) who found that 6 months after the diagnosis of cancer in a child, 65.7% perceived a worsening of their own physical health. A similar sample was studied by Alam, Barrera, D’Agostino, Nicholas, and Schneiderman (2012) at six and 18 months following their children’s deaths. They found that even at 18 months, mothers were more child-focused, expending their efforts on surviving children, while fathers returned to work quickly. However, some of these fathers had challenges with maintaining their work focus and sought more meaningful opportunities, similar to the findings of Arnold and Gemma (2008).

In their study of 82 adults suffering a traumatic loss between 40 and 80 years of age, Prigerson et al. (1997) found high levels of impaired sleep, and “anniversary reactions” 13 months following the loss. Findings of hypertension, suicidal ideations, grief, and changes in smoking behavior were significant ($p < .05$,) with depression being highly significant ($p < .001$). At 25 months following the loss, cardiac issues, suicidal ideation and grief remained significant ($p < .01$) and anxiety became significant ($p < .001$). Those who had suffered a non-traumatic loss were found to have significantly higher frequencies of cancer and heart disease ($p = .0002; \ p = .03$, respectively).
Traumatic or sudden death as opposed to death following illness was studied by Wijngaards-de Meij and colleagues (2008) finding that, up to 20 months post loss, parents who had lost their children traumatically had higher grief scores than those who lost their children following illness. This is in contrast to the supposition of McCarthy et al. (2010) who believed that the burden of caregiving might be a contributor to grief. In addition, the older the child was at the time of death, the greater the degree of depression following the loss (Wijngaards-de Meij et al., 2008).

**Grief in the living loss.**

Grief processes also occur when the idealized child has “died” and is replaced by a child who has a disability. That grief is difficult for parents as they struggle to define the loss (Perlesz, Furlong, & McLachlan, 1992). Societally there is no acknowledgement of the loss. Parents are often disenfranchised by statements addressing their good fortune in that their child is alive. In order to explore this precept, Collings (2008) conducted a qualitative evaluation of five parents of adult children living in permanent residential care facilities. She found that all participants experienced grief in the initial period, with four of them reporting that it became less severe over the following 12-18 months, but recurrent over time and one reporting that it continued unabated for 26 years.

Somatic concerns affect the grief-stricken parents of children with disabilities as well as parents of children who have died. Perhaps the largest study addressing health issues of parents was a Canadian population-based study of 9401 children and families (Brehaut et al., 2009). When compared with parents of healthy children, parents of children with health problems were more likely to rate their overall health as relatively poor and be more than twice as likely to have a chronic health condition.
Forinder and Norberg (2010) interviewed 11 parents of seven children who completed treatment for brain tumors 20 to 38 months prior. Several of the uncovered themes may be pertinent to the experience of parents of children who had HIE. The first identified theme was titled, “My child has a life-threatening disease!” The trauma of learning of the child’s potentially fatal illness was described as causing intense emotional pain. While the majority of parents had worked through this initial trauma by the time of the interviews, one parent did continue to describe still being in a state of shock. While posttraumatic stress was not evaluated, it is possible that this may have been a factor for this individual. “The world has become insecure” was the second theme. Parents worried about potential relapse, cognitive and psychosocial development, and that something would happen. The child was viewed as frail, despite participating in normal activities. Grief and sadness made up the third theme with parents reporting these feelings invading their lives. If the child suffered long term complications, parents expressed difficulty in accepting the disabilities. They often expressed guilt because they should be happy that their children survived and are “fine,” but they remain sad. While siblings were a source of joy and happiness, they challenged the parental ability to parent. Being a good enough parent to the child’s siblings was a theme that may also be anticipated in parents of children who had HIE. An element of neglect of healthy siblings created emotional distress to both the siblings and the parents. Togetherness and loneliness addressed disparate coping strategies between parents which may be viewed in a variety of life crises. In general, the researchers concluded that parents continued to be in the process of integrating their child’s illness and recovery into their everyday lives.
Grief has been described in parents of children with mental illness. They exhibit emotional distress, preoccupation with the ill child, difficulty in adjustment to the loss of their well child, intrusive thoughts, and avoidance (Godress et al., 2005). Children who had HIE with resultant neurologic damage may have behavioral issues, much like a child who had a traumatic brain injury. This may or may not be associated with a psychiatric diagnosis. It is not clear how much the diagnosis of mental illness is responsible for the aforementioned grief reactions or how much the behavioral issues contribute. Stancin, Wade, Walz, Yeates, and Taylor (2008) evaluated injury related burden and distress in parents of children with traumatic brain injury in comparison to orthopedic injury. Parents of children with severe and complicated brain injury reported a greater family and child burden compared with parents of children with orthopedic injuries. A similar burden was described in the siblings of injured children. The researchers found greater global parent distress and depression in the brain injury group.

In today’s society, many parents of children with disabilities work outside the home, which may be either an outlet or another demand on their time and therefore a stressor, possibly affecting parental grief. Vickers (2005) interviewed nine working mothers of children with disabilities. They identified long term, chronic grief from the life changing experiences of their children’s challenges which impacted upon all aspects of life. They expressed grief-associated depression with deep and pressing sorrow. The grief in these parents was described as labyrinthine in nature, irregular in degree and duration, and coming from multiple sources. She described grief exacerbations secondary to reminders or the insensitivity of others. This might be construed as consistent with chronic sorrow. Worthington (1989) advised that physicians and
presumably other health care providers reset their thinking from cure to care, as chronic
grief in such families is marked by vacillating emotions from sadness to happiness or
normalcy and everything in between, including anger with no end in sight.

2.2.2 Chronic Sorrow

The term, chronic sorrow was brought to light over 50 years ago by Simon
Olshansky (1962), a psychologist and parent of a child with an intellectual disability. It
described an unending grief in parents of children with mental disabilities. He purported
that the loss of the “perfect child” created periods of recurrent sadness. He noted that this
sorrow was a normal response to an abnormal situation. This concept became a middle
range theory in 1998 (Eakes, Burke, & Hainsworth). As a construct, it may be a portion
of the challenges faced by parents of children who have suffered from HIE. It is
applicable to a wide range of clinical situations and has been shown to affect both
caregivers and stricken individuals and is of increasing importance as today, people who
would previously have died, continue to live, often with disabilities.

Grief is generally considered to be time bound, ultimately resolving and more
customarily thought of as occurring after a loss due to death. Chronic sorrow has been
defined as the ongoing disparity following a loss and characterized by both pervasiveness
and permanence. Chronic sorrow and prolonged or chronic grief may be within the
continuum of grief-like responses to loss of life or health. Critical to this is that the
never-ending loss prevents resolution, leading to re-grieving or chronic sorrow, which
will continue for as long as the disparity caused by the loss exists (Eakes et al., 1998).

Characterized by waxing and waning symptoms, chronic sorrow has been the
subject of several concept analyses (Copley & Bodensteiner, 1987; Lindgren, Burke,
Hainsworth, & Eakes, 1992; Teel, 1991). The key feature is that an unending loss is re-experienced due to periodic trigger events, which would in essence, renew the loss. Some of the common triggers revolve around medical issues such as hospitalizations, medical crises, surgery, repeating the child’s history, the need for equipment, and chronic health issues. Developmental triggers included: adolescence, transitions to adult services, missed milestones, starting school, and birthdays. Social issues included the child’s exclusion from peer activities, the child’s recognition of his own differences, teasing of the child, criticisms, being pitied, and hearing stories of death. A variety of other triggers included: thinking of the child’s future, subsequent pregnancies, divorce, dealing with the school system, unending caregiving, behavioral issues, or any situation to which family would have to adapt (Bowes, Lowes, Warner, & Gregory, 2009; Burke, 1989; Cameron, Snowdon, & Orr, 1992; George et al., 2007; Gravelle, 1997; Guerriere & McKeever, 1997; L. Northington, 2000). Defining characteristics have therefore included (a) a perception of sorrow or sadness in a situation without an appreciable resolution. (b) cyclic recurrence of sadness. (c) sorrow triggered by events which remind the individual of those losses and (d) sorrow that may be progressive and may intensify (Lindgren et al., 1992). Chronic sorrow is different from the time-bound models of grief, as well as pathologic grief, and depression, although depression may be a consequence (Langridge, 2002; Roos, 2002).

Numerous of studies have addressed chronic sorrow in parents of children who are chronically ill or disabled. Two of these (Dunning, 1999; Hummel & Eastman, 1991) did not provide supportive data for the existence of chronic sorrow. Both studies used questionnaires rather than interviews. Hummel and Eastman (1991) described their
findings as more consistent with unresolved grief. Dunning (1999) identified that her scales may not have been adequate to measure chronic sorrow and she recommended longitudinal studies to capture the cyclical nature of chronic sorrow. A written survey was also used by Damrosch and Perry (1989) who showed that all but two of the 40 total participants exhibited chronic sorrow. These parents of children with Trisomy 21 were from a support group in an affluent area, thus results are not generalizable.

In her initial work on this subject, Burke (1989) conducted telephone interviews in mothers of children with myelomeningocele, finding that 91% had experienced chronic sorrow, with 51% of those reporting some lessening of symptoms over time and 16% reporting a worsening of symptoms. A question exists as to whether telephone interviews improved or impeded responsiveness to emotional and sensitive questions. One might ask about data interpretation given the inability to evaluate non-verbal communication. Cameron, Snowdon, and Orr (1992) conducted semi-structured, in-home interviews of 63 mothers of children with developmental disabilities, who reported that constant reminders of their children’s limitations stimulated profound sadness. In addition, many reported memory loss with associated shock and disbelief upon initial diagnosis. Consistent with posttraumatic stress, memory loss in this situation requires further evaluation.

Perhaps the earliest paper to evaluate this construct asked whether parents of children with intellectual disabilities experienced time bound grief or chronic sorrow (Wikler, Wasow, & Hatfield, 1981). The families of 32 children were interviewed, finding that 75% had chronic sorrow when asked to graph their emotions, while 63% confirmed chronic sorrow on direct questioning, suggesting a lack of complete awareness of their emotions. The researchers noted that many families declined interviews citing
that the study was too emotionally challenging; their responses may have been particularly beneficial. A few years later this construct was used to qualitatively evaluate parents of premature children (Fraley, 1986). Fortunate enough to be able to interview both mothers and fathers, Fraley found that shortly after birth parents expressed feelings of grief, loss, fear, helplessness and hope. The researcher found that fathers related more fear for their children’s present and future development, as opposed to mothers who feelings appeared to be more inward, expressing frustration, emptiness, self-pity, and blame. Both parents stated that their coping would have been made easier if health care professionals had provided more explanations and reassurance of the normality of their feelings. While vitally important information was gained, the sample size was relatively small. In addition, it would have been beneficial to evaluate responses based upon either the child’s gestational age, birth weight, or the degree of resultant disability.

In 1991, a small study was conducted by Phillips using a series of interviews with three mothers. While two mothers had chronic sorrow, one did not. The researcher noted that this mother was in complete denial of her child’s disability, making her incapable of appreciating a loss and exhibiting chronic sorrow. Meehan (2005) conducted a phenomenologic study of five mothers of children with hemiplegia. One of the described themes was “a heart filled with joy and sorrow,” which referred to the sudden onset of painful feelings interspersed with joyful or happy feelings. While not labeled as chronic sorrow, the description is consistent with that construct. Families with children with hemiplegia (Meehan, 2005) and traumatic brain injury (Guerriere & McKeever, 1997) were interviewed with data being consistent with chronic sorrow for all parents studied.
Observations of sorrow among parents of children with disabilities were not the only findings in these families. A variety of grief reactions such as sadness, sorrow, fear, helplessness, anger, and frustration have also been described (Burke, 1989; Damrosch & Perry, 1989; Fraley, 1986; Hummel & Eastman, 1991; Phillips, 1991; Wikler et al., 1981). Perhaps more importantly, this construct has been validated in parents of adult children, with mothers often asking when it will end and in essence describing a loss of themselves due to an unending parenting, caregiving role (Masterson, 2010).

Furthermore, this construct has been described by spousal caregivers of persons with disabilities and individuals with disabilities, themselves (Ahlstrom, 2007; Eakes, 1993; Hainsworth, Busch, Eakes, & Burke, 1995; Isaksson & Ahlstrom, 2008; Lichtenstein, Laska, & Clair, 2002; Liedstrom, Isaksson, & Ahlstrom, 2008). It has even been extended to foster children (Veltman, 2010).

Over the years, the concept of chronic sorrow was expanded from grief, sadness, and sorrow to include fear, helplessness, anger, and frustration (Copley & Bodensteiner, 1987; Teel, 1991). The fundamental finding was that unending loss was re-experienced due to the resurgence of “trigger events.” Trigger events are situations which remind the individual of the discrepancy between reality and the idealized situation (Burke, 1989; Burke, Eakes, & Hainsworth, 1999; Eakes et al., 1998; Schreier & Droes, 2010; Teel, 1991). They may be interpreted as the stressors of which Lazarus and Folkman (1984) speak. Trigger events with subsequent re-grieving is the hallmark of chronic sorrow. The antecedent of chronic sorrow was initially believed to be a multiplicity of losses. However, further research has described chronic sorrow as a response to a single loss for certain individuals (Teel, 1991). Each individual episode of sadness eventually abates,
but recurs with subsequent triggers which create a state of re-grieving (Eakes et al., 1998). The crucial feature within this theory is the cyclical nature of this process. A trigger event unique to family caregivers is simply the unending nature of the problem. The re-grief response may be unpredictable as compared with more commonly perceived triggers such as birthdays or anniversaries (Schreier & Droes, 2010). Teel (1991) described the inception of the concept of chronic sorrow as a reaction to Freud’s description of narcissism, explaining that the mother of a child with a disability not only mourns the loss of the idealized child, but also her own imperfection at not producing a healthy child. With the constancy of the child’s needs, the parent is unable to exert the necessary energies to resolve grief over the narcissistic injury. Although, not stated, it is inferred that the same narcissistic injury occurs in relationship to spouses of individuals with disabilities. This could be conceptualized as embarrassment and may occur in broader circumstances than those under current discussion. This may be especially notable in cultures which view the parent based upon the health of their offspring. An example of this might be seen within the Chasidic community, where the birth of an unhealthy child is often hidden because it will affect the marriageability of that child’s siblings. Eakes et al. (1998) also tell us that while, this cycle will continue as long as a discrepancy remains between the ideal and actual situation of the afflicted individual, it also reflects the disruption in the actual and idealized life course of the caregiver.

2.2.3 Depression

Whether maternal depression is secondary to an inherent depressive disorder or whether it is the result of child issues, it can have an effect on the child. The majority of studies evaluated depression based on the stress of caring for a child with a disability.
One of the earlier studies addressing this construct was conducted in 1982, (Breslau, Staruch, & Mortimer) which found significantly higher levels of depression and anxiety in mothers of children with disabilities as opposed to children without disabilities ($p < 0.001$). They found no association with the type of disability although, with the exception of cystic fibrosis, all children had some form of physical challenge such as CP, myodysplasia, or multiple physical challenges. Similarly, Miller, Gordon, Daniele, and Diller (1992) evaluated 69 mothers of children with and 63 mothers of children without disabilities, finding more depressive symptoms in mothers of children with disabilities ($p < .05$), with 14 mothers of children with disabilities as opposed to one mother of a child without a disability in treatment for depression ($p < .001$). Hanington, Ramchandani, and Stein (2010) evaluated the temperament of healthy children through the eyes of parental depression. They found that parental depression led to more difficult child temperaments, with little effect of the child’s temperament leading to parental depression. Kramer et al. (1998) found more frequent hospitalizations, emergency room, and physician visits in children of parents with depression. If these findings are combined with the multiple studies looking at depression in parental caregivers of children with disabilities, it provides empirical evidence for study of a cyclical component where the parental depression may feed into the child’s behavior, which in turn feeds into the depressive symptoms of the parent, thus creating a vicious cycle.

Many studies looking at depression in parental caregivers evaluate parents of children with mental illness. Both subjective challenges such as emotional responses and objective challenges such as strained financial resources and interpersonal relationships have been described. The caregiving burden in the parenting role is considered to be life
long, and as such grief and loss may be cumulative leading to grief and chronic sorrow which may contribute to depression (W. Chen & Lukens, 2011). Suicidal ideations are often reflective of depression; however, they may also indicate challenges in coping with the illness of a loved one. Peteet, Maytal, and Rokni (2010) bring attention to this issue through five case studies. While this study deals with imminent deaths, it may be possible to appreciate this challenge with long term medical issues. The researchers purport that there are three categories of threats of self-harm. First, worry about how an individual will live after the death of the loved one is considered a part of normal grief and not of particular concern for actual self-harm. Secondly, statements that included specific plans, such as “I plan to kill myself when Susie dies,” are considered to be reflective of specific intent and warrant psychiatric intervention. A third category could be characterized as wishes, but do not express a plan or specific intent. This might include statements such as, “I wish I could just die with him.”

Davies (2006) described two cases of mothers who took remaining narcotics and sedatives following their children’s deaths in the home. She advised greater effort in removing such medications from homes following an expected demise as well as trying to find measures to limit drug availability in the home without compromising care.

While these behaviors are rare in parents of children who are ill or disabled, the risk exists. Referrals have been, and will be made for parents of children with challenges for concerns about self-harm. While not studied, it is anticipated that parents of children with disabilities would continue on for the sake of the child. It would be beneficial to evaluate such parents following the death of their children for suicidal ideations.
Chen and Lukens (2011) compared parent and sibling caregivers of individuals with mental illness. These researchers found that parents exhibited more depressive symptoms ($p < .01$) with grief and stress being the greatest risk factors for depression ($p < .0001$ for each). The researchers reported pride to be a significant risk factor ($p < .01$,) although this term was not adequately defined. Protectors against depression included positive experiences with providers ($p < .001$) and available informal support ($p < .01$).

Cystic fibrosis is an inherited disorder which leads to diminished pulmonary and gastrointestinal function. While not the early death sentence it once was, cystic fibrosis remains a lifelong disorder, requiring meticulous caregiving. As such, a question of depression in these parents is viable. Glasscoe, Lancaster, Smyth, and Hill (2007) however, found that there was no higher rate of depression in parents of children with cystic fibrosis compared with controls at ten months or greater following diagnosis. However, prior to that, signs of vulnerability to depression, such as dysphoria, were appreciated at twice the frequency of controls. It might be more viable to evaluate for other constructs such as stress or chronic sorrow in this population. It would also be beneficial to evaluate how these families move from vulnerability to normalcy.

Olsson and Hwang (2001) hypothesized that levels of depression would be higher in parents of children with intellectual disabilities with autism than those without, who would have higher scores than parents of unimpaired children. This hypothesis was supported in mothers ($p < .01$,) but not fathers. Behavioral issues within autism spectrum disorders are believed to be stressful to parents (Benson, 2006) and have been the subject of the evaluation of 60 mothers and eight fathers of such children. Evaluations were stratified based on the parentally perceived degree of symptom severity. They found that
45% of parents within the entire cohort met diagnostic criteria for depression and that parentally perceived symptom severity was highly positively correlated with parent depression \( p = .000 \). Similar findings were obtained by Churchill, Villareale, Monaghan, Sharp, and Kieckhefer (2010) who found that both the number of chronic conditions and the parentally perceived severity of chronic condition were positively associated with the number of depressive symptoms within the parents \( p \leq .05 \) for both.

2.2.4 Stress

Lazarus and Folkman (1984) describe stress as a vital concept for the understanding of a variety of phenomena in human adaptation. Three categories of stressors are delineated. Major changes affecting population, such as earthquakes are viewed as cataclysmic events. Major changes affecting one or a few individuals could be death or incapacitating illness and is the primary insult for parents of children who had HIE. Daily hassles refer to inconveniences. While the effect upon the individual dealing with stressors in the first two categories may be devastating, the differences between them are the widespread nature of that devastation and the available methods by which individuals may cope with or adapt to that stressor. Within these categories, there are four types of stressors: acute time limited stressors; stressor sequences; chronic intermittent stressors; and chronic stressors, such as persistent disabilities. They view these as stimuli, not responses. They propose the following definition, “Psychological stress is a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (Lazarus & Folkman, 1984, p. 19). They emphasize that stressors are not single events, but rather dynamic, evolving processes (Folkman & Lazarus, 1985).
Stress in parents of children who are ill or disabled.

Phenomenology was used as the method of inquiry by Fernandes (2005) to gain understanding of the parental experience of five families of children with congenital heart disease. Families expressed disbelief, as if they were having a dream, that this experience could not be real. When reality hit, it was described as life shattering with time being stopped until the child was well. The feeling of a loss of control was palpable in the intensive care environment due to not only the characteristics of the surrounding itself, but also the parents’ inability to make their child better. Closing the curtain around the child or being asked to leave for medical interventions was a source of great anxiety. The parental experience of the child’s course was described as consisting of exhaustion, shock, and both physical and emotional stress.

Benson and Karlof (2009) addressed the proliferation of stress, which they described as the tendency for a stressor to create additional stressors. They described unending caregiving as a source of this proliferation. Stress proliferation was initially evaluated by Benson (2006) finding that the proliferation of stress was predictive of parental depression and that the child’s symptom severity was positively correlated to stress proliferation ($p = .001$). In a follow-up study, Benson and Karlof (2009) studied a larger sample of 110 children and their parents, confirming previous findings and additionally finding that both stress proliferation and anger were highly predictive of parental depression ($p = .000$, for both).

Hearing impairment with concomitant challenges in communication has been linked with parental stress. Quittner, et al. (2010) conducted a large multicenter study to evaluate this issue. They found that parents of deaf children reported more general stress,
context-specific stress, and child behavior problems than parents of matched hearing controls, \( p < .01 \), for each. In addition, they found that deaf children showed more negativity to their parents \( p < .01 \). Identified stressors for parents of children with hearing disabilities included communication, finances, education, and safety, as opposed to parents of hearing children, which included finances, discipline, safety, and routines. While hearing deficits occur in children who had HIE, they are less common than communication issues. As communication was the primary source of stress for this cohort, it may be a significant stressor for parents of children who had HIE.

Smith, Oliver, and Innocenti (2001) studied 880 parents of children with moderate to severe developmental delay, another possible long term complication of HIE. They evaluated family functioning in relationship to child personal/social functioning and communication, finding a positive correlation \( p < .05 \). Parenting stress was significantly correlated with both family and child functioning \( p < .01 \), each. This is congruent with the findings of Dyson (1991) who found that in middle class families the best predictors of parental stress were the presence of a disability and family relationships \( p < .00001 \) and \( p < .0001 \), respectively). Wilton and Renaut (1986) found that negative attitudes toward the disabled child, overprotection, lack of social support, over commitment, pessimism, financial strain, physical challenges, social obtrusiveness, and difficult child personality characteristics were all highly correlated with parental stress \( p < .001 \). It would be helpful to understand the relationships of these variables in terms of what contributes to and what may be a result of the stress. Further research to tease out these differences would be beneficial. Keller and Honig (2004) similarly found that
greater parental stress was negatively associated with child functioning. In opposition, however, they found no correlation between family functioning and stress.

Smith et al. (2001) found that family resources had the greatest impact in the prediction of parenting stress, followed by child functioning ($\beta = -0.261; \beta= -0.198$, respectively). The researchers differentiated between parental stress and parental distress, meaning that although a stress-producing situation may exist, the parents did not perceive it as causing specific angst. This would seemingly be indicative of the parents’ coping abilities, although coping was not a part of this study. This finding was supported by the later findings of Keller and Honig (2004) who proposed adaptation based upon the successfulness of coping as responsible for the ability to balance stressful events with familial coping. This is congruent with the resiliency model of stress, adjustment and adaptation (Robinson, 1997) which states that each family has specific characteristics which are used to address family crises, such as an ill child. The ultimate degree of adaptation is based upon the successfulness of these family characteristics in coping. Keller and Honig (2004) also looked at gender differences finding that fathers were more dramatically affected by their children’s physical disabilities than mothers, possibly due to greater difficulty in establishing a positive relationship with the child. Socioeconomic status, on the other hand, was found to be most significant for mothers in higher socioeconomic groups appearing to be more able to meet the needs of their children. This finding is in apparent contrast to the findings of Smith et al. (2001) who looked at family income rather than the whole of socioeconomic status.

A Dutch study evaluated the psychological well-being of 123 parents of children with intellectual disabilities as mediated by stress (Cramm & Nieboer, 2011). Three
indicators of psychological well-being were significantly correlated with parental stress. These included the child’s degree of fear and/or depression ($p = .007$), the child’s level of physical pain ($p = .005$), and the parents’ restriction in social activities ($p = .000$).

Graduate occupational therapy students interviewed and observed eight families of children with significant, chronic medical needs, at least one of whom had been affected by HIE, finding several important stressors (Case-Smith, 2004). Children with significant chronic medical needs require meticulous care. Rigorous schedules with multiple time-consuming care issues left little time for other children. Preparing the child for the day included not only hygienic care, but often time-consuming medications, treatments and therapies. Parents voiced concern due to inadequate time for their disabled child to have social interaction or play. As some of these children lacked an ability to play independently, guilt was voiced due to not being able to spend more time with the child due to the needs of siblings. While the word, “stress” was not used, the expressions of frustration and guilt are indicative of its existence.

Few interventional studies have evaluated stress in parents of children with disabilities. Dellve, Samuelsson, Tallborn, Fasth, and Hallberg (2006) provided an intensive family competence intervention for 244 parents of children with rare diseases. At baseline, the researchers found more parental stress in mothers than fathers, as well as with a comparison group of mothers. They found that this stress was related to feelings of incompetence, role restriction, social isolation, problems with spousal relationships, and health problems. More so, they found that stress levels were higher in single mothers and mothers with more than one child with a disability. Fathers, on the other hand experienced more stress relative only to their perceived incompetence as compared with
fathers of healthy children. The highest levels of stress at baseline occurred in parents of children whose disabilities were accompanied by behavioral issues. This finding is consistent with the results of numerous studies (Benson, 2006; Benson & Karlof, 2009; Hanington et al., 2010; Smith et al., 2001). Following intervention, decreased stress was appreciated in both fathers and working mothers. Benefits in working mothers included decreased fatigue, improved spousal support, increased coping knowledge, improved compliance with therapists, and decreased physical strain. Fathers showed increased active coping and improved compliance with therapeutic recommendations. While some improvements occurred, not all parents, particularly single mothers and mothers of more than one disabled child were able to appreciate that improvement, indicating a need for further research on not only interventions to help these families, but also perhaps a need to improve understanding of issues for individual parental types so that appropriate interventions might be more individually applied.

**Stress and somatic illness.**

Given these issues, it is important to realize that there is an association of stress with somatic illness (Pizur-Barnekow, 2010; Suarez et al., 2010). Both coronary artery disease and mortality have been linked with PTSD (Ahmadi et al., 2011). Furthermore, it is believed that one of the reasons for this association is a change in biological pathways, particularly within the hypothalamic-pituitary-adrenal and the sympathetic-adrenal medullary axes (Gu et al., 2012). This may be linked with altered release of glucocorticoids. Decreased cortisol levels have been associated with certain autoimmune diseases, such as rheumatoid arthritis (Stojanovich, 2010) and atopic dermatitis (Arndt et al., 2008). Psychological stress has been associated with hepatitis, cirrhosis, and cancer.
Insulin resistance secondary to chronic elevations in circulating glucocorticoids released during times of stress may challenge glycemic control in diabetics (Larzelere & Jones, 2008). Kuroki et al. (2011) purport that the physical effects of stress in patients with irritable bowel disease are not simply due to physiologic changes secondary to stress, but that these individuals possess an altered neuroendocrine response system which exacerbates symptoms of the disease.

There is little doubt that caring for a child with a disability is stressful. Murphy, Christian, Caplin, and Young (2006) used questionnaires and focus groups to evaluate health and coping in 40 parents of children with disabilities between the ages of four and 35. They found that 41% of parents reported a worsening in their physical and/or emotional health over the preceding year with 55% reporting that their health was impacted by the demands of providing care for their children. The most frequent reasons for this were lack of time, lack of control over life, and diminished psychosocial energy. Physical issues included back and shoulder pain from lifting, chronic fatigue, and sleep deprivation. Parents, particularly mothers neglected their own health issues, due to these issues being under-prioritized in comparison with their children’s needs. Raina et al. (2005) found that in their cohort of 468 parents of children with CP that behavioral problems within the child were associated with not only a decrease in the psychological health of the caregiver, but also the physical ($\beta_3 = -.22$, $\beta_4 = -.18$, respectively). In addition, it has been found that stress reduction may be associated with increased activity of natural killer cells, thus improving immunity (Fang et al., 2010).
Posttraumatic stress disorder.

Posttraumatic stress disorder (PTSD) can be disabling with flashbacks, disturbing memories, intense psychological or physical distress, detachment, amnesia, withdrawal from thoughts, people, and places that may trigger irritability, outbursts, anger, hyper-vigilance, an exaggerated startle response, insomnia, or poor concentration (Olszerski & Varrasse, 2005). It is differentiated from acute stress disorder, which resolves within four weeks, while PTSD lasts for more than 30 days (Gold, Kant, & Kim, 2008).

Diagnosis of cancer or preterm birth is associated with PTSD (Pierrehumbert et al., 2003). These researchers found that the intensity of PTSD is a predictor of later problems in their infants, suggesting long term implications for both the parent and child. Most of the literature addressing PTSD in parents relates to parents of children with cancer, finding incidences between 6% and 54% for lifetime PTSD (Manne et al., 2004; Norberg, Lindblad, & Boman, 2005; Pelcovitz et al., 1996; Santacroce, 2002, 2003; Stoppelbein & Greening, 2007). Davis, Parra, and Phipps (2010) longitudinally evaluated 199 parents of children with cancer. They found that symptoms of posttraumatic stress were highly correlated with both emotional and behavioral difficulties in the child \(p < .001\), each) and that these symptoms were related to the child’s ability to regulate anger \(p < .001\). Once anger regulation was instituted, they found that posttraumatic stress symptoms significantly decreased.

Kassam-Adams, Fleisher, and Winston (2009) studied 334 parents and guardians of children who had traumatic injuries, finding an association between the severity of acute stress disorder and the severity of PTSD. The child’s pain, acute stress disorder, and the perceived threat to the child’s life were significant predictors of parental acute
stress disorder ($p < .001$, for each). The most significant predictors for parental PTSD included the degree of the child’s physical recovery and health, the severity of parental acute stress disorder, and peri-trauma characteristics, such as the injury severity ($p < .001$, for all). These findings are in contrast with the findings of Allenou et al. (2010) who found that parental involvement in the trauma was associated with more symptoms of posttraumatic stress. While this may be expected, several differences are noteworthy: culturally stress responses may differ between the United States, where the first study was conducted, and France, the site of the second study; all participants in the second study were involved in motor vehicle accidents, as opposed to any type of accident in the first; and the first study involved a larger sample.

Parents of children with newly diagnosed diabetes have been shown to have PTSD (Landolt, Vollrath, Laimbacher, Gnehm, & Sennhauser, 2005). This group longitudinally evaluated 97 parents of 52 children. They found that the most prevalent symptoms included intrusive images, re-experiencing and hyperarousal. The frequency of PTSD progressively decreased from 14.6% of fathers at six weeks to 8.3% at 12 months. Mothers, while showing a decreased frequency, had an alternate pattern, with 22.4% of mothers having PTSD at six weeks, decreasing to 16.3% at six months, and then rising again to 20.4% at 12 months. The researchers hypothesize that the increased frequency in mothers may be related to carrying the greater burden for their children’s care. Interestingly four mothers and six fathers experienced a delayed onset of PTSD.

Epilepsy, as a source of posttraumatic stress, was studied by Iseri, Ozten, and Aker (2006). They found that 31.5% of this cohort of 77 parents exhibited PTSD, which was closely associated with a major depressive disorder, which was found in 56% of
those with PTSD. Of note, is that this sample was made up of parents who were largely uneducated with 78.8% have less than six years of formal education.

**Traumatic birth and posttraumatic stress.**

Giving birth is a frightening experience for the laboring woman (Bewley & Cockburn, 2002; Lyberg & Severinsson, 2010; Maestas, 2002; Scarborough, 2001). Pain and uncertainty combined with loss of control are contributors. These factors may make the delivery experience traumatic. Traumatic birth is associated with PTSD with an estimated 10,000 women per year developing PTSD following delivery in the United Kingdom (“The birth trauma association,” 2011). The greatest predictors of posttraumatic stress in this population were fear of childbirth (Wijma, Ryding, & Wijma, 2002) and fear for themselves (Ryding et al., 1998). Creedy, Shochet, and Horsfall (2000) found that one third of their sample of 499 women reported a stressful birth and at least three trauma symptoms, with 5.6% meeting criteria for acute stress disorder and an additional 22.6% reporting some symptoms. The most significant factor associated was the level of obstetrical intervention ($\beta = 0.351, p < .0001$). In addition, the birth of an infant requiring specialized care has also been associated with symptoms of posttraumatic stress. DeMier, Hynan, Harris, and Manniello (1996) found that mothers of both preterm and ill term infants endorsed more symptoms of posttraumatic stress than mothers of healthy term infants ($p < .001$).

Despite the birth of a newborn requiring resuscitation being considered traumatic, there is no literature which addresses HIE or birth asphyxia in relationship to PTSD. However, some mothers with PTSD have expressed guilt in relation to the birth of a child with a disability Beck (2006a). This internet study looked at 37 women who perceived
their labor and delivery as traumatic. Some of the traumas cited were preterm delivery, shoulder dystocia, emergency cesarean delivery, and prolapsed cord. She further identified that the child’s birthday was difficult for years, being filled with sadness and grief and that while these feelings continued for years, they did decrease over time.

Emergent cesarean section is a not uncommon method of delivery for the mother of a child who develops HIE, however there is a paucity of literature evaluating any referents for this phenomenon. However, Tham, Ryding, and Christensson (2010) found that 33% of women who experienced PTSD feared for the infants’ lives.

 Mothers who experienced traumatic births were interviewed by Beck (2004a). She uncovered four themes which identified issues that could be addressed by nursing and medicine. The first described a perception of a lack of caring for the laboring woman, associated with feelings of abandonment, loss of dignity, and depersonalization. The second addressed a perception of inadequate communication, with clinicians speaking with other clinicians leaving the mother out of the experience, at times arguing and making insensitive comments, such as “we may have lost this bloody baby.” The third identified feelings of betrayal of trust and powerlessness. One woman described being so traumatized by a difficult delivery resulting in an unresponsive newborn that when she went to the neonatal intensive care unit (NICU) to see her baby she felt “nothing,” that in her mind her baby had died. This theme and experience may be appreciated in the delivery of a neonate who develops HIE. The final theme she entitled, “The end justifies the means: At whose expense? At what price?” This relates to a lack of caring, but specifically refers to the perception that as long as the baby came out alive and okay, that the mother was unimportant. These findings have been corroborated by a
more recent study which points out difficulties in communication with mothers who went on to have emergent cesarean sections (Tham et al., 2010).

As a continuation to the original Beck study, further interviews addressed the long-term effects of these traumas (Beck, 2004b). Five themes were derived from the longitudinal follow-up. The first addressed flashbacks and nightmares which forced these women to relive “horrifying” deliveries, at times viewing their obstetricians as “rapists.” The second included feelings of detachment from the world around them and numbness. The third addressed a need that was at times obsessive, to understand the experience and included making multiple appointments with their physicians or midwives, revisiting the delivery room, or reading medical textbooks. Perhaps the fourth theme was the most frightening, as it involved a combination of anger, anxiety, and depression of the highest level, with rage, panic attacks, and suicidal ideologies. The final theme focused on the mothers’ isolation from the world of other mothers, at times even isolating them from their own children. Ayers, Eagle, and Waring (2006) found evidence of an effect on the mother-child bond for up to 18 years, with some women continuing to blame the child for their traumatic experience. Suicidal ideations, loss of intimate spousal relations, anger, and alienation from friends were also reported.

Few studies have evaluated posttraumatic stress in fathers following childbirth. However, Ayers, Wright, and Wells (2007) found that 5% of their sample (3 men and 3 women) scored above cut off values for severe symptoms of intrusion and avoidance. However, this group found no effect on the parent-child relationship. It is possible that avoidance within couples is more highly correlated due to its use as a coping mechanism within the dyad. Six couples, one of whom met criteria for PTSD were interviewed by
Nicholls and Ayers (2007). They found that both women and men avoided talking about the delivery experience. This avoidance, along with arguing impacted upon the couples’ relationships. Women expressed abandonment, whereas men expressed feelings of rejection. Coping as a couple was addressed by both men and women in terms of barriers, such as lack of time due to work, home, and child responsibilities. All participants believed that the traumatic birth experience affected some aspect of either their or their spouses’ relationship with their child. Many mothers reported avoiding their infants. If these kinds of responses occur following the traumatic birth of a healthy baby, one can anticipate that the traumatic birth of an ill infant, particularly if long term health consequences occur, may result in even more disturbed responses.

This may relate to the findings of Forcada-Buex, Borghini, Pierrehumbert, Ansermet, and Muller-Nix (2011) who observed mother-child play sessions along with evaluations of posttraumatic stress. They delineated three dyad types. The sensitive mother – cooperative infant dyad was significantly lower in preterm infants, which they defined as less than 34 weeks. A maternally controlling pattern of interaction was more frequent in mothers who had symptoms of posttraumatic stress, while a heterogeneous pattern was found more frequently in those with lower levels of posttraumatic stress. Perhaps the most clinically significant finding of this study is that women with high levels of posttraumatic stress held a more distorted representation of their infants than women with low levels ($p < .05$). This distortion may be important in the root of the interactional issues observed and is worthy of greater investigation. These results are consistent with this group’s previous study which found that at six months corrected gestational age mothers with higher levels of stress were less sensitive and more
controlling than mothers of term infants. Of note, is that by 18 months corrected age
there was improvement in interactional behavior, such that it was equivalent to the
interactional behavior of mothers of term infants (Muller-Nix et al., 2004).

2.2.5 Coping

The Resiliency Model of Family Stress, Adjustment and Adaptation addresses
inherent coping abilities as a contributing factor to mal-adaptation, adaptation, and bon-
adaptation. While inherent coping abilities are a contributor, it is also important to
analyze this concept a bit further in terms of what the constituents of coping may include
and how this particular factor intermingles with others in reaching a particular level of
adaptation. Lazarus and Folkman (1984) address coping psychoanalytically, looking at
two models. The animal model views coping as acts that control environmental
conditions in order to diminish psychophysiological disturbances. Cognitive appraisal, an
often-subconscious process, refers to the method by which individuals determine the
significance of an event to his or her well-being (Folkman, Lazarus, Dunkel-Schetter,
DeLongis, & Gruen, 1986; Lazarus & Folkman, 1984). Along with cognitive appraisal,
vulnerability comes to the forefront and may be thought of as how the effectiveness of
coping affects the individual. This might include setting up medical equipment away
from bedrooms so that the family might have fewer sleep disturbances. The
psychoanalytic ego psychology model looks at coping as a method of reducing stress by
variable thoughts or actions used to solve problems, also using cognitive appraisal. The
emphasis is on the cognitive process involved in seeking the goal of decreasing the
effects of a stressor rather than on actual behavior (Lazarus & Folkman, 1984).
The concept of coping (Lazarus & Folkman, 1984) relates well to the Resiliency Model of Family Stress, Adjustment and Adaptation. A hierarchy of response mechanisms is delineated and aligned with the successfulness of various family characteristics within the Resiliency Model. First order coping devices include such strategies as self-control, humor, crying, working off energy, and thinking through a problem. These would be examples of family strengths and resources. When taken to an extreme or used inappropriately, these devices become signs of a lack of control or equilibrium. In the Resiliency Model this would exemplify families who do not have adequate resources, coping abilities, or support. Second order devices may be termed withdrawal by dissociation. Examples of this may include amnesia, depersonalization, aversion, compulsions, self-intoxication or narcotization. Third order devices include episodic explosive outbursts, assault, and panic attacks. The fourth and fifth orders represent further disorganization of the self, with the latter representing a complete disintegration, as in a psychotic break. Mechanisms which entail a loss of equilibrium are not coping, but mal-adaptation in terms of the Resiliency Model.

The ego psychology model evaluates coping traits or styles. These traits refer to characteristics which determine how people respond to stress. Based upon family typology and family appraisal, as described in the Resiliency Model, they address the learned responses to stressful situations from both family and culture. With this in mind Lazarus and Folkman (Lazarus & Folkman, 1984, p. 141) define coping as “Constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person.” They further describe coping as a process, with the duration of grief-work being used in
exemplar and delineating stages in the process similar to the stages of grief described by Kubler-Ross (1969).

**Problem- and emotion-focused coping.**

Problem-focused and emotion-focused coping are two broad categories of coping styles. Problem-focused coping, also known as positive coping, uses methods by which an individual confronts problems, gathering and utilizing resources, and developing strategies to improve a situation. In emotion-focused coping, an individual may find himself venting frustrations or using denial or displacement. Emotion-focused coping may also be termed, avoidance or negative coping. The Resiliency Model looks at coping as neither positive nor negative; rather it is the success in coping that contributes to the ultimate degree of adaptation. Kishore (2011) evaluated the use of these mechanisms in parents of children with either intellectual or multiple disabilities and found that parents of children with cognitive disabilities alone used both forms of coping more than parents of children with multiple disabilities (p < .01, p < .05, respectively). Furthermore, the perceived positive effects of the disability were correlated with the used of problem-focused coping in parents of children with intellectual disabilities only (p < .05). The researcher suggested that the reason for this may be that challenges with children with intellectual disabilities are greater. In this situation, the perceived positive effects of the disability may be considered bon-adaptation.

Issues with communication have been cited as sources of stress for parents (Quittner et al., 2010; T. B. Smith et al., 2001). As children with multiple disabilities often have both cognitive and communicative challenges, further evaluation and validation of these findings is warranted. Few studies have evaluated the severity of
children’s disabilities with coping styles. Cavallo, Feldman, Swaine, and Meshefedjian (2008) found that parents of children with greater mobility challenges made greater coping efforts in terms of understanding their children’s medical conditions as a problem-focused method as opposed to parents of children with less significant challenges ($p < .05$). In general parents of children with both greater and lesser levels of disability sought community resources and found social support to be helpful.

Somewhat opposed to Kishore’s (2011) findings, Miller et al. (1992) found that mothers of children, both with and without disabilities, used problem- and emotion-focused coping techniques in approximately equal proportions. They found that the emotion-focused mechanisms of self-controlling and escape-avoidance, as well as the problem-focused mechanism of responsibility taking were highly correlated with psychological distress ($p < .001$). Problem-focused coping, specifically planful problem solving was negatively correlated with psychological distress in mothers of children with disabilities ($p < .001$). A similar sample was studied by Paster, Brandwein, and Walsh (2009) who found that parents of children with disabilities used seeking social support, escape/avoidance, and positive reappraisal, all-emotion-focused mechanisms. Faerstein (1986) found that while mothers in her cohort used problem-focused coping, which was viewed as effective in obtaining services for their children with learning disabilities, this method was abandoned when directly involved with their children. The mothers reported using more defensive, emotion-focused approaches, such as denial and anger towards the child. This exemplifies issues in both family and situational appraisal and may be linked with the findings of Stoneman and Gavidia-Payne (2006) who found that in general, 67 parent pairs of children with disabilities viewed their marriages negatively. However,
when fathers used problem-focused coping techniques, both parents exhibited an improvement in their marital adjustment.

**Success in coping.**

The effects of successful coping may be widespread. Churchill et al. (2010) surveyed 129 parents of children with special healthcare needs, finding that 54% of respondents had depressive symptoms. When evaluated with coping skills it was found that greater coping skills were correlated with fewer symptoms of depression ($p < .001$). In particular, Cheshire, Barlow, and Powell (2010a) found that positive reinterpretation was negatively correlated with depression ($p = .007$).

Lazarus and Folkman (1984) address various degrees of successfulness in coping with positive outcomes being called “bon adaptation,” a term borrowed by the Resiliency Model. This is exemplified in the findings of Garungaard, Andersen, and Skov (2011) who found that parents used a creative method of coping, *positive illusions*. In this situation parents perpetually formulated and maintained their ability to tap into their supports by means of cognitive appraisal. This may be envisioned as finding the silver lining and is referred to as “resource-creation.” On the other hand, positive illusions may be fragile, as resource-deterioration may occur when fear, despair, or external factors come invade. In this situation, parents lose the ability to grab hold of their supports. The interviews in this qualitative study found nine pathways to coping. These included:

- Emotional bonding which provided parents with energy and a sense of purpose,
- Social support, which decreased stress by creating feelings of support, camaraderie, self-efficacy, and acceptance of the child,
- Creating mental respite referred to time spent on oneself, often with imagery,
• Meaning making referred to trying to understand the purpose of their child being afflicted,

• Benefit finding may be thought of in terms of the silver lining principle,

• Evaluation of existential beliefs brings one closer and further from belief systems, and was described as “knowing” that there is no higher power,

• Taking action is a positive activity, wherein parents advocate for their child or themselves.

• Normalization addresses finding the new pattern of daily family living, and

• Maintaining hope, despite medical opinions.

These pathways intertwine such that parents replete in one pathway may rely more heavily on another, in order to maintain their lives in the most optimal way possible.

Positive psychological states during caregiving and bereavement in families dealing with AIDS were evaluated by Folkman (1997). She found that positive reappraisal was key in maintaining a positive psychological state, as were problem-focused coping, spirituality, and placing a positive spin on occurrences. The common thread was that the individuals sought and found meaning in their situations by activating these methods. The researcher reevaluated this model, adding the concept of meaning-focused coping, also known as appraisal-based or transformational coping. In this type of coping, belief systems, values, and existential goals are used during demanding times to spur and maintain coping and well-being. This may be directly related to the Resiliency Model where the individual, in times of crisis, has six sources from which he or she may draw strength or have strength depleted. It includes benefit finding, such as growth in wisdom, confidence, patience, competence, strengthened social relationships, and
strengthened faith or spirituality. It may also include benefit reminding, where the individual searches for benefits in a negative situation. Reordering priorities, while difficult, was necessary as it required that the individual accept that life has changed. Goal adjustment, later described by Seltzer, Greenberg, Floyd, and Hong (2004) depicted the adaptation toward realistic goals based upon a challenging situation.

**Coping in parents of children with illness and disabilities.**

One of the earlier studies to evaluate coping in parents of children with chronic illness focused on 100 families of children with cystic fibrosis (H. McCubbin et al., 1983). Three coping patterns were delineated which focused on family life (pattern I), social life and support (pattern II), and understanding of the medical situation (pattern III). The researchers found that in mothers, coping which was focused on family and medical issues was correlated with family cohesiveness \( p < .01 \) whereas in fathers these coping patterns were associated with family organization and control \( p < .01 \). They further found that coping patterns were associated with changes in their children’s health indices. Parents of children who had better indices used social support more than parents of children with poorer indices. Parents were therefore able to focus on their own psychological health. Similarly, Svvavarscottir and McCubbin (1996) found that coping pattern III was positively correlated with the infant’s illness severity in parents of infants with congenital heart disease \( p < .05 \). Using this framework for fathers of children with epilepsy, Mu (2005) found negative correlations between family coping and uncertainty in all three coping patterns (pattern I: \( p = .001 \), pattern II: \( p = .046 \), pattern III: \( p = .0001 \)). Uncertainty was also highly correlated with depression \( p = .0001 \).
Trute, Benzies, and Worthington (2012) evaluated family adjustment with maternal positivity in families of children with severe disabilities. They found that positive outlooks in mothers were associated with greater family adjustment ($p < .01$). The only maternal factor associated with positive outlooks was maternal age ($p < .05$). The researchers posit that older mothers have maintained positivity for a longer period of time thus increasing their personal resilience and abilities to cope with stress.

Positive illusions or reinterpretations were evaluated using a triangulated methodology by Cheshire, Barlow, and Powell (2010a). They found that positive reinterpretation was frequently used among 66 parents of children with CP. Its benefits included self-efficacy, fewer depressive symptoms, and lower perceived stress ($p \leq .001$, $p = .007$, $p \leq .002$, respectively). Qualitatively two themes were associated with positive reinterpretation: focusing on the positive aspects of the situation and finding meaning in the situation. This latter was noted in lessons learned and refocusing lives, at times even changing careers. This finding was in agreement with the findings of Arnold and Gemma (2008) and Garungaard and Skov (2006) who also found that these images would range from thinking about the worst case scenario to realistic imaginings to positive illusions.

Taanila, Syrayala, Kokkonen, and Jarvelin (2002) sought to determine the effect of the diagnosis of a chronic childhood disorder on the family and how that family coped. They found three categories of coping strategies used by families, classified as both high and low coping. These included information acceptance, family cooperation, and social support. The difference between the two groups was merely the frequency to which these categories were addressed within interviews, with high coping families utilizing each of these more frequently than low coping families. In addition, low coping families also
frequently had multiple problems due to issues other than the child, such as spousal difficulties. The researchers further found that high coping families reached acceptance and an optimistic outlook to the future following the initial shock. In low coping families mothers reached acceptance, more readily than fathers. Rather than optimism, these parents tended to be fearful regarding an uncertain future. Other than additional outside stressors in some low coping families, there is little information regarding possible reasons for parents to cope in such different manners.

Having a child with a disability is often a lifelong experience. Seltzer, Greenberg, Floyd, and Hong (2004) described accommodative coping as common during midlife for parents of adults with mental health problems and developmental disabilities. It involves *flexible goal adjustment*, where an individual modifies goals in response to an unrelenting problem. The use of this mechanism may be related to the developmental stage of middle adulthood, where the primary task is to create or nurture things that will outlast the individual or possibly looking back, as in the stage of maturity to death (Domino & Affonso, 1990). This study evaluated 218 parents of adults with developmental disabilities and mental health disorders, along with a control group of parents of healthy adults. They found that parents of those with mental health disorders, but not developmental delays, exhibited more depressive and physical symptoms than the control group (Seltzer et al., 2004). While unclear, a genetic link to mental illness may be present, accounting for more frequent depression or that the challenges of caring for an individual with a mental health disorder may be more taxing than caring for an individual with a developmental challenge. Despite accommodative coping being negatively correlated with depression, it was used more frequently in parents of youth with mental
health issues. It is suspected that this is a useful mechanism as lower scores for flexible goal adjustment were associated with more frequent physical symptoms in parents of both physically and mentally disabled individuals ($p < .01$, for both). These findings suggest that in addition to looking at the needs of children with disabilities, health care providers may also benefit their clients by evaluating and supporting parental needs.

Resiliency, a major theme in the Resiliency Model of Stress, Adjustment and Adaptation, is closely related to coping and addresses the ability of the family to return to a semblance of normalcy. McCubbin, Balling, Possin, Frierdich, and Byrne (2002) evaluated this concept in families of children diagnosed with cancer. These researchers found that internal family strengths and resources were key factors in parents’ abilities to create new patterns of functioning which incorporated their children’s illnesses, bringing them to mal-adaptation, adaptation, or bon-adaptation.

Only a single study looked at parents of children who had HIE. Heringhaus, Blom and Wigert (2013) spoke with 26 parents of children who were cooled. These parents described an emotional rollercoaster, frightening conversations with physicians, and fears of an uncertain outcome.

In summary, parents of children who had neonatal HIE may be challenged by a wide variety of psycho-emotional responses. The once imagined, joyous birth with the resultant healthy child is mutated into grief for the loss of that child with the concomitant replacement of that child with a child who undergoes a frightening resuscitation, an intensive care stay, and may ultimately be left with a wide range and degree of disabilities and challenges. Resultant parental stress may be generalized, acute, or chronic with the possibility of developing PTSD. Depression or chronic sorrow may
further challenge these parents. Parental skills and resources influence the ability and success of coping. All of these combine to potentially influence not only the child’s health and well-being, but also the parents.

2.3 Gaps in the Literature

The literature tells us much about the parenting and challenges involved in caring for children who have a variety of disabilities from both the qualitative and quantitative perspectives. Inferences in the grief literature may be made to this population, as so with parents of children with a variety of challenges. However, it was not until 1950 that parental grief in relationship to a child’s disability was described in the medical literature (Fotheringham & Creal, 1974). However, at that time assisting the parent was for the sole purpose of helping the child with little regard for the parents’ psychological and emotional well-being (Richmond, 1954). Olshansky (1962) is the first to refer to chronic sorrow in such parents, emphasizing that this is not an inherent problem in the parents.

Chronic sorrow has been described in parents of children with a variety of disabilities and challenges. We also know that stress has been linked with a variety of somatic responses and that physical care of the disabled child may be accompanied by physical ailments in the parents. While we know that PTSD may follow a traumatic birth experience, we presume that the birth of a child who develops HIE may be traumatic. We know that a variety of coping mechanisms, such as positive reinterpretation was frequently used and found to be effective for coping in parents of children with CP (Cheshire et al., 2010a; Cheshire, Barlow, & Powell, 2010b).

We also know that depression occurs more frequently in mothers of children who have disabilities and that it may affect not only the parent, but also the child. In addition,
the proliferation of stress is not only correlated with a child’s symptom severity, but is also predictive of parental depression. Parents of children with significant chronic medical needs, who require time consuming care have voiced concerns and distress related to inadequate time for both the target child and their siblings. Furthermore, it has been found that stress was related to feelings of incompetence, role restriction, social isolation, problems with spousal relationships, and health problems. More so, it has been found that stress levels are higher in single mothers and mothers with more than one child with a disability, while fathers tend to experience more stress relative to their perceived incompetence.

There is however, much more that we do not know about this population. The greatest gap in the literature is that there is only a single study addressing parents of children who had, which specifically addressed the cooling therapy experiences and the discussions regarding outcomes with the ensuing fear (Heringhaus, Blom, & Wigert, 2013). While parental responses to children with a variety of challenges have been explored, this is the only study which addressed parents of children either with birth asphyxia or HIE and the effects of cooling on the parent. These infants, in addition to being cold, are often sedated, still, and pale, in essence appearing “dead.” Furthermore, parents are restricted in their physical contact with their infant.

Chronic sorrow, due to potential long-term sequelae, may be a particular issue for some parents of children who had HIE. Stress, PTSD, and depression have also not been evaluated in this parental group. As physical care of the disabled child may be accompanied by physical ailments in the parents, efforts to aid parents may be beneficial, although this has not been evaluated to date. Given long-term parental responsibilities,
with children often outliving their parents, parental health is a vital issue. Similarly
coping has not been evaluated in this population, with only inferences able to be made
based upon findings in populations with related, yet dissimilar characteristics. The
unique nature of this population requires that validation of these findings and
explorations of experiences in this parent group be examined.

2.4 Summary

Hypoxic-ischemic encephalopathy secondary to perinatal asphyxia can be
neurologically and subsequently devastating disorder for survivors. At the same time
children who have been labeled as normal in early childhood following this event may
subsequently be found to have challenges during the school years. A trio of therapies has
been used in children with HIE: traditional supportive medical care, total body cooling,
and head cooling. Numerous physiologic and developmental studies have been used in an
attempt to predict outcome in children who had HIE. Many of these were conducted
prior to the more routine use of cooling therapies, making further evaluation a necessity,
although beyond the scope of this study.

Parents of children with HIE are asked to take in great numbers of difficult
experiences. It begins with a frightening, traumatic birth experience with either an
emergent cesarean section delivery or witnessing the resuscitation of one’s own child.
Efforts at that time are focused, not on the parents, but on the preservation of the child’s
life and health.

Complex physiologic changes demand timely interventions which leave little time
for parents to absorb and comprehend the child’s potential course and necessary
therapies. With the advent of head and body cooling over recent years, in combination
with sedation and mechanical ventilation, the neonate will feel cold, appear pale and still, in essence, lifeless. In addition, due to an inability to hold or even adequately touch their child, parents may feel disconnected with their newborn. Communication with parents by nurses and physicians may or may not be understood. This may be related to various style of communication as well as the parents’ own emotional and physiologic stress as well as previous stressful encounters and relationships. As such, misunderstandings may be prevalent which can create further stress, creating a vicious cycle.

Lack of clarity in terms of physiologic outcomes and expectations are influenced by the inherent inability to adequately predict later developmental outcomes. Neural plasticity is variable and influenced by multiple factors. As plasticity is most active during infancy, modifications of neural structure may occur with resultant improvement in physical status. At the same time, a full range of resultant sequelae may be appreciated following HIE. Most of the studies involving plasticity following HIE have been done in animal models and are believed to be at least partially influenced by environment as well as a variety of molecular mechanisms, that are not yet fully understood.

Cognitive disorders, CP, seizures, auditory, and visual disorders of any severity may result from HIE. In addition, children labeled as “normal” following HIE have been later found to have learning and memory challenges. This may be anticipated as a challenge for parents who may have thought that all was well.

Traumatic birth experiences may have life-long effects. While it has not been studied, it is suspected that the birth of a child who develops HIE is traumatic. Having a disabled child is associated with a multiplicity of psychoemotional responses which may include grief, chronic sorrow, depression, stress, and posttraumatic stress. Coping with
these responses is influenced by an array of factors such as previous stressful experiences, relationships and supports, financial and time constraints, responsibilities for other children, and the degree of support needed for the child with a disability.

The goals of this study were to examine the life experience of parents of children who had HIE in combination with evaluating some of the known and related constructs associated with parenting children with a variety of other disabilities or chronic illnesses, which may be applicable to this population. It is anticipated that the findings from this study may be beneficial to future parents of such children by developing a more in depth understanding of the life experiences of these parents; thus, laying the groundwork for future research and the development of interventions which may aid parents in their struggles to parent survivors of this malady.
CHAPTER THREE

METHODS

This chapter describes the methodology used in this study. It includes a discussion of the study design of mixed methods. It further discusses phenomenology and, in particular, Heideggerian phenomenology. Settings and recruitment methods used for both qualitative and quantitative participants is described. Instruments used, data collection procedures, procedures for the protection of human subjects, and data analysis procedures are described in order to address the following research questions:

1. What is the lived experience of parents of children who had HIE?
2. What is the relationship between the parentally perceived degree of disability, and the impact of childhood neurologic disability?
3. Do parents of children who had HIE exhibit more stress than parents of children who do not have disabilities, as measured by the Parenting Stress Index-Short Form (PSI-SF)?
4. Do parents of children who had HIE meet criteria for depression?
5. What coping mechanisms are used by parents of children who had HIE?

The Resiliency Model of Family Stress, Adjustment and Adaptation was used as the theoretical framework through which the researcher approached and analyzed the resultant data. Both family protective and family recovery factors within the participants in conjunction with the perceived degree of familial burden were evaluated.

3.1 Design

This exploratory, mixed methods study used both qualitative and quantitative measures in order to explore the experiences, perceptions, feelings, and self-identified
needs of parents who have a child who had HIE in the neonatal period. The combination of phenomenologic inquiry to gain an appreciation for the life experiences of these parents along with various quantitative measures which have been used in the measuring of an array of constructs at play in parents of children with a variety of physical challenges, some of which may be occurring in parents of children who had HIE, laid the foundation for further studies of parents of children who have suffered from HIE. As there is currently a paucity of literature addressing the issues for this population, these previous studies provided the basic groundwork from which exploration was begun. The purpose of this study was to determine issues of importance for these families in order to eventually provide more complete care to the family.

3.1.1 Mixed-Methods

Few formal studies have been published which address either needs, stressors, coping, or issues of concern to parents of children who had HIE. Numerous studies have been published which evaluate multiple aspects of parenting children with a variety of disabilities, some of which coincide with being a parent of a child who had HIE. The unique characteristics of this population, particularly the potential for the effects of the birth and intensive care experiences, as well as both short term and long-term sequelae which have been unstudied and may be involved in the experience of having had a child with HIE warranted exploration from a mixed-methods perspective. Morse (1991) refers to this as an immature concept that may be well addressed using a mixed-methods approach. While the previous studies of having children with disabilities permit quantitative analysis of some of the anticipated constructs, qualitative data was required in order to explore the dimensionality of parenting issues in this population. Various
research methodologies which employ single methods or observers contain inherent weaknesses or biases. These deficiencies may be diminished by means of a mixed-methods approach. While challenging, it may be posited that multiple types of knowledge are not only possible, but also required in order to evaluate a complex or heretofore unexamined construct, such as carried out in this study (Foss & Ellefsen, 2002). This study used a between methods strategy which utilizes multiple data collection strategies to evaluate and/or elaborate findings (Duffy, 1987; Kimchi, Polivka, & Stevenson, 1991).

With a lack of study in this population, qualitative exploration has the potential to uncover issues at play in this population. At the same time, literature exists which looks at parenting children with a variety of disabilities, such as hearing loss, CP, and cognitive delay; as well as parenting a child who has been in an intensive care environment. This body of literature provided the basis for the use of selected quantitative measures.

Qualitative and quantitative data were collected concurrently and then merged in order to analyze the experiences and feelings of parents of children who had HIE in the most comprehensive manner possible. However, quantitative data was not analyzed until the completion of qualitative analysis, so that quantitative findings did not color the analysis of the qualitative data (Morse, 1991). This allowed for the comparison of the two databases in terms of the degree of convergence of data as well as strengthening of the data obtained (Banik, 1993; Creswell, 2009a, 2009b; Polit & Beck, 2008). In addition, the qualitative data in combination with the results from the quantitative portion of the study laid the groundwork for further evaluation of this population from a more specific vantage point, such that interventions to support families in this situation may be designed and tested.
There are disagreements within the literature as to both the purpose and benefits of mixed-methods approaches (Risjord, Dunbar, & Moloney, 2002). While some believe that triangulation, or the mixing of data sources cannot and should not be done, others argue that various types of knowledge are necessary and should be combined, particularly in a non-hierarchical order (Foss & Ellefsen, 2002). Multiple sources and types of knowing are key and well-founded within nursing (Carper, 1978, 1988; Chinn & Kramer, 2008; Jacobs-Kramer & Chinn, 1988; Silva, Sorrell, & Sorrell, 1995). For the purposes of this study, the mixing of qualitative and quantitative data achieved several ends: 1) enhance the rigor of the study in those instances where identified qualitative themes are in concert with quantitative findings by confirming the findings of each other (Adami & Kiger, 2005; Bekhet & Zauszniewski, 2012; Williamson, 2005). However, it must be noted that some view confirmation of findings as questionable (Risjord et al., 2002). As most of the quantitative measures chosen were to identify the presence, absence, or degree of resultant constructs within this population, confirmation was viewed as valid within this study. 2) Augment the analysis of quantitative findings by adding depth and breadth from the qualitative findings thereby augmenting the understanding the phenomenon (Adami & Kiger, 2005; Bekhet & Zauszniewski, 2012; Williamson, 2005); and 3) In those instances where qualitative findings and quantitative findings are divergent, it is likely that the quantitative measures utilized did not adequately capture the phenomenon of being a parent of a child who had HIE (Adami & Kiger, 2005; Morse, 1991). With this in mind, it has been found that new potential instruments for this heretofore unstudied population are necessary. The comparison of the quantitative data with the qualitative allowed the researcher to evaluate the value of the chosen
quantitative instruments in the evaluation of this population. In addition, Risjord et al. (2002) identified “abductive inspiration” as a benefit. The authors define this as a process by which the researcher identifies a new explanation for a particular phenomenon, and describe this as primarily deriving from qualitative data. In essence this looks at the new inspiration derived from the data to develop hypotheses.

With this in mind, the blending of qualitative and quantitative data occurred not in the analysis of the data, but rather in the fitting of the qualitative and quantitative portions of the study into a coherent outcome in which existent theory could be confirmed or revised (Morse, 1991). Risjord et al. (2002) state that triangulation occurs when one body of theory is supported by both qualitative and quantitative inquiry. They refer to this as the coherence model of theory structure and confirmation. This is the case with the chosen theoretical framework, the Resiliency Model of Stress, Adjustment, and Adaptation. Given this model as the basis for this study, it was both possible and plausible to undertake methodological triangulation, or blending of the anticipated qualitative and quantitative data. The blending of the qualitative and quantitative data sets could thereby confirm, augment or alter existent theory.

### 3.2 Phenomenology

Phenomenologic inquiry was used in order to answer research question one, “What are the lived experiences of parents of children who had HIE?” Socrates is often thought of as the father of phenomenology. It is not only a research approach, but also a philosophy marked by variable interpretations by multiple philosophers. Simply stated, truth or reality is subjective and based upon individual interpretation, therefore consistent with the existence of multiple realities (Flood, 2010; Vivilaki & Johnson, 2008). They
explained that, in contrast to conventional thought, the phenomenological researcher should develop hypothetical questions, explaining that they will enable the researcher to delineate the research destination. They posit that the hypothesis, in this situation, is not viewed as a traditional scientific hypothesis. Rather they refer to the original Greek interpretation, “I make through my question a hypothetical argument” (Vivilaki & Johnson, 2008). They underscore that the true aim of research is falsification as described by Popper (Popper, 1969). When one asks about the lived experience of group A, it is therefore interpreted as a hypothesis that group A is different in some way from other groups. Falsification would be thought of as findings that state that group A is the same as other groups, thus compelling the researcher to develop a new hypothesis and a new research question, which takes into account the lack of a difference.

Epistemologically, individual perceptions of life experiences are the avenue to the reality or truth of the experience for that individual.

As data was made through open-ended interviewing, conversations were transcribed verbatim. Along with memoing, the researcher reflected upon the shared verbalizations, as well as personal experiences, observations and other experiences such as those within literature or film (L. Richards & Morse, 2007). One of the particularly notable features of phenomenology is that the act of participation has been shown to validate a difficult experience for some participants and in and of itself could have therapeutic benefit (Drury, Francis, & Chapman, 2007; Munhall, 2007). In order to gain understanding of the phenomenon as experienced by the participants, the researcher sought out the fore-structures or the contexts of the data (Mackey, 2005). The Hermeneutic circle, as espoused by Heidegger, is a process for the expression of context,
or fore-structures and refers to the back and forth movement which brings the researcher from a state of partial understanding to a greater insight into the whole and refers to the interpretation of the phenomenon by both the participant and the researcher (Flood, 2010; Mackey, 2005; Vivilaki & Johnson, 2008). He viewed prior knowledge vital to ensure that proper, pertinent questions are posed (McConnell-Hentry, Chapman, & Francis, 2011). It is more than mere description. Through listening, writing, rewriting, reflection and the delineation and analysis of emergent themes the researcher interprets the meaning of the lived experience of phenomenon in question.

The term, phenomenology is derived from two Greek words. Phainomenon is defined as appearance. In and of itself, appearance weakens the phenomenon as it is viewed. What makes this term appropriate for the purposes of phenomenology is the second term, logos, which addresses the interpretation of that appearance or phenomenon (Vivilaki & Johnson, 2008). This is in line with the works of Martin Heidegger, who placed great emphasis on reality as interpreted by the individual (Harman, 2007).

3.2.1 Heidegger’s Philosophy

Heideggerian Phenomenology is an interpretive rather than objective approach to research. It assumes that perceptions provide us with evidence of the lived world or experience of “being in the world” (Mackey, 2005). It further assumes that human existence, in and of itself, is meaningful and of interest (L. Richards & Morse, 2007). He refers to “dasein,” which he views as human existence, specifically, “being there.” Dasein only exists for human kind, as only humans may be thought of as being completely open to and existing within the world (Harman, 2007; Heidegger, 1962). Being, in terms of the existence of items, beings, and other daseins outside of the dasein
cannot be thought of as simply present or absent, but must be thought of as partially absent as there cannot be a complete view or knowing of that other existence.

Dasein.

Most of Heidegger’s career was spent on the concept of dasein or being, in the human sense. He derived his philosophy from the works of Aristotle, who viewed “to be” as ambiguous, as a particular word could refer to a variety of entities that were essentially unrelated. For example, the animal horse does not belong to the same genus as a rocking horse (Inwood, 1997). While any entity may be, only humans possess dasein, which in his view, requires greater consciousness than exist in non-human entities, such that humans may contemplate their own existence. Heidegger describes dasein as having particular components. The first characteristic he describes is *suchen*, or seeking. He states that seeking or questioning is cognitively guided by what is sought (*das gefragte*) (Heidegger, 1962). In addition to that which an individual questions, is that something or someone of which something is sought, in other words, the sources from which the inquiry is made (*das befragte*). The third component is the answers or what may be found by the asking (*das erfragte,* which is the intent. Being, in and of itself, is not composed of merely questions, desires, and actions by which these desires may be addressed. As may be expected, dasein and its understanding must be appreciated prior to any type of inquiry in order for it to have meaning. Furthermore, the understanding of being is a characteristic of dasein. The final characteristic of dasein is termed transcendence, which addresses the ability for humans to see beyond the obvious and to ask about what is beyond the obvious. Included within transcendence is introspection; only the dasein may look into himself. Dasein is completely entwined with
its potential and can exist based upon its own perceived possibilities. It may also be influenced and exist based upon its interpretations of what others expect.

Basically, all ontology, no matter how rich and firmly compacted a system of categories it has at its disposal, remains blind and perverted from its own aim. If it has not first adequately clarified the meaning of Being, and conceived this clarification as its fundamental task (Heidegger, 1962).

**Temporality.**

One of Heidegger’s more challenging concepts is that of temporality, as it may not be entirely thought of in the chronological sense. He rather views life as a threefold structure of past, present, and future, but again, not in the chronological sense (Harman, 2007; Heidegger, 1962). Time instead addresses the fact that no matter what comes into presence, there is a further hidden reality. That which is perceived and that which is hidden are what make up the past, present, and future. Life, its challenges, and highlights occur. One does not have the ability to change a current situation. Dasein exists within a specific environment, it is never isolated. Other things, animals, and humans also inhabit the dasein’s surroundings. The past is when the dasein finds himself in a situation that must be assessed and addressed in some way. This creates a tension based upon the characteristics of a situation and how the dasein encounters it. It is this tension which Heidegger refers to as the present. The future may be thought of as how the dasein addresses the situation, viewing potential ways by which to approach it. Most of life’s encounters go through this process effortlessly, usually being taken for granted, according to Heidegger, as opposed to Husserl who viewed encounters as only occurring within consciousness. For Heidegger, chronological time had little meaning. He refers to
“being in time,” which referred to what makes an event or phenomenon stand out from the flow of time (McConnell-Hentry, Chapman, & Francis, 2009).

One cannot discuss Martin Heidegger without discussing the negative feelings toward him and his political views. Heidegger was a Nazi, which does cause some hesitation in some for using his philosophy in a study (McConnell-Henry et al., 2009). Atrocities were committed by the Nazi party against Jews, homosexuals, and other “deviants.” Whether a researcher agrees or disagrees with his political viewpoints, Heidegger’s views on being and its meaning have a place in the caring professions and allow the researcher to engage in hermeneutic inquiry in a logical meaningful manner.

**Heideggerian Phenomenologic Inquiry.**

In contrast to other phenomenological approaches, Heideggerian phenomenology does not bracket out the researcher’s a priori knowledge, rather Heidegger’s stance is that our understanding cannot and should not be divorced from our thinking (Smythe, Ironside, Sim, Swenson, & Spense, 2007). In fact, Heidegger’s philosophy actually encourages the use of preconceptions, and views this use as a legitimate component within research (McConnell-Henry et al., 2009). This is in contrast to the work of Husserl, Heidegger’s mentor, who espoused the bracketing of the researcher’s prior understanding. Attempting to bracket a priori knowledge and not being able to completely do so could bring resultant findings into question. Acknowledging a priori knowledge and using it helps the researcher to frame questions and thereby glean a more complete understanding of the phenomenon of being for the research participants.

Heideggerian phenomenology focuses more on understanding than description alone, as espoused in the phenomenology of his predecessor, Husserl. Heidegger
believed that presence within the world or the meaning of being was the primary phenomenon of interest, with all else being arms of this (Dowling, 2005). For example, the phenomenon of the lived experience of being a parent of a child with HIE is a piece of the meaning of being, in and of itself. He purports that reciprocity is vital to the understanding and refers to it as a hermeneutic circle. With this in mind, Heideggerian phenomenology has been viewed by some as being useful in studies which involve caring encounters (Dowling, 2005; Mackey, 2005). In particular, the access to everyday life is vital for determining the character of being.

3.3 Quantitative inquiry

Quantitative inquiry was undertaken in order to assess several constructs associated with having a child with a disability and were used in order to answer questions two through six. The parentally perceived degree of disability was important as the parental perception, rather than the medical categorization of disability has been deemed more important in how a parent responds to their child’s real or perceived challenges. With this in mind, it was similarly important to assess the parentally perceived degree of impact of that disability on the family. The two constructs are slightly different in that whether one perceives their child as having no disability or having a severe disability, the impact of that disability on the family may differ. Uncovering this potential relationship was addressed by question two, “What is the relationship between the parentally perceived degree of disability and the impact of childhood neurologic disability?”

Stress has been well described in parents of children with disabilities. Question three, “Do parents of children with HIE exhibit more stress than parents of children who
do not have disabilities as measured by the Parental Stress Index- Short Form (PSI-SF)?” addressed this issue. Similarly, depression has been described and was addressed by question four, “Do parents of children with HIE meet criteria for depression?”

It is impossible to address life’s challenges without addressing how one copes with these challenges. The WCQ was used in order to determine what coping mechanisms are used by this unique population. In addition to determining what coping mechanisms were used, the frequency of the use of the various mechanisms was determined. This is addressed by question five, “What coping mechanisms are used by parents of children who had HIE?”

Once these initial questions were addressed, multiple analyses were done in order to determine the variables which impact upon stress, depression, coping and depression. These were addressed by questions three through five by means of nonparametric statistics.

3.4 Ethical considerations

Permission to conduct this study was obtained from both the Duquesne University Institutional Review Board (IRB) and the Cooper University Hospital IRB. Following IRB approval, the investigator obtained formal, written consent from each participant, prior to any in-person interviews (See Appendix A). Participants were asked to read the consent form. Opportunities to ask questions and clarify portions were offered as necessary. The consent form contained information about the study purpose and details, risks and benefits of participation, right to withdraw, and assurance of confidentiality. The researcher reminded potential informants that their participation was voluntary and would not have an effect on the healthcare of either their child or themselves.
Prospective participants were told that their consent may be withdrawn at any time, for any reason, and without explanation.

All written memos, journals, field notes, transcripts, audiotapes, data forms, consents, demographic questionnaires, and raw data forms were stored in locked file cabinets in the investigator’s home. All electronic data entered into either SPSS or NVIVO was maintained on a password protected drive, which was similarly maintained in a locked file cabinet in the investigator’s home.

Data collected from on-line support group sites was devoid of identifiers. The researcher was not able to connect the survey link with the participant, thus ensuring confidentiality. On-line survey participation inferred voluntary consent. The only exception to this was if a parent volunteered to participate in an interview, however there were no interview volunteers from this group. As data saturation was not achieved from participants recruited from Cooper Hospital, the researcher modified her IRB proposal from Duquesne and sought an advertisement from a local radio station, which did not work out. In addition, the researcher posted single-page fliers (Appendix B) in a variety of venues in public areas in both the Philadelphia and Southern New Jersey areas. This yielded two additional participants.

3.5 Setting

Qualitative interviews took place in the participants’ homes. The quantitative questionnaires were completed following the interview for qualitative participants or on line from support group web sites.

Cooper University Hospital (CUH) is a tertiary center located in Camden, New Jersey. The population from 2010 census data is 77,000. It has been listed as one of the
nation’s most dangerous cities, having gained the top spot in 2004 (Associated Press, 2004). Cooper University Hospital has been one of the largest employers in this economically depressed area with a median per capita income of $26,752 (“Camden, New Jersey,” 2012). The hospital has drawn its clients from not only Camden, but also the surrounding areas of Cherry Hill and Voorhees, New Jersey, as well as Philadelphia. In addition, both maternal and neonatal transports have come from as far as Atlantic City. The Children’s Regional Hospital at CUH has been the home to multiple specialty services applicable to infants and children who have and had HIE. There are more than 2200 deliveries per year at Cooper. The level III neonatal intensive care unit has cared for more than 400 neonates per year and over the past nine years has provided total body cooling for neonates with HIE. Prior to that time, neonates who required treatment were transported to Philadelphia for head or body cooling therapies and were later transferred back for completion of care. These children have been primarily followed at the clinics at CUH. The population seen at CUH has consisted primarily of people of Caucasian, African American, and Hispanic descent, although all ethnic backgrounds have been represented. Socioeconomically, while Camden has been a depressed area and has provided care for many with limited means, it has also provided multiple services to families of all socioeconomic circumstances.

Children who had HIE were followed in several areas: the pediatrician’s office, the neonatal follow-up clinic, the pediatric neurology clinic, and the epilepsy clinic if indicated. Depending upon the child’s needs, multiple appointments occurred on the same day, with all of the clinics being housed in the same area, therefore families were frequently present for multiple hours. The neonatal follow-up clinic has seen children up
to five years of age, using a multidisciplinary approach which included a neonatologist, pediatric advanced practice nurse, nutritionist, various developmental specialists, a physical therapist, speech therapist, and social worker. All other subspecialties have seen children up to 18 years of age. The neurology and epilepsy clinics utilized a neurologist, pediatric advanced practice nurse, and social worker. The pediatric clinic used pediatricians, pediatric residents, and registered nurses, with social work being available on a referral basis. In addition, the department of developmental and behavioral pediatrics has been available as needed for individual cases.

3.6 Sample

The qualitative sample consisted of nine participants, based upon the achievement of data saturation. The quantitative sample consisted of 51 parents of children aged 15 months to four years 11 months who experienced neonatal HIE, thus encompassing the preschool and toddler age ranges. For both groups of participants, the resultant sample was stratified based upon the parental perception of degree of disability: none to mild, moderate, or severe. Parental perception of no and mild disability were combined because only one child was perceived to have no disability following HIE. This may have been because these children did not require as much follow-up in the various clinics and their parents may not have reached out to internet sources of support as frequently as parents of those who have greater resultant disabilities.

3.6.1 Inclusion criteria.

1. Participants were the birth mothers and birth fathers of a child who met standardized criteria for hypoxic-ischemic encephalopathy at birth as determined by hospital records for the qualitative portion or by parental recollection of
perinatal details for the quantitative portion. If only one parent was available for participation, that parent was included.

2. Participants were 18 years of age or older.

3. Participants were able to speak, read, and write in the English language

4. Participants had children who were less than 18 years of age and were born between 35 and 43 weeks gestation.

3.6.2 Exclusion criteria.

1. Foster parents, grandparents, adoptive parents, and stepparents were not eligible for participation.

2. Parents of children with severe congenital or chromosomal abnormalities, such as the trisomies or any form of congenital heart, renal, hepatic, or pulmonary disease not secondary to the initial intensive care unit experience, were not eligible for participation.

3. Parents of children who are no longer living were not eligible to participate in this study.

4. Parents who required that they be interviewed together were not included in this study.

3.6.3 Sample size.

A power analysis was conducted using G*Power 3.1 software (Faul, Erdfelder, Buchner, & Lang, 2009). Programming was set for an F-test for correlation using a small effect size of 0.25, alpha of .05, and power of 0.8. It was determined that a sample size of 84 participants would be needed for each level of stratification for a total of 252 participants for the quantitative portion of the study. While stratification was not used for
all analyses, it was found that this estimation gave the largest anticipated sample size. As only 42 web surveys and nine surveys associated with interviews were obtained, non-parametric testing was most often required.

Qualitative interviews continued until data saturation was obtained for most themes. Two parents expressed thoughts that were more individualized and deemed unlikely to achieve saturation in this population. One was a father with multiple sclerosis who experienced panic attacks on the way to his own doctor’s appointments. He described that he would have flashbacks of driving to the hospital to see his son. This symptom of post-traumatic stress was not repeated by any other participants. The other was a father with self-described mental health issues who purposively opposed his son’s medical care plan.

3.6.4 Recruitment procedures.

The investigator met with the chairman of the department of pediatrics who was also the division head for pediatric neurology. The basic aim of the study was explained and his verbal support was received.

Prior to recruiting participants for the qualitative portion of the study, the investigator met with team members from the department of pediatrics, including not only attending physicians, but also pediatric house staff, advanced practice nurses, psychologists, nurses, and therapists who would be seeing children and families who meet study criteria. The study was presented by means of a power point presentation in order to aid in the recruitment of participants.

Single page fliers (see Appendix B) were unable to be posted in common areas within the pediatric clinic waiting areas, due to hospital regulations. Colored tri-fold
fliers (see Appendix C) were placed in both the check-in areas and examination rooms of these clinics. There were several methods by which potential participants could contact the investigator in order to indicate possible interest in participation in the study. There was also a locked box, labeled “Contact me for participation.” Index cards for the potential participants with spaces to insert contact information was attached to the right-hand side of the box, as was a pen. The box had an open slot on the top through which the potential participant could insert the card.

All care providers in these clinics were apprised of the study and requested to discuss it with potential participants, providing them with tri-fold fliers. The researcher physically presented herself to the clinic physicians and practitioners at least bi-weekly in the clinic area in order to keep the study fresh in their minds and answer any questions. This method proved to provide many names and numbers for potential participants, however, the vast majority either did not answer the phone or when the researcher contacted them they stated that they had changed their minds.

Upon reaching an interested parent via their preferred method for contact, the investigator introduced herself and described the study, including compensation for their time. The investigator then offered the opportunity to ask any questions the potential participant may have. The investigator offered that individual the opportunity to discuss their potential participation in person at their next appointment time or at their home at another time. The potential informant was given the consent form. The following points were discussed: 1) anonymity; 2) the interview process, including the fact that an audio-recording would be made and the researcher would take written notes; 3) the ability to link the individual with supportive services, such as social work, if they so desired; 4)
compensation; and 5) an opportunity to see the findings following the completion of the study. It is noted that seven potential participants who provided their contact information either did not answer their phones on multiple attempts, even when those calls were made from a hospital location, or did not return messages. Two potential participants were not home on two occasions, each, when appointments were made.

The Connecticut Parent Advocacy Center, Incorporated provided the links to post to their nationwide branches to distribute the quantitative questionnaires on line. The surveys were posted on these sites with the aid of Survey Monkey, which used a randomization feature, such that the order in which the surveys appear to the participant will be randomly changed.

In addition, the researcher added two final questions to the on-line surveys: 1) Would you be interested in aiding this study further by taking part in an interview? 2) If you are interested, would you please provide your preferred method for the researcher to contact you in order to schedule the interview? This final section also included the following: 1) Interviews may be conducted either by telephone or on-line via Skype, whatever you may prefer. 2) At the completion of the interview, the researcher will send you twenty dollars as a token of appreciation for your time.

3.7 Measurement and Instruments

3.7.1 Demographic Questionnaire and Intake Form.

A demographic questionnaire (Appendix D) and intake form (Appendix E) were designed in order to glean basic demographic information about both the parents’ and children’s birth experiences. In addition, the intake form will be used to screen for eligibility to participate in the full study and was completed by both on line and in person
participants. The stated parental perception of degree of disability, item number six from the intake form, was used to stratify participants for analysis. Piloting of these instruments was undertaken to determine the length of time required for completion. Pilots were completed by two parents of children with disabilities, one a secretary and one a unit clerk at the researcher’s place of employment. It was found that the surveys in total took approximately 40 minutes.

### 3.7.2 Impact of Childhood Neurologic Disability Scale.

The Impact of Childhood Neurologic Disability Scale (ICNDS) evaluated parental perceptions of the impact of disability with epilepsy, cognition, behavioral, physical, and neurologic function. Evaluation of parental perception of the impact of disability is important in terms of parental responses to that disability. A Cronbach’s α of 0.92, demonstrates internal consistency. The scale shows a test-retest reliability of 0.89 (Camfield, Breau, & Camfield, 2003). The ICNDS is scored by summing the scores, ranged from zero for not at all to 3 (a lot) for each of the four realms: behavior, cognition, physical/neurologic disability, and epilepsy. The maximum scale for each realm is 33, for a total of 132 for the entire scale. As a check list, it is anticipated to take less than 10 minutes to complete this questionnaire. Higher scale scores indicated greater impact. In addition, a numeric scale for overall quality of life was completed. See Appendix F.

### 3.7.3 Parenting Stress Index.

The Parenting Stress Index-short form (PSI-SF) (Appendix G) was used to evaluate the degree of stress experienced by each participant. The full PSI contained 101 items measured on a Likert scale. The short form consisted of 36 items broken into three
sections or domains: parental distress, parent-child dysfunctional interaction, and difficult child. In addition to these three domains of parenting stress, the PSI-SF also determined a total stress score. The short form was able to be completed in less than 10 minutes (Abidin, 2012). Reliability of the short form is high with all alphas being close to .90. Test-retest reliability was .84 for total stress; .85 for parental distress; .68 for parent-child dysfunctional interaction; and .78 for difficult child. When the full PSI was compared with the PSI-SF high correlations were obtained: total stress was .99; parental distress was .99; and parent-child dysfunctional interaction was .97. The instrument has been validated in multiple cultures and has been administered both on-line and with in-person participants.

3.7.4 Ways of Coping Questionnaire

The Ways of Coping Questionnaire (Appendix H) is credited to Folkman and Lazarus, who define coping for many of these studies (Ahlstrom & Wenneberg, 2002; Broger & Zeni, 2011; Glidden & Natcher, 2009; Pisula & Kossakowska, 2010). It has been used for adults with muscular dystrophy, fathers of chronically ill children, parents of children with developmental disabilities, and parents of children with autism. It has been used both as a single tool, as well as in conjunction with other instruments. This 66-item, self-report questionnaire assessed individuals’ coping abilities with stressful encounters. It consists of eight subscales which address eight coping strategies: confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, planful problem solving, and positive reappraisal. A four-point Likert scale indicates the frequency with which each mechanism is used. Raw or relative scores were then calculated. Raw scores are the summed responses to the
items on each scale. Relative scores control for the unequal numbers of items in the individual scales and are calculated by: a) computing the mean item score for the items on each scale by taking the raw score for each scale and dividing by the number of items for the respective scales, b) then summing of the average item scores across all eight scales, and c) then finally dividing the average item score for a given scale by the sum of the average item scores across all eight scales. Internal consistency for each of the subscale yielded a Cronbach α between 0.60 and 0.93 for the above studies utilizing this instrument. As a check list, it took pilot participants less than 13 minutes to complete this questionnaire.

3.7.5 Two-Item Patient Health Questionnaire

Depression often has aspects seen in various other psycho-emotional processes. For this reason, a brief depression scale which screens for depressed mood and loss of interest, the most cardinal symptoms of depression, was used. The two-item Patient Health Questionnaire (PHQ-2) has been found to be useful for both clinical applications and research studies (Lowe, Kroenke, & Grafe, 2005). Its brevity decreases the risk for participant fatigue. Each response was scored from zero for “not at all” to three for “nearly every day. The score for each response was summed for a potential score from zero to six. A cut-off score ≥ 3 has the greatest balance of specificity and sensitivity for both major and any depressive disorder and will therefore was considered as consistent with depression for the purposes of this study. The developers demonstrated substantial correlations with other established measures of depression, such as the Beck Depression Inventory (r ranging from .67 to .87) and demonstrated internal consistency with α = .83. In addition, the diagnostic accuracy of the PHQ-2 was high with an area under the curve
of 0.90 for a major depressive disorder and 0.89 for any depressive disorder, similar to other measures. With only two questions, it took less than two minutes to complete the PHQ-2. See Appendix I.

In summary, four formal questionnaires in addition to a demographic and intake form were completed by participants. It required less than one hour’s time for most participants to complete these forms. It took somewhat longer for the participants for whom English was a second language and for a couple who were cognitively challenged. Qualitative interviews took approximately one hour, although some were shorter or longer based upon each participant’s need and comfort in expressing their thoughts.

3.8 Procedures for Data Collection

Invitations to participate in the online survey were posted on the following websites: Parent Advocacy Center of New Jersey, Parent Advocacy Center of New York, Parent Advocacy Center of Connecticut, and the Parent Advocacy Center of Minnesota, which can distribute the survey nationwide (See Appendix K). A link was provided which brought the participant to the surveys. At the end of these surveys, an invitation for participation in an interview was placed along with a request for the best method to contact the potential participant to schedule either a telephone or skype interview.

In person participants, recruited from the aforementioned clinics at Cooper Hospital, and following informed consent, were interviewed in the participants’ homes, based upon the participant’s preference. Due to the relatively small number of potential informants, recruitment was by convenience sampling. Potential informants were invited in the order by which their information was received by the investigator. When data saturation was not achieved from participants recruited from Cooper Hospital and on-line
participants did not volunteer an opportunity for an interview, the researcher, following an amended IRB approval, posted signs with tear-away contact information were posted in local businesses. This yielded two additional participants. No participants were referred by snowballing. When both the mother and father agreed to participate in interviews, the investigator explained to them the following: “Often parents have different feelings about the same situation. For this reason, it is important to interview you separately. This can be done either one after the other or on two separate occasions, whatever you prefer.” This was not a problem for any of the three couples interviewed. While some interviews surpassed 100 minutes in duration second interviews were not conducted, as a time to close was not afforded and the individuals had opened up and were speaking freely. In addition, based on the principles of Heideggerian phenomenology, additional interviews may skew data received due to the ability to “think about” the interview over time. Two mothers were called to provide closure following an intense interview experience, they declined additional in-person time.

Following assurances of participant comfort, such as availability of drinking water and tissues (provided by the investigator), the investigator reiterated and confirmed the acceptability of audio taping the interview. A review of the issues of consent was conducted. Demographic and intake forms, along with a pencil was provided to participants following confirmation. The digital voice recorder was turned on. Each open-ended interview began with the question, “Will you please tell me what it is like for you to be (child’s name) mother (or father)?” The investigator actively listened without interruption. When follow-up questions were deemed necessary in order to bring the researcher from a state of partial understanding to one of greater insight, as espoused by
Heidegger, they were based on the participants’ answers, again allowing the participant an uninterrupted opportunity to express him or herself (Flood, 2010; Mackey, 2005; Vivilaki & Johnson, 2008). Throughout the interview, the investigator actively listened with an eye toward interpretation and clarifying questions during the interview. In addition to recording the interview, the investigator made written field notes which addressed the setting and the participant’s attire, posture, facial expressions, tone of voice, and body language, as well as notes of areas which required clarification. At the conclusion of each interview, the investigator expressed gratitude with an opportunity to close the experience. She then provided the participant with a $20 WAWA gift card. Provision of a portion of payment as an incentive to complete the study is acceptable (Sears, 2001). All qualitative participants expressed that they preferred to complete the questionnaires following the interview. When these were completed, an additional $10 WAWA gift card was provided.

3.9 Procedures for Data Analysis

3.9.1 Description of the Sample

Data collected from quantitative measures were entered into SPSS version 20. The original data was proofread against the computerized data file. Univariate descriptive statistics were run including mean, median, mode, range, standard deviation, variance, skewness, and kurtosis for all of the continuous variables to include: parent age, child age, number of children, number of children living with the participant, quality of life, WOCQ scores, PSI-SF scores, PHQ-2 scores and WCQ scores. Scatter plots of the variables along, with Boxplots of the data were examined to search for outliers.
Based upon a univariate outlier, one case was eliminated from analyses which addressed the outlying responses. While a variable could be eliminated if it was highly correlated with other variables or not critical to the analysis (Tabachnick & Fidell, 2013), this was not necessary. There were few outliers, therefore transformations to lessen their impact were not required. Categorical data, such as gender, parental perception of degree of disability, or the existence of chronic sorrow, or depression were evaluated to finding no scores out of range. When initial numbers were found to be out of range, they were checked against the original data files and cleaned by means of correcting inaccurate entries. When data was missing, those cases were examined to determine if there is any particular pattern involved. As there were only a few cases of missing data on the various surveys, which appeared to be random in nature, those cases were deleted from analysis.

Data from the demographic and intake forms from qualitative participants was similarly entered into SPSS version 20 under a separate file. The same descriptive statistics were calculated. Based upon the answers to question eight on the intake form, which addresses the parentally perceived degree of disability, participants were stratified for analysis.

3.9.2 Procedures for Qualitative Analysis of Participant Interviews.

Data collection and analysis occurred concurrently throughout the study. Miles and Huberman (1994) endorse this strategy as it forces an increase in back and forth evaluation of the data; thus, cueing the researcher to correct “built in blind spots” and generating strategies for improvements in data collection and generation.
Before any analytical processes began however, the Heideggerian hermeneutic researcher first addressed her “fore-structures” or preconceptions in terms of understanding how individual preconceptions and experiences may have colored potential interpretations of the qualitative data (Geanellos, 1998). Heidegger has espoused that bracketing may actually impede the reliability of the study. While it is impossible to lay aside all presuppositions, efforts must be made to assess and check these presuppositions in order to minimize their effects (Koch, 1994). A research diary, as recommended by Drew (1989) is a method by which the researcher may document and thereby reflect upon the effects of presuppositions on data. In conducting her interviews, this researcher maintained a diary which included her reflections of her interviews, participants, and her own feelings, going back to her initial self-evaluation. She found that interviews which she classified as “bad” for various reasons, actually revealed important data about the participants. Peacock (2011) began her self-reflection prior to data collection.

For this reason, the researcher evaluated herself, her motivations, and her potential biases prior to conducting the initial interview, which focused on concerns, questions, or random thoughts about the upcoming experience. While field notes were taken during the interviews and prior to data transcription, the researcher returned to the diary, again reflecting upon feelings about the interview. In this way, as data was analyzed, the researcher was able to look back upon feelings which may have impacted upon the understanding of that data and take those feelings into account, thus shedding a new light upon not only the transcripts, but the field notes as well. Drew (1989) found that her diary added to her understanding of the data and actually aided in the elucidation
of new categories. Acknowledgement of the researcher’s emotional responses was cited as aiding the researcher in several ways. First, it aided the researcher in the endorsement of enough interest in the phenomenon to study it. Secondly, and more importantly, it aided the researcher in the identification and exploration of personal bias, thus enabling the researcher to consider the potential effects of that bias on the analysis of the data. Thirdly, as researchers have an effect on study participants, understanding the researcher’s own emotional responses allowed the researcher to diminish unconscious bias during the interview process which may have been perceived by the informant, thus leading to altered responses. Therefore, while Husserl would have researchers “bracket” their preconceptions, Heidegger would have researchers acknowledge their a priori knowledge and feelings, then take them into account during both the interview and analysis processes. Lindseth and Norberg (2004) refer to this as “bracketing our judgments” as it is impossible to bracket our preconceptions. In fact, Heidegger’s philosophy actually encourages the use of preconceptions, and views this use as a legitimate component within research (McConnell-Henry et al., 2009).

Geanellos (1998) challenged nurse researchers to not only identify, but also challenge and qualify preconceptions and presuppositions regarding not only the phenomena in question, but also the informants. Ongoing analysis of the transcripts, memos, and field notes was used to guide the researcher in the establishment of data saturation. The use of Heideggerian phenomenology demanded that the researcher use both descriptive and interpretive analysis (Mackey, 2005) and may be known as interpretive phenomenology or also simply, hermeneutics (Dowling, 2004).
Audiotapes were immediately transcribed verbatim and entered into NVIVO 10, using pseudonyms. After data was entered and checked for accuracy, memos and field notes were added to the system. The researcher then entered the hermeneutic circle by reading and then rereading the transcripts and field notes several times in order to immerse herself into the data. In addition, the researcher re-listened to the taped interviews in order to better appreciate inflection and emotion, allowing her to better appreciate the informants’ story intents. As texts are reviewed, the Heideggerian researcher is taught to “lose oneself” in the data in order to allow the thoughts to just come together (Smythe et al., 2007). Heideggerian hermeneutics provided a venue for not merely telling, but truly listening to what participants chose to share. This comprised the first steps of analysis and created a “ naïve understanding” (Lindseth & Norberg, 2004).

The following phase of analysis is known as a structural thematic analysis or a thematic analysis (Lindseth & Norberg, 2004). In this phase meaning units, which may contain multiple, seemingly inconsequential statements, were identified. The text was then reread with these units in mind and described in common language (condensed) Liamputong (2009) recommends that as the researcher reviews the text, he/she asks what? Who? How? When? How long? Where? Why? What for? and by which? Similarities and differences between the units were sought. At this point the meaning units were sorted and were then further condensed into sub-themes (Lindseth & Norberg, 2004).

Continued rereading with these units and sub-themes in mind were used to create themes and even major categories of themes or main themes. It is at this point that the
researcher returned to the naïve understanding in an attempt to determine if these themes were in agreement with the naïve understanding. When the structural analysis was in disagreement, the text was reread and a new naïve understanding was created. This process was repeated until both the naïve understanding and structural analysis were united.

It is at this point that the researcher went back to the research question and preunderstandings. Critical reflection upon the question, the researcher’s identified preunderstandings and the text allowed the investigator to contextualize and deepen awareness with the text. The addition, the researcher’s imagination led to the inclusion of relevant literature to illuminate findings within the text (Lindseth & Norberg, 2004).

Further interpretation of parental experiences of children with HIE was sought through the experiences of other parents in similar, albeit differing challenges with their children as well as through the lay literature. The goal at this point was for the researcher to gain insight into the varying “truths” about the phenomenon, which may be disseminated to others. Hidden meanings, subtexts, or implicit meanings, often called semiotics, were elucidated. The participants’ stories were retold in a framework that would be meaningful to readers (Liamputtong, 2009). This dissemination is considered vital, as it is only through the dissemination of the newly acquired knowledge that care may be impacted.

Data was reviewed with the researcher’s qualitative expert in order to add insight and validity through discussion with the primary investigator (McConnell-Hentry et al., 2011). Heidegger believes that understanding and interpretation are impossible without taking both a temporal and spatial view, as time and space are basic tenants of human
existence and may be conceptualized in many ways and is therefore vital to ontological understanding (Annells, 1996; Mackey, 2005).

As opposed to traditional phenomenologic inquiry, member checking is not customarily done in Heideggerian phenomenologic inquiry. The rational for this is that according to Heidegger, context is vitally relevant. Therefore, repeated visitations of the experience may alter the inherent meaning, depending on the disposition of either the participant or the investigator and may actually be considered a threat to the rigor of the study. When revisiting a concept for clarification, the participant may believe that the researcher views the particular concept to be of importance, thus creating a halo effect where the participant may say what he or she believes the researcher wants to hear (McConnell-Hentry et al., 2011). For this reason, repeat visitations to add to the interview were not conducted.

**Personal aspects of the researcher.**

This researcher has over 35 years of nursing experience, 30 of which have been as a neonatal nurse practitioner in both the neonatal and pediatric intensive care units, as well as in home care for children who required technologically supported health care. The interest in this particular research topic likely arouse from a variety of experiences, both personally and professionally. The researcher had two relatives who experienced “birth asphyxia,” one of whom had significant physical and cognitive challenges, ultimately dying at a young age. This lead to observations of his parents over the years, providing a “bird’s eye view” of the effects this young man’s life had on his family. It is believed that these experiences led to an interest in families of children with neurological issues. Finally, just as data collection was to begin, the researcher’s life was placed on
hold following a hypoxic-ischemic insult to her husband. At this time, the researcher’s emotions were raw and were not able to be adequately controlled in order to conduct an interview which was not overshadowed by her own emotions. As the researcher and her husband recovered from this event, the researcher was ultimately able to embrace her traumatic experience and use it to empathize and hear her participants better.

Reflecting back upon the use of the researcher’s experience, it is believed that it led to a greater level of personal understanding of the horror of family members during the crisis, of outbursts, anger, and helplessness, as well as some of the day to day challenges. Ultimately, it is believed that the lessons learned from the personal experience led to a greater level of empathy for parents in crisis as well as a greater ability to hear and comprehend parental voices during this research process. It may also have led to greater parental disclosure based upon the manner in which the researcher presented herself and actively attended to their stories.

3.9.3 Quantitative Analysis Procedures

In addition to the aforementioned data screening techniques, the assumptions for normality, homogeneity, linearity, homoscedasticity, and absence of multicollinearity were tested. Outliers were sought by means of examination of standardized residuals, scatter, and box plots as appropriate. Following the evaluations of these assumptions for anticipated parametric testing, it was determined that many of the analyses required non-parametric testing. Outliers were dropped from analysis as appropriate. The sample was described in terms of the respondent’s age and gender, child’s age and gender, marital status, living situation, number of children, income, and ethnicity obtained from the demographic questionnaire (Appendix D). The sample was further described in terms of
type of birth, type of anesthesia and its effectiveness, presence of a delivery support
person, and the parentally perceived degree of disability as obtained from the intake
questionnaire (Appendix E). The Impact of Childhood Neurologic Disability Scale
(Appendix F) was be used to determine the impact of that child’s disability on family life.

In order to evaluate the demographic data with existence of stress, descriptive
statistics were used, followed by a one-sample t-test to compare PHQ-2 scores with the
general population. Spearman’s rho was used to evaluate the PPDD, total impact of
neurologic disability, total stress and duration of hospitalization with depression. All
findings were considered statistically significant at $\alpha = .05$.

**Statistical measures addressing quantitative research questions.**

*What is the relationship between the parentally perceived degree of disability,
and the impact of childhood neurologic disability as measured by the Impact of
Childhood Neurologic Disability Scale (ICNDS)?*

In order to determine if a relationship exists and its direction between the
parentally perceived degree of disability, an ordinal level variable, and the impact of
childhood neurologic disability, a ratio level variable, Spearman’s rank order correlation
was conducted, using the parentally perceived degree of disability as the dependent
variable and the impact of childhood neurologic disability as the independent variable.
The strength of the correlation was determined by evaluation of $r_s$. Significance was set
at $\alpha = .05$. However, despite significance, the relationship strength is more helpful in
determining the meaning of the data. For this reason, the following $r_s$ absolute values
were used: $0-.1$ is a very weak or absent relationship; $.1-.3$ is a weak relationship; $.3-.5$ is
a moderate relationship; and $.5 – 1$ is a strong relationship (Choudury, 2009).
Do parents of children with HIE exhibit more stress than parents of children who do not have disabilities as measured by the Parental Stress Index (PSI-SF)?

In order to determine if parents of children who had HIE exhibit more stress than parents of children who do not have disabilities, the results of the PSI-SF were evaluated. Normative profiles are available for a wide variety of both parents and children with a variety of challenges applicable to families who had a child with HIE which include: impairments in hearing, vision, movement, and language; developmental delay; multi-impaired, cerebral palsy, behavioral disorders, physical abusers; mothers or fathers at risk to be child abusers, maternal depression, and parents with conduct disorders (Abidin, 2012). In order to determine if parents of children who had HIE exhibit more stress than parents of healthy children, a series of one sample T-Tests were used. Effect size was based upon Cohen’s criteria.

Do parents of children with HIE meet criteria for depression as measured by the Patient Health Questionnaire II (PHQ-2)?

In order to determine if parents of children who had HIE meet criteria for depression, the results of the PHQ-2 were evaluated. In order to diagnose depression, participants must score \( \geq 3 \), which had the greatest balance of specificity and sensitivity for both major and any depressive disorder. Spearman’s rho was used to compare parents of children with HIE against the general population in terms of the mean frequency of depression. Effect size was based upon Cohen’s criteria.
What coping mechanisms are used by parents of children with HIE, as measured by the Ways of Coping Questionnaire (WCQ)?

The eight subscales contained within the WCQ address eight specific coping strategies. Three of these strategies: accepting responsibility, self-controlling and planful problem solving are considered problem-focused coping. Emotion-focused coping consists of confrontive coping, distancing, positive reappraisal, seeking social support, and escape/avoidance. Total usage of coping strategies, total usage of specific coping subscale types, and usage of problem-focused and emotion-focused coping strategies was calculated and then weight adjusted based upon the number of items for each subscale within the survey to make two new variables: problem-focused coping and emotion-focused coping. The individual subscales were evaluated via descriptive measures and then further analyzed along with parent gender, child gender, and parentally perceived degree of disability by means of the Mann Whitney U. In addition, each coping mechanism subtype was considered as an independent variable. The frequency scores of each particular coping subtype is a ratio level variable. Parent age and child age are ratio level, while parentally perceived degree of disability and parental gender are nominal independent variables. In order to evaluate the eight coping strategies in terms of the four independent variables, a Friedman test was used in order to determine potential differences in coping based upon the level of parentally perceived degree of disability. In order to compare the use of problem-focused versus emotion-focused coping mechanisms, a paired samples t-test was used. The use of both problem-focused and emotion-focused coping were then evaluated based on gender using a Mann-Whitney test. Age, income, marital status, number of children, child age, and the PPDD were
similarly evaluated using a Kruskal-Wallis test, as assumptions for parametric testing were not met. In order to compare the use of emotionally-focused techniques by gender, the Mann-Whitney U test was performed.

3.9.4 Mixed methods analysis

As stated previously, quantitative data and qualitative data were collected concurrently. However, in accord with mixed methods convergent design, the qualitative data was analyzed prior to and independently of the quantitative data. Once the qualitative data was analyzed, the quantitative data was analyzed and the results from the two methods were then explored (Bazeley, 2009; Bekhet & Zauszniewski, 2012; Casey & Murphy, 2009; Creswell & Plano-Clark, 2011). Based upon the resultant data, the researcher quantified some of the qualitative data and qualified some of the quantitative variables, as recommended by Creswell and Plano-Clark (2011). For example, when themes of depression were identified, a score of one indicated that the construct was present, whereas zero would indicate that the construct was not present. Qualifying that same construct led to a theme of “I am depressed” or based upon the identified themes, “Life in the Negative.” The analysis of the two data sets dictated multiple dimensions by which the results were compared. The determination of those dimensions was based upon the resultant data in light of the research questions. The researcher then made side by side comparisons between identified themes and quantitative data by means of a summary table. The goal was to determine areas of convergence and divergence, as recommended by Creswell (2009a; Creswell & Plano-Clark, 2011). In addition, the summary table was used to evaluate findings through the lens of the Resiliency Model of Stress, Adjustment and Adaptation. Thoughts, additional questions, and interpretations
were reviewed with the researcher’s committee in order to assure appropriate interpretation.
CHAPTER FOUR

FINDINGS

4.1 Introduction

This exploratory, mixed methods study used a convergent parallel design in order to explore the experiences, perceptions, feelings, and self-identified needs of parents who have a child who had HIE in the neonatal period. Phenomenologic inquiry was used to gain an appreciation for the life experiences of these parents was combined with various quantitative measures which have been used in exploring constructs that affect parents of children with physical challenges, such as in parents of children who had HIE.

Quantitative data and qualitative data were collected concurrently. However, in accord with mixed methods convergent design, the qualitative data was analyzed independently and prior to the analysis of the quantitative data. In this way, the qualitative analysis would not be influenced by the results of the quantitative analysis. On-line participants were asked if they would be willing to participate in an interview, however none of them answered in the affirmative. All qualitative participants were recruited from either follow-up clinics or outside advertisement. Once the qualitative data results were analyzed the quantitative data was analyzed, the results from the two methods were then analyzed for convergence and divergence (Bazeley, 2009; Bekhet & Zauszniewski, 2012; Casey & Murphy, 2009; Creswell, 2009a; Creswell & Plano-Clark, 2011).

Heideggerian Phenomenology is known as an interpretive rather than objective approach to research. It assumes that perceptions provide us with evidence of the lived world or experience of “being in the world” (Mackey, 2005). He refers to “*dasein,*”
which he views as human existence, specifically, “being there.” He states that seeking or questioning is cognitively guided by what is sought (das gefragte) (Heidegger, 1962). In the qualitative strand of this study, the researcher sought to uncover the lived experience of being the parent of a child who had HIE. Interviews were conducted with nine parents of such children and yielded copious and meaningful data. Data collection and analysis occurred concurrently until saturation of the data was obtained. Most participants shared issues that addressed views of the child, their lives, the medical community, and society at large. It was found that many of these expressions and concerns were articulated by most of the participants, thus yielding saturation of the data.

Quantitative analysis initially used descriptive statistics and testing for assumptions for parametric testing. At that point, t-tests and non-parametric statistics for analysis of the research questions were conducted. Impeded by a smaller than anticipated sample size (minimum of 88 participants per group to reach a power of .80, effect size of .25 and an alpha of .05). and a small number of males compared to females, non-parametric statistics including Spearman’s rho, Kruskal-Wallis, Friedman test and Mann-Whitney U were used for additional analyses of the research questions.

Finally, data from the qualitative and quantitative strands were mixed in order to provide a more complete picture of the sample. Areas of both convergence and divergence were appreciated. Furthermore, both strands yielded data that were not appreciated in the other.
4.2 Study Participants

A description of study participants (Table 4.1) from both the qualitative strand and the quantitative strand was compiled from the Demographic Questionnaire (Appendix D) and the Intake Questionnaire (Appendix E).
Table 4.1

Participants’ Demographic Data (N=51)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Qualitative n</th>
<th>Online n</th>
<th>Overall n</th>
<th>Overall %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-25</td>
<td>2</td>
<td>9</td>
<td>11</td>
<td>21.5</td>
</tr>
<tr>
<td>26-35</td>
<td>2</td>
<td>17</td>
<td>19</td>
<td>37.3</td>
</tr>
<tr>
<td>36-45</td>
<td>3</td>
<td>12</td>
<td>15</td>
<td>29.4</td>
</tr>
<tr>
<td>46-55</td>
<td>2</td>
<td>3</td>
<td>5</td>
<td>9.8</td>
</tr>
<tr>
<td>&gt;55</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>2.0</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>4</td>
<td>19</td>
<td>23</td>
<td>45.1</td>
</tr>
<tr>
<td>Single</td>
<td>1</td>
<td>11</td>
<td>12</td>
<td>23.5</td>
</tr>
<tr>
<td>Divorced</td>
<td>0</td>
<td>9</td>
<td>9</td>
<td>17.6</td>
</tr>
<tr>
<td>In relationship</td>
<td>4</td>
<td>2</td>
<td>6</td>
<td>11.8</td>
</tr>
<tr>
<td>Widowed</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>2.0</td>
</tr>
<tr>
<td>Dwelling</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single Family Home</td>
<td>9</td>
<td>34</td>
<td>43</td>
<td>84.3</td>
</tr>
<tr>
<td>Apartment</td>
<td>0</td>
<td>8</td>
<td>8</td>
<td>15.7</td>
</tr>
<tr>
<td>Live with</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>4</td>
<td>15</td>
<td>19</td>
<td>37.3</td>
</tr>
<tr>
<td>Alone</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Significant Other</td>
<td>2</td>
<td>6</td>
<td>8</td>
<td>15.7</td>
</tr>
<tr>
<td>Spouse and grandparent</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>2.0</td>
</tr>
<tr>
<td>Significant Other and other</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>2.0</td>
</tr>
<tr>
<td>Friends</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>2.0</td>
</tr>
<tr>
<td>How Many Children</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One</td>
<td>6</td>
<td>16</td>
<td>22</td>
<td>43.1</td>
</tr>
<tr>
<td>Two</td>
<td>0</td>
<td>19</td>
<td>19</td>
<td>37.3</td>
</tr>
<tr>
<td>Three</td>
<td>3</td>
<td>6</td>
<td>9</td>
<td>17.6</td>
</tr>
<tr>
<td>Five</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>2.0</td>
</tr>
<tr>
<td>Yearly Income</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $25,000</td>
<td>4</td>
<td>4</td>
<td>8</td>
<td>15.7</td>
</tr>
<tr>
<td>$25,000-$50,000</td>
<td>3</td>
<td>6</td>
<td>9</td>
<td>17.6</td>
</tr>
<tr>
<td>$75,000-$100,000</td>
<td>1</td>
<td>11</td>
<td>12</td>
<td>23.5</td>
</tr>
<tr>
<td>More than $100,000</td>
<td>1</td>
<td>9</td>
<td>10</td>
<td>19.6</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>2.0</td>
</tr>
<tr>
<td>Ethnic Background</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>4</td>
<td>28</td>
<td>32</td>
<td>62.7</td>
</tr>
<tr>
<td>African American</td>
<td>0</td>
<td>7</td>
<td>7</td>
<td>13.7</td>
</tr>
<tr>
<td>Hispanic</td>
<td>5</td>
<td>2</td>
<td>7</td>
<td>13.7</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>7</td>
<td>7</td>
<td>13.7</td>
</tr>
</tbody>
</table>
Nine parents participated in the qualitative strand and 51 parents participated in the quantitative strand. The 51 parents who completed the quantitative surveys included the nine parents who completed the qualitative interviews, as well as 42 online participants. Participant representation was heavily female with 43 women and 8 men. Ages ranged from 18-25 to over 55 years of age with a mean age of 40.1 years of age. Parents had a mean of 1.8 children with a range of one to five children. Interestingly, while 23 participants identified themselves as married, only 19 reported living in the same household. In general, higher incomes were reported in the internet sample than in the qualitative sample, where four of the nine participants (44/4%) reported their income to be less than $25,000 per year. The Intake Form (Appendix E) provided more detailed data in regards to the parents and their children. This included both the type of delivery and analgesia, as well as its effectiveness and the presence of support persons. It is of note that only 23 (45.1%) of the participants reported that their pain management during labor and delivery was effective. A variety of support persons were present for deliveries. Most frequently were the spouse or a significant other, 42/59 (82.4%). Other participants reported a variety of support individuals identifying: no one, parent, spouse and parent, spouse and child, significant other along with parent and friend, parent and sibling, parent and friend, parent and grandparent, and spouse and grandparent (Table 4.2).
Table 4.2

Participants’ Delivery Data (N=51)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delivery Type</td>
<td>n</td>
</tr>
<tr>
<td>Emergency cesarean birth</td>
<td>33</td>
</tr>
<tr>
<td>Hospital instrumented vaginal birth</td>
<td>12</td>
</tr>
<tr>
<td>Home birth</td>
<td>3</td>
</tr>
<tr>
<td>Planned cesarean birth</td>
<td>2</td>
</tr>
<tr>
<td>Hospital, vaginal birth</td>
<td>1</td>
</tr>
<tr>
<td>Anesthesia/Analgesia</td>
<td></td>
</tr>
<tr>
<td>Spinal or epidural</td>
<td>18</td>
</tr>
<tr>
<td>General anesthesia</td>
<td>18</td>
</tr>
<tr>
<td>General anesthesia and spinal or epidural</td>
<td>8</td>
</tr>
<tr>
<td>Spinal or epidural and intravenous analgesia</td>
<td>4</td>
</tr>
<tr>
<td>Nothing</td>
<td>2</td>
</tr>
<tr>
<td>Intravenous analgesia</td>
<td>1</td>
</tr>
<tr>
<td>Support Presence</td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>31</td>
</tr>
<tr>
<td>Significant Other</td>
<td>11</td>
</tr>
<tr>
<td>Parent and someone(s) else</td>
<td>7</td>
</tr>
<tr>
<td>Spouse and child</td>
<td>1</td>
</tr>
<tr>
<td>No one</td>
<td>1</td>
</tr>
</tbody>
</table>

In terms of the child, duration of hospitalization ranged from 18 to 92 days with a mean of 47.6 days (sd = 16.58). The parentally perceived degree of disability (PPDD) was queried and the 49 responses are presented in Table 4.3.

Table 4.3

Parentally Perceived Degree of Disability (N=49)

<table>
<thead>
<tr>
<th>Disability</th>
<th>Parentally Perceived</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>15</td>
</tr>
<tr>
<td>Mild</td>
<td>18</td>
</tr>
<tr>
<td>Moderate</td>
<td>12</td>
</tr>
<tr>
<td>Severe</td>
<td>4</td>
</tr>
</tbody>
</table>

165
4.3 Quantitative Analysis

4.3.1 Introduction

A variety of quantitative research questions were posed addressing parental perceptions of disability, stress, impact of the disability on the family, depression and coping. In addition to the demographic data obtained (Table 4.1,) a Parent Intake Form (Appendix E) was used to glean more specific information in regards to the delivery experience and their child (Table 4.2, Table 4.3,) above. In addition to the first research question addressing the lived experience of parents of children who had HIE, four additional questions were posed addressing the aforementioned issues. While parametric testing was possible for some analyses, non-parametric testing was required for most, primarily due to a small sample size. These analyses yielded important data that may be used to improve the care health care providers give to families in the future.

4.3.2 Research Question 1: What is the relationship between the self-rated parental perception of degree of disability of their child and the impact of childhood neurologic disability as measured by the Impact of Childhood Neurologic Disability Scale (ICNDS)?

In order to evaluate the parentally described degree of disability, the medical records of the five children (seven parents) for whom medical records were available were compared with parental responses (Table 4.4).
Table 4.4

*Comparison of Parentally and Medically Described Degree of Disability*

<table>
<thead>
<tr>
<th>Parent</th>
<th>Parentally Described</th>
<th>Medically Described</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Moderate</td>
<td>Moderate</td>
</tr>
<tr>
<td>2</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td>3</td>
<td>Moderate</td>
<td>Severe</td>
</tr>
<tr>
<td>4</td>
<td>Severe</td>
<td>Severe</td>
</tr>
<tr>
<td>5</td>
<td>None</td>
<td>Mild</td>
</tr>
<tr>
<td>6</td>
<td>None</td>
<td>Mild</td>
</tr>
<tr>
<td>9</td>
<td>None</td>
<td>Mild</td>
</tr>
</tbody>
</table>

The perceptions of two parents who identified their children as having moderate and severe degrees of disability were on target with the medically described degree of disability. All other participants from whom children’s medical records were available described their children’s challenges as less significant than the medically described degree of disability. The two parents interviewed of children who did not have medical records available described their children as having severe disabilities, but were not included due to a lack of medical record evaluation. By the descriptions provided by those two parents, it appeared as if those descriptions would have stratified their children as having a severe disability. Both of these children were non-verbal, were unable to walk or sit unassisted, required gastrostomy feeds, and remained in diapers at over three years of age. Given a lack of congruity between the parentally described and the medically described degrees of disability as well as that the parentally described degree reflects the parents’ views of their children, the parentally described degree of disability was used for analysis.

The first sub-realm on the Impact of Childhood Neurologic Disability Scale queried the effect of behavior upon the family unit. While 51 total surveys were provided, four (7.8%) participants did not address this realm and six (11.8%) reported
that this realm was not applicable to them. The second sub-realm addressed cognition with only one (2%) participant not addressing the questions and three (5.9%) reporting that this realm was not applicable. The third sub-realm evaluated physical and/or neurologic challenges. Four (7.8%) participants did not answer these questions with one (2%) reporting that this category was not applicable. The final sub-realm was epilepsy with 7 (13.7%) omitting these questions and 12 (23.5%) reporting that this category was not applicable to them. Three participants (5.9%) filled out the survey reporting that none of the sub-realms had any impact, with all scores being zero.

A few participants either did not answer this survey at all or only answered questions in a single category, with questions in other sub-realms being reported as non-applicable. In situations where the entire survey was not answered, missing data was deleted from analysis. In cases where a respondent answered the questions in one, two or three categories, the questions for the unaddressed categories were scored as zero (meaning no impact) and included in analysis. Given this, it was determined that the total impact score would be used for the first analysis (Figure 4.1).
Given both a lower sample size and an unequal sample size for each of the groups based on the PPDD, non-parametric testing was required. The relationship between the impact of childhood neurologic disability (as measured by the ICNDS) and the PPDD was investigated utilizing Spearman’s rho. There was a moderate positive correlation between the two variables, $r_s = .348$, $n = 50$, $p = .013$. It is noted that parents who described their children as having a severe disability exhibited a slightly lower impact upon the family. It is presumed that this group of parents have children who are perceived as more neurologically devastated. Given this, it is likely that behavioral issues are less frequent, which lowered the total impact score. With this in mind,
correlations were calculated based upon the individual sub-realms. As expected, there was no correlation between either behavior, cognition or epilepsy with the PPDD. High correlations were found in terms of neurophysiologic disabilities, only (Table 4.5).

Table 4.5

<table>
<thead>
<tr>
<th>Subrealm</th>
<th>N</th>
<th>r_s</th>
<th>Sig</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavior</td>
<td>48</td>
<td>-.580</td>
<td>.695</td>
</tr>
<tr>
<td>Cognition</td>
<td>49</td>
<td>.244</td>
<td>.092</td>
</tr>
<tr>
<td>Neurophysical</td>
<td>47</td>
<td>.433</td>
<td>.002*</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>44</td>
<td>.157</td>
<td>.308</td>
</tr>
</tbody>
</table>

These data were further analyzed based upon a variety of demographic variables by means of the Kruskal-Wallis test. It was found that only neurophysiologic disabilities were a significant sub-realm in terms of both age and income, with both older parents and parents having greater incomes reporting a greater impact upon themselves and their families (n = 47, χ² = 9.793, df 4, p=.044; n = 47, χ² = 11.989, df 5, p = .035, respectively). While the age of the child was not statistically significant, it did approach significance (p = .052,) with parents of older children reporting a greater impact in terms of neurophysiologic disabilities.

4.3.3 Research Question 2: Do parents of children with HIE exhibit more stress than parents of children who do not have disabilities as measured by the Parental Stress Index (PSI-SF)?

The PSI-SF provides normative data collected from 1,056 parents which was used to make comparisons with this sample (Abidin, 2012). It provided mean profiles for parents of children with a variety of disabilities. While data for the subscale of Defensive Responding was obtained, it was not utilized, as this subscale evaluates the potential for
abusive situations, which was beyond the scope of this study. When evaluating the data, it was found that all subscales of the PSI (Parent Child Dysfunction, Child Domain, Life Stress, and Parent Domain,) were normally distributed. Skewness ranged from -1.204 -.125 and kurtosis from -.083 – 1.463. A series of one-sample t-tests was done, finding that there was no significant difference between the Parent Domain in this sample and the normative parent domain (Abidin, 2012). Four participants did not address all questions on the survey. When the data was reviewed, it was found that the questions that were not answered fell into individual domains. For this reason, respondents who did not address questions were deleted from that domain’s analysis and from the analysis of total stress as it is an additive category. Significant differences were found between Child Domain, Life Stress and Total Stress. Normative data was not available for Parent-Child Dysfunction; however, raw scores and percentiles were available for each question on the survey. For this reason, the percentiles of Parent-Child Dysfunction were examined, finding that the mean percentile for this sample was 88.98 with a range of 24 - >99. Sixteen of 51 (31.4%) participants scored greater than the 99th percentile for parent child-dysfunction, with 36 (71%) scoring at the 85th percentile or greater (Table 4.6).

Table 4.6

<table>
<thead>
<tr>
<th>Domain</th>
<th>n</th>
<th>Mean</th>
<th>SD</th>
<th>t</th>
<th>Sig.</th>
<th>Cohen’s d</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child</td>
<td>49</td>
<td>37.80</td>
<td>7.87</td>
<td>-3.74</td>
<td>.000</td>
<td>.53</td>
</tr>
<tr>
<td>Life Stress</td>
<td>50</td>
<td>20.88</td>
<td>6.19</td>
<td>18.38</td>
<td>.000</td>
<td>2.60</td>
</tr>
<tr>
<td>Total Stress</td>
<td>47</td>
<td>112.51</td>
<td>22.73</td>
<td>10.17</td>
<td>.000</td>
<td>1.48</td>
</tr>
</tbody>
</table>

Spearman’s Rho was then used to correlate the PPDD with total stress. There was a medium positive correlation between the two variables, r = .382, n = 47, p = .008, indicating that that greater the degree of disability as perceived by parents was associated
with greater degrees of stress (Figure 4.2). The degree of parental stress was highly correlated with the total impact of neurologic disability, $r = .528$, $n = 47$, $p < .001$, indicating that higher stress levels were associated with greater impact of neurologic disabilities upon the family. Depression and parental stress were similarly highly correlated, $r = .678$, $n = 47$, $p < .001$, indicating that the greater the level of depression, the higher the stress level. The age of the child was similarly correlated with parental stress, again revealing a medium positive correlation between the two variables, $r = .448$, $n = 47$, $p = .002$, indicating that parents identified with greater levels of stress with older children. There were no correlations appreciated between stress and the number of
children in families, \( r = .041, n = 47, p = .784 \) or income and stress, \( r = .158, n = 47, p = .235 \).

4.3.4 Research Question 3. Do parents of children with HIE meet criteria for depression as measured by the PHQ-2?

All 51 participants answered the two questions in the PHQ-2, finding that 22/51 (43%) of participants’ answers were consistent with depression with 7 (13.7%) participants exhibiting scores consistent with major depression. According to the National Institute of Mental Health (2015), the overall incidence of major depression for adults in the United States is 6.6%; with 8.2% in women, 4.8% in men, 9.8% in adults age 18-25, 7.2% in those between the ages of 26 and 49, and 5.2% in those over 50. It was found that the data was normally distributed with a skewness of .647 and kurtosis of -2.36. A one sample t-test was conducted comparing PHQ-2 scores with the general population, finding a significance difference, \( t = -11.607, p < .001, CI: -3.17 \) - -2.24). Cohen’s d showed a very large effect size of -1.63. There was no significant difference based upon gender, possibly secondary to the small group of male respondents compared with female. When females, alone were evaluated, it was found that 7/43 (16.3%) exhibited scores consistent with major depression. This was almost twice the incidence of which occurred in the general population of women, who exhibited 8.2%.

Spearman’s rho was used to correlate PHQ-2 scores with the PPDD and duration of the child’s hospitalization, finding a significant correlation \( r_s = .564, n = 51, p < .001; r_s = .316, n = 51, p = .024 \), respectively). Parents who perceived their children as having greater degrees of disability and had longer initial hospitalizations exhibited greater degrees of depression. As these two variables may be expected to be related, it is not
unexpected that these are both significant. Total impact of neurologic disability and total stress were similarly significantly positively correlated. While there was not a statistically significant correlation between child age and depression, there was a tendency for parents of older children to exhibit more depression (Table 4.7).

Table 4.7

<table>
<thead>
<tr>
<th>Category</th>
<th>n</th>
<th>r_s</th>
<th>sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>51</td>
<td>.126</td>
<td>.380</td>
</tr>
<tr>
<td>Age</td>
<td>51</td>
<td>.171</td>
<td>.231</td>
</tr>
<tr>
<td>Income</td>
<td>51</td>
<td>-.184</td>
<td>.195</td>
</tr>
<tr>
<td>Child Age</td>
<td>51</td>
<td>.238</td>
<td>.092</td>
</tr>
<tr>
<td>Parentally Perceived Degree of Disability</td>
<td>51</td>
<td>.564</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td>Duration of Hospitalization</td>
<td>51</td>
<td>.316</td>
<td>.024*</td>
</tr>
<tr>
<td>Total Impact of Neurologic Disability</td>
<td>50</td>
<td>.304</td>
<td>.032*</td>
</tr>
<tr>
<td>Total Stress</td>
<td>47</td>
<td>.678</td>
<td>&lt;.001*</td>
</tr>
</tbody>
</table>

4.3.5 Research Question 4. What coping mechanisms are used by parents of children with HIE, as measured by the Ways of Coping Questionnaire (WCQ)?

In order to evaluate the various coping mechanisms used in parents of children who had HIE, relative scores were calculated based upon the number of questions in each category. In this sample, the most frequently used mechanism of coping was seeking social support. The relative frequency refers to the total relative frequency of the use of a particular mechanism over the sample; whereas the mean and standard deviation refer to the mean score for the related questions of each mechanism, which were scored zero to three, reflecting not used to used a great deal (Table 4.8). Two parents did not answer all questions and one individual did not address any questions. That one individual was
Table 4.8

<table>
<thead>
<tr>
<th>Mechanism</th>
<th>n</th>
<th>Mean</th>
<th>SD</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distancing</td>
<td>48</td>
<td>.736</td>
<td>.390</td>
<td>.17</td>
<td>1.83</td>
</tr>
<tr>
<td>Confrontation</td>
<td>48</td>
<td>.844</td>
<td>.476</td>
<td>.17</td>
<td>2.00</td>
</tr>
<tr>
<td>Accepting Responsibility</td>
<td>48</td>
<td>.870</td>
<td>.565</td>
<td>.00</td>
<td>2.00</td>
</tr>
<tr>
<td>Positive Reappraisal</td>
<td>48</td>
<td>.896</td>
<td>.617</td>
<td>.00</td>
<td>2.29</td>
</tr>
<tr>
<td>Self-Controlling</td>
<td>48</td>
<td>1.188</td>
<td>.430</td>
<td>.29</td>
<td>2.29</td>
</tr>
<tr>
<td>Planful Problem Solving</td>
<td>48</td>
<td>1.319</td>
<td>.590</td>
<td>.00</td>
<td>2.33</td>
</tr>
<tr>
<td>Escape-Avoidance</td>
<td>49</td>
<td>1.367</td>
<td>.518</td>
<td>.38</td>
<td>2.38</td>
</tr>
<tr>
<td>Seeking Social Support</td>
<td>49</td>
<td>1.449</td>
<td>.509</td>
<td>.33</td>
<td>2.50</td>
</tr>
</tbody>
</table>

test was used to evaluate the differences among the eight ways of coping. The outcome indicated that there were significant differences between the types of coping mechanisms used within this sample, $\chi^2 (7, n=48 = 78.366, p < .001$. It is of note that at least one participant did not rank accepting responsibility, positive reappraisal, or planful problem solving as being a mechanism used.

In order to compare the use of problem-focused versus emotion-focused coping mechanisms, a paired samples t-test was used. There was no significant difference between the use of problem-focused coping ($M = 1.103, SD = .386$) and emotion-focused coping ($M = 1.058, SD = .274$), $t(48) = .781, p = .44$ (two-tailed). The use of both problem- and emotion- focused coping were then evaluated based on gender using a Mann-Whitney test. Significant differences were revealed in the use of problem-focused coping by males ($Md = 1.355, n = 8$) and females ($Md = 1.052, n = 41$), $U = 66.00, z = -2.651, p = .008, r = .38$, for a small to moderate effect size. Age, income, marital status, number of children, child age, and the PPDD were similarly evaluated using a Kruskal-Wallis test, as not all assumptions for parametric testing were met. Significant differences were revealed in the use of coping style according to income with participants who had higher incomes using more problem-focused mechanisms; number of children

175
with participants who had more children using more problem-focused methods; and the parentally perceived degree of disability with parents perceiving their children to have a moderate disability used more emotion-focused mechanisms than parents of children who perceived their children to have no, mild or severe degrees of disability (Table 4.9).
Table 4.9

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Emotion Focused Mean Rank</th>
<th>χ²</th>
<th>Sig</th>
<th>Problem Focused Mean Rank</th>
<th>χ²</th>
<th>Sig</th>
</tr>
</thead>
<tbody>
<tr>
<td>Income (thousands of dollars)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;25</td>
<td>8</td>
<td>28.63</td>
<td>1.254</td>
<td>.870</td>
<td></td>
<td>9.971</td>
<td>.041*</td>
</tr>
<tr>
<td>25-50</td>
<td>9</td>
<td>21.22</td>
<td></td>
<td></td>
<td></td>
<td>18.33</td>
<td></td>
</tr>
<tr>
<td>50-75</td>
<td>11</td>
<td>24.45</td>
<td></td>
<td></td>
<td></td>
<td>20.41</td>
<td></td>
</tr>
<tr>
<td>75-100</td>
<td>10</td>
<td>23.60</td>
<td></td>
<td></td>
<td></td>
<td>26.45</td>
<td></td>
</tr>
<tr>
<td>&gt;100</td>
<td>10</td>
<td>25.10</td>
<td></td>
<td></td>
<td></td>
<td>35.75</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-25</td>
<td>9</td>
<td>20.00</td>
<td>1.307</td>
<td>.727</td>
<td></td>
<td>5.538</td>
<td>.136</td>
</tr>
<tr>
<td>26-35</td>
<td>18</td>
<td>24.94</td>
<td></td>
<td></td>
<td></td>
<td>21.58</td>
<td></td>
</tr>
<tr>
<td>36-45</td>
<td>16</td>
<td>25.50</td>
<td></td>
<td></td>
<td></td>
<td>29.75</td>
<td></td>
</tr>
<tr>
<td>46-55</td>
<td>5</td>
<td>27.80</td>
<td></td>
<td></td>
<td></td>
<td>29.60</td>
<td></td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>21</td>
<td>23.81</td>
<td>5.758</td>
<td>.218</td>
<td></td>
<td>5.432</td>
<td>.246</td>
</tr>
<tr>
<td>Single</td>
<td>12</td>
<td>19.67</td>
<td></td>
<td></td>
<td></td>
<td>17.71</td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>9</td>
<td>32.78</td>
<td></td>
<td></td>
<td></td>
<td>24.00</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>1</td>
<td>38.00</td>
<td></td>
<td></td>
<td></td>
<td>20.00</td>
<td></td>
</tr>
<tr>
<td>Relationship</td>
<td>6</td>
<td>27.00</td>
<td></td>
<td></td>
<td></td>
<td>26.08</td>
<td></td>
</tr>
<tr>
<td>Number of Children</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One</td>
<td>21</td>
<td>19.48</td>
<td>6.939</td>
<td>.031</td>
<td></td>
<td>11.751</td>
<td>.003</td>
</tr>
<tr>
<td>Two</td>
<td>18</td>
<td>26.72</td>
<td></td>
<td></td>
<td></td>
<td>30.75</td>
<td></td>
</tr>
<tr>
<td>Three or more</td>
<td>10</td>
<td>33.50</td>
<td></td>
<td></td>
<td></td>
<td>31.60</td>
<td></td>
</tr>
</tbody>
</table>
Table 4.9 (cont.)

*Coping Style by Demographic Variables*

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Emotion Focused Mean Rank</th>
<th>( \chi^2 )</th>
<th>Sig</th>
<th>Problem Focused Mean Rank</th>
<th>( \chi^2 )</th>
<th>Sig</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 1 year</td>
<td>8</td>
<td>25.13</td>
<td>8.846</td>
<td>.452</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 – 2 years</td>
<td>9</td>
<td>18.11</td>
<td>9.474</td>
<td>.395</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 – 4 years</td>
<td>8</td>
<td>19.63</td>
<td>8.846</td>
<td>.452</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 – 6 years</td>
<td>6</td>
<td>34.50</td>
<td>9.474</td>
<td>.395</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 – 8 years</td>
<td>6</td>
<td>26.83</td>
<td>9.474</td>
<td>.395</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 – 10 years</td>
<td>2</td>
<td>18.50</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11 – 12 years</td>
<td>3</td>
<td>24.67</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13 – 14 years</td>
<td>1</td>
<td>34.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15 – 16 years</td>
<td>2</td>
<td>25.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17 years</td>
<td>4</td>
<td>35.25</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PPDD</td>
<td></td>
<td></td>
<td>8.604</td>
<td>.035*</td>
<td></td>
<td>4.671</td>
<td>.198</td>
</tr>
<tr>
<td>None</td>
<td>14</td>
<td>22.36</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>17</td>
<td>18.12</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate</td>
<td>12</td>
<td>32.67</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Severe</td>
<td>4</td>
<td>28.75</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The Kruskal-Wallis test was used to evaluate specific coping mechanisms within emotion and problem-focused styles according to age, income, marital status, number of children, child age and the PPDD. No significant differences in the use of specific emotion-focused mechanisms was revealed when evaluated by child age. Confrontive coping refers to mechanisms which address taking charge of a situation. While not statistically significant, there was a trend toward significance in the use of confrontive coping mechanisms by age (18-25 years, n = 9; 26-35 years, n = 18; 36-45 years, n = 16; 46-55 years, n = 5), $\chi^2 (3, n = 48) = 6.739$, $p = .081$. Those in the 46-55 year age group used more confrontive mechanisms than younger participants (Md = 1.333) than 18-25 year olds (Md = .667), 26-35 year olds (Md = .667), and 36-45 year olds (Md = .917). A trend toward significance was also appreciated in terms of the use of escape and avoidance mechanisms based on income, with those participants who had lower incomes utilizing more escape and avoidance techniques than those with higher; (Under $25,000, n = 8; $25,000-$50,000, n = 9; $50,000-$75,000, n = 11; $75,000-$100,000, n = 10; over $100,000, n = 10), $\chi^2 = 7.41$, $p = .116$. Those with the lowest incomes, under $25,000 per year recorded a higher median score (Md = 1.938) than those with higher incomes which ranged between 1.125 for those in the highest income bracket to 1.375 for those earning $25,000-$50,000 per year.

Likely related to the number of children a parent had was relationship status, where a significant difference across the groups was appreciated in terms of the use of positive reappraisal mechanisms (Married, n = 21; Single, n = 12; Divorced, n = 9; Unmarried, living in the same household, n = 6; Widowed, n = 1), $\chi^2 (4, n = 49) = 11.729$, $p = .019$ with unmarried individuals living in the same household using positive reappraisal more than all other groups.
(Md = 1.143) as opposed to both married and divorced parents (Md = .857, for both) and single parents not in a relationship (Md = .357,) (Table 4.10).

Table 4.10

<table>
<thead>
<tr>
<th>Relationship Status and Positive Reappraisal</th>
<th>N</th>
<th>Mean Rank</th>
<th>Median</th>
<th>χ²</th>
<th>Sig</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>21</td>
<td>29.90</td>
<td>.857</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unmarried in relationship</td>
<td>6</td>
<td>28.50</td>
<td>1.143</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>9</td>
<td>27.72</td>
<td>.857</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>1</td>
<td>19.00</td>
<td>.571</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>12</td>
<td>13.13</td>
<td>.357</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Positive reappraisal was found to be used significantly more based upon the number of children a parent had, with a significant difference appreciated across the groups; (One child, n = 21; Two children, n = 18; Three or more children, n = 10), χ² (3, n = 49) = 11.214, p =.004. Those parents who had three or more children recorded a higher median score (Md = 1.07) than those with one (Md = .429) or two children (Md = .929). This indicates that parents of multiple children tended to view negative situations with a positive spin more than parents of one child. Self-control was also revealed to be significantly positively associated with the number of children (One child, n = 21; Two children, n =18; Three or more children, n = 10), χ² (3, n = 49) = 12.021 p = .002. While the value was statistically significant, the median for parents with two children (Md = 1.286) was slightly higher than those for three or more children (Md = 1.214), likely secondary to a difference in sample size. Both however were obviously higher than parents of a single child (Md = .857).

Evaluation of the use of particular coping mechanisms based upon the PPDD revealed statistical significance in term of the use of escape-avoidance and accepting responsibility (Table 4.11). Interestingly the median scores for parents who perceived their child as having a moderate disability was greater for parents of children with severe, none, or mild disabilities.
Table 4.11

*Selected Coping Mechanisms Based on the Parentally Perceived Degree of Disability*

<table>
<thead>
<tr>
<th>Mechanism</th>
<th>PPDD</th>
<th>N</th>
<th>Mean Rank</th>
<th>(\chi^2)</th>
<th>Sig</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive Reappraisal</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>16</td>
<td>25.16</td>
<td>3.441</td>
<td>.328</td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>17</td>
<td>20.47</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate</td>
<td>12</td>
<td>29.75</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Severe</td>
<td>4</td>
<td>29.38</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Planful Problem Solving</td>
<td></td>
<td></td>
<td></td>
<td>6.186</td>
<td>.103</td>
</tr>
<tr>
<td>None</td>
<td>16</td>
<td>23.56</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>17</td>
<td>20.09</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate</td>
<td>12</td>
<td>30.29</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Severe</td>
<td>4</td>
<td>35.75</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Escape-Avoidance</td>
<td></td>
<td></td>
<td></td>
<td>8.536</td>
<td>.036*</td>
</tr>
<tr>
<td>None</td>
<td>16</td>
<td>21.22</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>17</td>
<td>20.62</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate</td>
<td>12</td>
<td>34.17</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Severe</td>
<td>4</td>
<td>31.25</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accepting Responsibility</td>
<td></td>
<td></td>
<td></td>
<td>10.604</td>
<td>.014*</td>
</tr>
<tr>
<td>None</td>
<td>16</td>
<td>17.97</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>17</td>
<td>31.53</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate</td>
<td>12</td>
<td>28.63</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Severe</td>
<td>4</td>
<td>14.50</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seeking Social Support</td>
<td></td>
<td></td>
<td></td>
<td>1.916</td>
<td>.590</td>
</tr>
<tr>
<td>None</td>
<td>16</td>
<td>26.44</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>17</td>
<td>22.15</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate</td>
<td>12</td>
<td>28.50</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Severe</td>
<td>4</td>
<td>20.88</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In order to compare the use of emotionally-focused techniques by gender, the Mann-Whitney U test was performed. No significant differences in the use of positive reappraisal, escape avoidance, seeking social support or confrontive coping were revealed. A statistically significant difference was found in the use of distancing behaviors, with males using this technique significantly more often than females, (Md = 1.083, n= 8) and females (Md = .667, n = 41), \(U = 76.50, z = -2.391, p = .016, r = .34\), consistent with a very large effect size.

**4.3.6 Summary of Quantitative Findings**
Parametric and non-parametric testing were used to answer research questions one through four for 51 quantitative respondents. While not all participants answered all questions, some significant findings were revealed.

The PPDD was assessed using a simple question asking if a parent viewed their child as having no disability, a mild, moderate, or severe disability, as previously described. When compared with the medically defined degree of impairment, it was found that five of the seven parents, for whom medical records were available, perceived their children’s degree of impairment as less severe than medically defined.

The findings from the ICNDS determined that the total impact of disability was significantly correlated with the PPPD. Of note, despite this correlation, parents of children who were described as having a severe disability exhibited a somewhat lesser degree of impact on the personal and family unit than those who described their children as having a moderate impairment. Of the four types of disabilities of the scale: behavioral, cognitive, neurophysiologic, and epilepsy, only neurophysiologic impairments were significantly correlated with PPDD, household income, and parental age.

The PSI-SF was used to assess parenting stress in this sample. It was found that the respondents exhibited significantly high stress levels in terms of total stress, life stress, parent-child dysfunction, and child related stress. Stress is often linked with depression, which was also found to be significantly high in this sample. Depression was found in 43% of participants with major depression in 13.7%. Women, in particular, exhibited depression rates of approximately twice that of the normative population of U.S. women. Significant correlations with depression were also appreciated in relationship to PPDD, duration of hospitalization, total impact of neurologic disability and total stress.
Seeking social support was used significantly more than any other coping mechanisms. In general there was no significant difference between problem and emotion-focused coping mechanisms, as a whole. It was found that males used problem-focused coping significantly more than females, those with higher incomes and those who had more children. Alternatively, more emotion-focused mechanisms were used by parents who perceived that their children had a moderate impairment. The specific emotion-focused coping mechanism of positive reappraisal was significantly positively associated with the presence of a relationship and number of children. Number of children was also found to be significantly positively associated with the use of confrontive coping.

A variety of quantitative surveys were used to assess the impact of childhood neurologic disability, parenting stress, depression and coping. Several significant findings were appreciated in each of the areas evaluated. It is anticipated that this valuable information in combination with the qualitative findings as well as the mixed-methods analysis will yield data that will be beneficial to future families of children who have HIE.

4.4 Qualitative Analysis

The qualitative strand for this convergent parallel design mixed-methods study utilized Heideggerian Phenomenology. This method is known as an interpretive rather than objective approach to research. It assumes that perceptions provide us with evidence of the lived world or experience of “being in the world” (Mackey, 2005). Heidegger refers to “dasein,” which he views as human existence, specifically, “being there.” He states that seeking or questioning is cognitively guided by what is sought (das gefragte) (Heidegger, 1962). In the qualitative portion of this study, the researcher sought to uncover the lived experience of being the parent of a child who had hypoxic-ischemic encephalopathy (HIE). Interviews were conducted with nine parents
of such children and yielded copious and meaningful data. Data collection and analysis occurred until saturation of the data was obtained. Most participants shared issues that addressed views of the child, their lives, the medical community, and society at large. It was found that many of these expressions and concerns were articulated by the participants, thus yielding saturation of the data.

Member checking is a commonly used technique in which, after the completion of an interview, the researcher goes back to the respondent specifically for the purpose of enhancing understanding of the participants’ responses. Unlike other phenomenologists, member checking is believed by Heidegger to negatively affect the findings, as the context of the interview is changed; therefore, validations and questions requiring more detail were addressed during the interview. Also, unlike other phenomenologists, Heidegger has stated that reciprocity is vital to the understanding of the phenomenon (Dowling, 2005; Mackey, 2005). This allows for a more conversational style of interviewing, which is the likely reason that Heideggerian phenomenology has been found to be particularly useful in caring encounters. He refers to this reciprocity as the Hermeneutic circle.

There were two interviews in which the researcher was asked about her own experience. Heidegger’s works view this as beneficial, seeing the respondent and researcher as partners. Seeking or questioning is cognitively guided by what is sought. The researcher sought to understand this person’s life experience. The respondents sought to understand the researcher’s perspectives as well. The interview experience is a two-way street. For this reason, these questions were answered honestly and succinctly. The first, by a father with a physical disability, who inquired about any friends the researcher might have who had that issue. Upon affirmation of such a friend, she was further asked about that friend’s degree of disability and if
the friendship continued. After these questions were answered, the participant continued with his concerns of parenting with a disability. The second question was from a homosexual woman who wanted to know if I had any “gay” friends. The researcher answered in the affirmative. After this was done, the woman opened up more about herself. These questions and answers are consistent and congruent with Heidegger’s concept of dasein (being). He states that seeking or questioning is cognitively guided by what is sought (das gefragte) (Heidegger, 1962). In addition, the researcher, who maintains an unbracketed base knowledge, questions the respondent (das befragte,) who similarly cannot separate him or herself from their reality. Therefore, questions from the respondent are valid. In these two cases, answering these questions honestly and succinctly is believed to have augmented the responses from the participants who then knew that the researcher had some understanding of their personal reality.

The third component is the answers or what may be found by the asking (das erfragte,) which is the intent. Being, in and of itself, is not composed of merely questions, desires, and actions by which these desires may be addressed. It is therefore logical for the person from whom information is being sought to desire a better understanding of das befragte (the source of the inquiry or the investigator).

4.4.1 Interview Process

Interviews were open-ended began with the question, “Please tell me what it is like for you to be (child’s name) mother/father. As the participants shared their stories, an in-depth understanding of the participants’ contexts, was revealed, thus aiding in the revelation of the phenomenon of interest in light of the participants’ individual experiences. As needed, various probes were added, such as “tell me more,” or “then what happened.” Other times supportive statements, meant to encourage further dialogue were made, such as, “I’m sorry that happened”
or when a father said that he was happy that he was preparing for his son’s first birthday party and he doesn’t even know it, the researcher stated that he would figure it out. This latter statement brought some laughter to both the participant and the researcher, which then led to further disclosure on the part of that father. Toward the end of each interview, the researcher glanced at her field notes to inquire about issues that required further elucidation.

4.4.2 Participant Characteristics

Nine parents of seven children participated in the qualitative strand of this study. Seven of whom were from the primary study hospital, while two were from outside advertisement (Table 4.12).
### Table 4.12

**Qualitative Participant Characteristics**

<table>
<thead>
<tr>
<th>Name</th>
<th>Education</th>
<th>Employment</th>
<th>Marital Status</th>
<th>Children</th>
<th>Age</th>
<th>PPDD</th>
<th>Background</th>
</tr>
</thead>
<tbody>
<tr>
<td>Martin</td>
<td>Some HS</td>
<td>Unemployed</td>
<td>Living together</td>
<td>1</td>
<td>11 Mos.</td>
<td>Moderate</td>
<td>Cognitive and mental health issues</td>
</tr>
<tr>
<td>Lisa</td>
<td>Some HS</td>
<td>Unemployed</td>
<td>Living together</td>
<td>1</td>
<td>11 Mos.</td>
<td>Mild</td>
<td>Cognitively impaired</td>
</tr>
<tr>
<td>Debbie</td>
<td>College</td>
<td>Unemployed</td>
<td>Married</td>
<td>1</td>
<td>18 Mos.</td>
<td>Mild</td>
<td>Chronic health condition</td>
</tr>
<tr>
<td>Jim</td>
<td>College</td>
<td>Employed</td>
<td>Married</td>
<td>1</td>
<td>18 Mos.</td>
<td>Mild</td>
<td>Chronic health Condition</td>
</tr>
<tr>
<td>Carla</td>
<td>HS</td>
<td>Unemployed</td>
<td>Married</td>
<td>3</td>
<td>11 Mos.</td>
<td>Moderate</td>
<td>From Honduras</td>
</tr>
<tr>
<td>Luis</td>
<td>HS</td>
<td>Employed</td>
<td>Married</td>
<td>3</td>
<td>11 Mos.</td>
<td>Severe</td>
<td>From Honduras</td>
</tr>
<tr>
<td>Kathy</td>
<td>Masters</td>
<td>Unemployed</td>
<td>Single</td>
<td>1</td>
<td>3 Years</td>
<td>Severe</td>
<td>Identifies as homosexual</td>
</tr>
<tr>
<td>Melissa</td>
<td>Doctorate</td>
<td>Employed</td>
<td>Married</td>
<td>1</td>
<td>4 Years</td>
<td>Severe</td>
<td>Medical professional</td>
</tr>
<tr>
<td>Nina</td>
<td>HS</td>
<td>Unemployed</td>
<td>Married</td>
<td>2</td>
<td>19 Mos.</td>
<td>None</td>
<td>From Honduras</td>
</tr>
</tbody>
</table>
4.4.3 Qualitative Findings

A single research question was posed for the qualitative strand: What is the lived experience of being a parent of a child who had HIE? In order to gain a delineation of the characteristics of the life of parents of children who had HIE, the researcher listened to the recordings of each interview at least three times prior to coding to better appreciate inflection, emotion and the informants’ story intents. During this period, the researcher added memos to the existing field notes regarding inflection and remembrances of non-verbal forms of communication during each interview. The interviews were then transcribed verbatim, using assigned pseudonyms and read several times prior to initial coding. The Heideggerian researcher is taught to “lose oneself” in the data, allowing the thoughts to just come together (Smythe, Ironside, Sim, Swenson, & Spense, 2007). This comprised the first steps of analysis and created a “naïve” understanding (Lindseth & Norberg, 2004).

The following phase of analysis was a structural thematic analysis (Lindseth & Norberg, 2004). In this phase meaning units, which may contain multiple, seemingly inconsequential statements were identified. The text was then reread and these units were described in common language. The units were then sorted and condensed into subthemes, at times discarding insignificant units. Nine response categories were initially identified, many of these contained multiple sub-categories (Table 4.13).
Table 4.13

**Response Categories**

<table>
<thead>
<tr>
<th>Child Comparisons</th>
<th>Child Health</th>
<th>Child Caregiving</th>
</tr>
</thead>
<tbody>
<tr>
<td>All a bad dream</td>
<td>Economic Influences</td>
<td></td>
</tr>
<tr>
<td>Avoidance</td>
<td>Emotions</td>
<td></td>
</tr>
<tr>
<td>Defensive</td>
<td>Anger</td>
<td></td>
</tr>
<tr>
<td>Denial</td>
<td>Blinded by the Situation</td>
<td></td>
</tr>
<tr>
<td>Higher Power</td>
<td>Fear</td>
<td></td>
</tr>
<tr>
<td>Just Keep Going</td>
<td>Frustration</td>
<td></td>
</tr>
<tr>
<td>Negative Coping</td>
<td>Grateful</td>
<td></td>
</tr>
<tr>
<td>Outlet</td>
<td>Guilt</td>
<td></td>
</tr>
<tr>
<td>Personal Support System</td>
<td>Happiness</td>
<td></td>
</tr>
<tr>
<td>Positive Imagery</td>
<td>Helpless</td>
<td></td>
</tr>
<tr>
<td>Positive Talk</td>
<td>Hope</td>
<td></td>
</tr>
<tr>
<td>Professional Help</td>
<td>Dashed Hopes</td>
<td></td>
</tr>
<tr>
<td>Rationalization</td>
<td>I miss my life</td>
<td></td>
</tr>
<tr>
<td>Take Charge</td>
<td>Memory loss</td>
<td></td>
</tr>
<tr>
<td>The Negative Wish</td>
<td>Mistrust</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pride</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Resentment</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sadness</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Stressed</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Post-Traumatic Symptoms</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Under Attack</td>
<td></td>
</tr>
<tr>
<td></td>
<td>We Don’t Fit In</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Worry</td>
<td></td>
</tr>
<tr>
<td>Health Literacy</td>
<td>Parent Health</td>
<td></td>
</tr>
<tr>
<td>Misunderstanding</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parenting</td>
<td>Relationships</td>
<td></td>
</tr>
<tr>
<td>Interruptions to Parenting</td>
<td>Community</td>
<td></td>
</tr>
<tr>
<td>No Time</td>
<td>Environment</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Family</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Health Care Staff</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Partner</td>
<td></td>
</tr>
</tbody>
</table>

This process was repeated to create themes. The researcher then returned to the naïve understanding to determine if these themes were in agreement. When the thematic analysis was in disagreement, the text was reread and a new naïve understanding was created. This process
was repeated until both the naïve understanding and thematic analysis were aligned.

As Heideggerian phenomenology focuses more on understanding than description alone, these initial response categories became a stepping stone to the deeper understanding necessary to understanding being the parent of a child with HIE. The Hermeneutic circle, as espoused by Heidegger, is a process for the expression of context, or fore-structures and refers to the back and forth movement which brings the researcher from a state of partial understanding to a greater insight into the whole and refers to the interpretation of the phenomenon by both the participant and the researcher (Flood, 2010; Mackey, 2005; Vivilaki & Johnson, 2008). He viewed prior knowledge vital to insure that proper, pertinent questions are posed (McConnell-Hentry et al., 2009). It is more than mere description. Through listening, writing, re-reading, re-listening and rewriting, the researcher is able to develop a more complete understanding of the phenomenon of being the parent of a child who had HIE. This process allows the researcher to gain a salient understanding of both the varied and shared life experiences of these individuals. Ultimately six themes and a variety of respective sub-themes were identified and found to be reflective of the life experience of these parents (Table 4.14).
Table 4.14

Major Themes and Sub-themes

Unmet Expectations
- My Child is not what I Expected
- My Life is not what I Expected Because of my Child
- My/Our Delivery Experience was not what I Expected
- The Care for Myself and My Child was/is not what I Expected

The Source of My Strength
- I get my Strength from Beyond Myself
  - I get my strength from others
  - I get my strength from God
- I get my Strength from Within
  - Positive self-talk
  - Taking the bull by the horns

Life in the Negative
- The Negative Wish
- Negative Behavior
  - My own
  - Health care providers
  - Others

Outside of Reality
- Dreams and Wishes
- Blinded by the Situation
- The World is Against Me

Lemonade from Lemons
- If Only…The Desires of Parents

After theme development, the Resiliency Model of Family Stress Adjustment and Adaptation \(^{32,33}\) was used to help understand parental efforts, both conscious and subconscious, to cope with their individual situations.

The researcher then returned to the research question and preunderstandings. Reflection upon the research question, preunderstandings, and the text, allowed the investigator to achieve a deepened understanding of the text (Lindseth & Norberg, 2004). In the final phase of analysis, further interpretation of being the parent of a child with HIE was sought through the experiences of other parents in similar, albeit differing challenges with their children, as well as through the lay literature. The goal was for the researcher to gain insight into the varying “truths” about the
phenomenon.

**Theme 1: Unmet Expectations.**

Every parent interviewed expressed that some expectation(s) were not met. These primarily involved his/her child, life, delivery experience, and the health care system. The majority of these (7/9) revolved around their child, most of which addressed their child today, and some of which involved the intensive care experience.

*My child is not what I expected.*

Parents were found to make comparisons of children to another child, as well as to a parent. There were also unmet expectations based upon perceived societal norms. Despite Martin and Lisa being cognitively, psychologically, and educationally challenged, their expressions were consistent with others. Martin described his son.

Like with me, I got ADHD and I... uh [have issues with] anger management, … and [I have] bipolar and …it felt like he got all them symptoms right along with me, because I see it. If his mom leaves the room, he’ll throw a fit, I grab him, put him right here (motioning holding child up to his chest/shoulder), he cries. He’s happy one minute and he can just snap on her in the next. . . He bites her, he scratches her, he hits her… he forgets what he’s doin’… like, I put the phone down in front of him, I said “Boppy” he turned around, forgot about the phone…. when my nephew was his age …he would go back. He would go back for like if it’s like that to a pen. And he called him and he came over to us and he gave us a hug or … a handshake. He would go back to where he was goin in the first place. And I seen that.

Interestingly, Lisa was focused on the delivery and post-delivery experience and made no mention of her son, with the exception that she loves being his mother.

But at the same time when I gave birth to him and I seen him the way he was, it was like kinda upsetting because it was like he had all this tubes down his throat, and he was on the warmer, and it was like, we like couldn’t really touch him, we had to wear gloves if we wanted to touch him. It was kinda difficult, but we got through it.
Carla, a Hispanic mother in her mid-thirties with two other school-age children, looked both at her older children and society in terms of Rosa, her daughter with multiple and severe disabilities. “Is hard, she can no do like my other children. She no sit, she no stand, she no eat.” Her husband, Luis, mirrored her description. “Rosa, she no good. She no eat, she no talk, she no do anything.”

Kathy speaks of her child, itemizing some of Kristin’s challenges, “She’s so far behind…but she has seizures a lot. She’s three and she still doesn’t walk. She doesn’t talk very much. She just kind of grunts.” Melissa told of her challenges with daily care for Mary, identifying specific challenges for her “…She’s so stiff…odor emanates from the G-tube site…she whines and grunts at me. Sometimes she screams…she doesn’t move around much.”

*My life is not what I expected because of my child.*

Where most parents looked specifically at their child in terms of what his or her differences were and are, many also talked about the changes in their lives. In those parents of children with significant medical issues, life changes appeared to be prominent, specifically in terms of providing care. Kathy lamented her past, wishing that her present was back to the career she misses and loves.

I feel like an outsider, I know it’s all me, but I can’t go out…since I have to take care of Kristin…I love Kristin, I just hate her life, and I guess I hate mine too. I want my life back. I want to go back to work again…[speaking of her career in art] it’s more than just the art. It’s the history, the society, people, politics. It tells us so much if we let it…Oh yes, I miss it.

Melissa, a highly educated medical professional, described her days with Mary:

I get up at five… to get her bathed. That’s a real challenge because she’s so stiff. I…bring her in with me… I’d get wet anyway… I can hold her on the seat… as I bathe her… that way she gets really clean…after that I… get her dried and dressed. That’s a struggle. She whines and grunts … she screams. Since she doesn’t move
around much. I do chest PT. It makes her cry some, but it does help keep her lungs open. I help her stretch… then I put her into her chair and strap her in. I feel like I’m torturing her. I give her her meds and then start her feeding, so that she’s done in time to go to medical day… The bus comes at 8:30. That’s when I breathe… When she gets home I have to get her cleaned up again… She sweats a lot.

She also voiced anger and frustration as she lays her feelings on the line in terms of the changes in her life.

My marriage is on the rocks, my career is on the rocks, I resent Mary and I hate myself… I don’t feel alive anymore. I can’t stand my life; I can’t stand Mary’s. She cries, she screams. I know she’s in pain… but she can’t tell me… I think my husband is probably having an affair. Funny thing is, I don’t really care. I can’t even tell you the last time we had sex. Oh well, I don’t even want it anyway.

Carla voiced concern that people are uncomfortable attending to Rosa; whereas her husband, Luis, laments their past life and expressed concern for his wife. Carla said, “But not like when she baby. Then people hold her, love her. They don’t anymore. She no look the same. I think people afraid they hurt her by accident.”

Luis expressed his concern for Carla “She very sad. Sometime she no want get out of bed. She can no work anymore. But she get housework done, she cook, she help Juan and Maria with homework. Make me sad, she think Rosa laugh, but Rosa no laugh. She think Rosa see, but doctor say Rosa's brain no can see.” (cortically blind). “Carla no same any more. I don' know how to help. I so busy with work, Carla stuck here… She [woman in church] say should put Rosa in home. I no tell Carla. Sometime I think this be good. Would have family back to normal”

My/our delivery experience was not what I expected.

This sub-theme address delivery and peri-partum expectations. Most responses had to do with lack of contact, communication, fear, and pain. Martin describes anger. Carla and Luis, parents with two school age children, describe issues with communication, as does Nina, a married
woman with a ten-year-old daughter. These parents additionally described differences between the
deliveries of their previous children and this child. Martin described his experience:

I was only angry because I couldn’t pick him up, I couldn’t touch him. At that time that’s when they took my son outa my girlfriend. They hauled him off…we didn’t see his face, we did see his hands, we didn’t see his feet. All we seen was his hair inside a box …and she was in the operation, I don’t even think she seen him. I think only I seen him. He was hauled off in the operating room…so when they hauled him upstairs…they started I guess doin’ what they do um, checkin’ him, seein’ what’s wrong with him, puttin’ him on the two machines. And then once we got upstairs, they said we gotta cool his body off. We didn’t even get a chance to hold him.

Lisa is focused on herself, her fear and her physical pain.

That was most scary … I think they like cuttin’ your whole part. That was like scary… I was trying, and trying, and trying to push, but it didn’t work, so they said we had to do the C-section …I felt everything. It was so painful…It was like hours, literally crying and I fell asleep crying. I didn’t wake up til…they was…stitchin’ me up and the baby was already upstairs… It was painful … I really couldn’t do anything for myself… I caught an infection …Every time they gave me the medicine, you taste it… I said “Ugh.” … I had trouble gettin’ up, using the bathroom, I needed help…to me it felt like I was handicap cause I needed help for everything… when they was gonna release me I had caught a fever again…So I hadda stay there a extra day. I was upset, I wanted to go home. The bed was so uncomfortable. I was so upset; I…started cryin’ my mom had to come to the hospital and calm me down. … I wanted to go home.

Debbie stated her experience of seeing Stevie for the first time simply and succinctly before she moved on. “Well, when I finally got to see him it was awful. He was white as chalk. He had two tubes in his throat, they had IVs in his belly, a catheter in his penis.”

Communication and lack of communication remained forefront in the minds of several parents. Nina described her remembrances and her husband’s responses and thoughts during the delivery. It must be stated here that the investigator was the practitioner who conducted this resuscitation.
Juan tell me Juanita not breathe. He watch you when she born. He say you put tube in mouth. He hear you call orders to nurses. He say they take things out of cart. Another doctor come running in. He working on Juanita's belly. People calling out, counting, doing CPR. They give me oxygen. She was too far down for me to have operation. They use forceps get her out. I don' remember too much other than so much pain… I just remember doctor saying that have to get baby out, have to get baby out…Nobody talk to him [Juan] when working on baby. He think she dead.

_The care for myself and my child was/is not what I expected._

This subtheme specifically addressed issues of care from members of the health care team that did not meet parental expectations. Carla remembered, When Juan and Maria (her other children) born nurses and doctor spend time talking to me about how they doing, not now. They just come in, don't talk, just ask about my pain and bleeding, then leave. They no ask about Rosa.” Children who require complex home care are frequently asked to spend the night caring for their child in the hospital prior to discharge in order to trouble shoot areas of misunderstanding prior to being without support and to increase parental confidence in caring for their child with special health care needs. Martin’s perception of this, however, was somewhat different.

They made us stay the night at [hospital name] to find out if we could take care of him the right way. Then one of the nurse that didn’t like me (pause)… was givin’ me a hard time… like she would have this attitude… it felt like she was the one who didn’t want me with the baby…Yeah, it felt like I was being tested to see like I a bad parent or I was good parent. I felt like [hospital name] did not trust me, like some of the nurses ganged up and told them “Oh let’s see how good they do here”…they decided like as soon as we was about to leave…two weeks before that they put the jestroscopy tube in and they started teachin’ us… they started uh exercising both of us separately and at that time I was getting’ so tired of him goin’ through all these testses, x-rays, MRIs, physicals, other people touchin’ him. It made me want to snap to the point where I don’t care if they lock me up, send me to jail.

He additionally spoke of inadequate communication from the medical team both in Eddie’s early course and in follow-up.
Well the doctors hardly talk to you. The come in, they go in there, they’re tellin’ the nurses, go on the computer, and then they tell you some big words, and then go on…to the next patient… when the doctor told me my symptoms my son had, I did not understand a word he said. I had to ask a nurse.

Communication during follow-up was similarly perceived as inadequate.

They was just tellin’ me to feed him this or feed him that, um, (pause) that’s the real big problem…I stop listenin’ to them. I started feedin’ him regular food… regular milk and I told the doctor, “I’m not listenin’ to what you say cause what I did it already. Like one month, I listen to what he said, the baby was 15 pounds, the exact as what he was, so… I listened to myself, the baby was 16 pounds and some odd ounces … he asked me what did I give the baby, so I tell him what I give the baby, he was like, “oh none of this is good for the baby”…I didn’t see what he gave the baby gain weight…cause all he wanted to do was just give the baby straight Enfamil, no ingredients, no cereal, no nothing, just the milk, that’s it…

Carla and Luis voiced concerns regarding the physician’s advice to discontinue life support. Carla described Luis’s and her discussions with the physician.

Every day doctor tell Luis to take off machine…The doctor come, he say again Rosa no can breathe, need to take off machine and let her go. We say God no want. When Rosa two weeks old, doctor say still no can take out tube, Rosa no breathe, but we see Rosa breathe sometime. We say try. So doctor take out breathing tube, but Rosa no breathe. Doctor say to leave tube out, let Rosa die. We say no, God no want this. Doctor say God decide, but we stopped it. We say no. Doctor put tube back. Doctor say if Rosa’s heart stop, we should no bring her back. We say no. Doctor no talk to us no more, he say he can do nothing.

In addition to Rosa’s description, Luis added: “Doctor say brain very sick. They give medicine for brain fit (phenobarbital). They give medicine to make heart work better. They say when Rosa’s brain not seeing (seizing), brain no do nothing. They say I should take her off machine and let her die. I say I can no make such decision without Carla, but Carla no there. I say God no want this. Doctor say God no want any child suffer. I say God no want me to kill my child. He walk away then.”
Debbie described her frustration in her “lack of voice” in regards to Stevie’s abilities.

I try to explain to them [doctors/therapists] what he’s like at home, but I don’t know if they really hear me. Every time we go to [hospital name] they tell me that he’s not doing this or he’s not doing that, but I see what they ask for at home, doesn’t that count?... It’s very frustrating to try to deal with all the doctors and therapists... they seem to be in such a hurry. I just want them to understand that Stevie is completely normal…

She also addressed discussion with her obstetrician, “My doctor never talked to me. I kept asking and asking what happened and he always evaded the question.” She similarly expressed concerns about communication in the post-partum unit. “The nurses … just kind of came in, asked how I was feeling, but when I started to talk about Stevie, they didn’t stay long… I feel like I just didn’t have a voice.”

**Theme 2: My Source of Strength**

Most parents identified something or someone which was found by them to be helpful either at the beginning of their child’s course or has time has gone on. This could be a family member, God, or a professional. In addition, it was clear for some participants, the source of strength could be the participant him/herself.

*I get my strength from beyond myself.*

This subtheme addressed sources of strength to the participant other than him or herself.

*I get my strength from others.*

Martin, father of Eddie, is a young man who had a difficult youth. He provided an interview, rich with insight into not only being a parent of a child who had HIE, but also an enlightening window into the world of poverty, mental health, and cognitive challenges, which opened this investigator’s eyes. While he still faces challenges, he identifies the benefits of his therapist during this difficult time.
I talked to my therapist cause like I don’t know, my girl she was like…on this certain vibe against the baby, its like she wasn’t around the baby as much as she was supposed to, so… her mom was puttin in my head to take her to counseling to see if like she’s okay because like she could hurt the baby…me and her went… come find out…It was me, I had the problem I was the one that was gonna put the baby in danger cause I was the one that wanted to go to the hospital, take the baby, take him home and that’s what my counselor told me.

He explained to the researcher how he is able to handle his situation, “I was a juvenile. I went to [residential facility] …we were taught about our feelings, that’s why I have no problem talking about my feelings (said with pride that he can handle his anger). I talked about my feelings over there…they taught me anger management. I graduated anger management. They taught me something true.”

Eddie’s mother, Lisa, a bit more shy and “child-like” than Martin, however found herself asking for her mother. “…I was so upset; I was ready to go home. I started cryin’ my mom had to come to the hospital and calm me down…” Debbie also identified her mother as a daily source of strength. “I call my mother all the time…I cry. She’s always there for me. She reminds me to take care of myself.” Carla and Luis identified themselves as a routine source of strength to each other. Carla stated, “Luis a very good man. When he come home, children sleeping, just us. Very good…He my strength. Always there for me and children.” Luis clearly admires Carla, identifying her strength. “Doctor come over, tell us to take off machine again. Carla say God no want. Doctor say Rosa no breathe, no get better ever. Carla say ‘no’, she strong woman. She say ‘God have reason for this.’ When doctor took off breathing machine, Carla say, ‘See, I told you she get better.’” Nina, on the other hand, has a very large and supportive family who she appreciates and loves tremendously. She additionally identified the investigator, during the time she cared for Nina, as a source of strength.
During week, my mother, abuela, sisters, they come spend time with me... They take care of me. One would stay every night when Juan at work. They make sure I eat, rest, so good to me... Could not do without. Here let me show you. [She takes a large picture down from the mantle showing Juanita in her great grandmother’s arms (abuela), surrounded by numerous family members]. These people, my family are my life... I remember you say you (this investigator) worry about brain, but that babies can adapt better than adults. I hang on to that a lot, especially when Nita not eat good, when go to clinic.

I get my strength from God.

Four of the nine parents identified God as a source of support and comfort. These four parents identified themselves as Hispanic. While frustrated with a prolonged hospitalization, Martin identified God as a source of support. “…then when I look up, I look up and it’s like God just say “you gone through too much, here, I’ll throw a little hand and like God gave me his little finger.” It felt like that because it felt like I wasn’t gonna get him and then all his symptoms, all his frustrating like problems…, it was never gonna end. So, it felt like, it’s like God reached out and said, “here, I’ll help you.” However, he never identified what he believed God did.

Carla utilized God as a source of strength both when Rosa had been born and now. In concert with this, is the time spent at church drawing an element of support from their church community. Carla described her experience with Rosa’s doctor, wearing God as her armor. “We say no, God no want this. Doctor say God decide, but we stopped it… When Rosa two weeks old, doctor say still no can take out tube, Rosa no breathe, but we see Rosa breathe sometime. We say try. So doctor take out breathing tube, but Rosa no breathe. Doctor say to leave tube out, let Rosa die. We say no, God no want this. Doctor say God decide, but we stopped it. We say no. Doctor put tube back.” Luis, on the other hand, identifies God as a source of strength, but at the same time, it seems that he has his doubts.

Carla talk to priest... He call Carla every Wednesday... Carla say she feel better after. She say, God must have reason… we must care for
Rosa, love her, and God love us…I just don' know…I talk to priest, I go confession. I tell priest I think doctor right. I guilty for thinking this. He try give me strength. He tell me to keep pray to God for strength, that we are not to understand God’s will, that there is reason, but we can no understand til go to God ourself. Priest say Rosa no suffer, that she does no know enough to suffer. I say, but we suffer. Priest say must be reason for us suffer now.

While Carla and Luis speak from a platform of grief for their child and the change in their life situation, Nina, whose daughter is doing well jubilates. “We thank God every day. We go to church together. We praise God. We ask him to help babies. We ask him protect you and doctors, nurses who save Nita.”

I get my strength from within.

This subtheme addressed the parent finding a source of strength within him or herself; whether it was telling oneself words of encouragement, using a positive illusion, or choosing to take charge of a situation. Most parents found strength from themselves. The two who didn’t, interestingly, were on both ends of the spectrum. Kathy who has a daughter with severe disabilities and came across as quite depressed and in need of support; as opposed to Nina, whose daughter has the mildest of challenge, came across as the complete opposite of Kathy in terms of disposition, and has numerous family members and her faith to support her.

Positive self-talk.

Martin and Debbie, respectively give themselves words of encouragement. Martin would tell himself, “I knew like he would (pause) pull in. I knew he would pull in.” Similarly, Debbie knows that her son will catch up, “He’s going to catch up just fine.”

Carla, on the other hand uses an element of denial in regards to her daughter, Rosa. As described previously, Rosa has significant challenges. She is cortically blind; she cannot control
her secretions as she does not swallow; she has seizures and makes no voluntary movement. She
does not respond to sound, although it is unclear if she is hearing impaired. “Ola’ Rosa, my
beautiful baby (looking to me). She how she smiles and laughs when I call her name.” (I see no
change in facial expression, no smile, clearly no laugh. Carla does not touch Rosa).

*Taking the bull by the horns.*

Seven of nine participants took charge of a variety of situations: feeding, unkind behavior,
planning for the future, and supporting their child. Rosa, who had been relatively quiet, depressed
seemed to almost come to life as she told me about a woman on the street. “Most time just stare.
Some say, “poor baby.” This one lady, she say, “that poor baby should die, we all pay for her.”
She think I no hear, but I hear…I very angry. I say to her, “You want me to wish on your baby!”
She walk away fast.” Melissa was similarly pushed to the brink due to a woman staring at her
daughter. It seemed as if it happened one too many times.

You know, I cornered this one woman who just kept staring at the mall. (she’s smiling at this point) My hands were full and I was trying to manipulate the [wheel] chair …. I said, “So I guess you’re interested in my daughter.” I told her all about Mary and just watched her squirm. It was the best feeling to make her so uncomfortable. I thought to myself, “why not?”… she was obviously curious, I’ve got nothing to be ashamed of. Every time she tried to excuse herself, I told her more. I told her all about my delivery. I even told her all about the MRI, her pain, her doctor’s visits, her EEGs. I really enjoyed it. Then I said to her, the next time you stare at a disabled child, remember there’s a story behind that disability, there’s a story for the parent and then maybe instead of staring, maybe you’ll hold a door or ask if they need some help. She apologized …. I took charge of it. I actually felt more like my old self.

Martin took charge of a situation when he abandoned the prescribed feeding regimen for
his son. He believed he was doing what was in his son’s best interest and was fortunate that there
were no obvious deleterious effects on his son.
What did I do? I stop listenin’ to them. I started feedin’ him regular food…I told the doctor, “I’m not listenin to what you say cause what I did it already. Like one month, I listen to what he said, the baby was 15 pounds, the exact as what he was, so I did what I did. I listened to myself, the baby was 16 pounds and some odd ounces and…all he wanted to do was just give the baby straight Enfamil …. I did what I wanted to do. I gave him regular milk, I gave him baby food, I gave him cereal. After that he would drink the bottle. I wait two hours, I’ll give him regular food…like when we eat, he eats…but he gets the bottle at the same time… but he eats more than us so he can gain weight.

Luis and Jim want nothing more than to do the best they can for their families. Luis simply stated, “Well not all bad (voice almost sounds perky). We cut bills really good. Look, not one light on (said with sense of pride; it is noted that a large window in the front of the living room provides more than ample light) I fix refrigerator last month, no call someone to fix. I fix much here.” Jim is concerned with making sure their future is secure, not just for Stevie, but also for himself and Debbie, given their physical challenges. “We're moving in a couple of weeks; a ranch house, no steps to deal with for when it gets hard… That'll make it easier for us if we're not feeling well. Debbie doesn't get that … I had to talk her in to it… I work a lot of overtime so we can have savings for when I can't work. I guess I just want to be prepared.” His wife, Debbie is determined to help Stevie be “completely normal… I spend every waking moment with him; doing his therapy, playing with blocks. He's going to catch up just fine…So we come home and practice. Like after his last visit we came home and practiced blocks til he needed to nap.”

**Theme 3: Life in the Negative.**

This theme addressed a variety of experiences, wishes, dreams that were painful or caused an element of shame as well as actions that were potentially harmful. It also addressed negative behaviors or the perceptions of negative behaviors by others.
The negative wish.

This subtheme specifically addressed wishes of harm to the participant or the participant’s child. At times, these created feelings of shame or guilt. Luis asked for God’s forgiveness for his wish. “Sometime, I wish Rosa no live, God forgive me. Not fair to Carla, Luis or Maria… I wish doctor one night take Rosa off breathing machine and just tell us she go to God. I know that can no happen.” “She [Carla’s mother] say like doctor, she say we stop God’s will, that Rosa was to be angel. I no tell Carla, but sometime, I think so too. God no want child suffer, God no want my children suffer.”

Kathy spoke of both self-harm and harm to her daughter. “…sometime I wish someone would kill me while I’m walking alone. [name of city] can be dangerous you know. Then I wouldn’t have to worry about anything anymore.” “Sometimes I wish Kristin had just died, then I get mad at myself. Don’t get me wrong, I would never act on that wish…I do sometimes wish that Kristin would just not wake up someday. I could have my life again.”

Melissa wishes that things had been different in the beginning. “Sometimes I think it would have been better if they hadn’t cooled her. She probably would have died. I wasn’t okay with that then. I wanted to do everything, but now” … (voice trails off).

Negative behavior.

This subtheme addressed specific behaviors of the participants. It also looked at negative behaviors and the perceptions of the negative behaviors by health care providers and others.

My own.

Both Kathy and Melissa used alcohol to numb themselves a bit. Kathy stated, “If it’s in the evening, I’ll go out for a drink (pause) or three, just to forget for a while.” Melissa however, drank daily. “You know I told myself I wouldn’t do this today (Investigator: Do what?) Drink.
(Investigator: Ah, do you drink every day?) Don’t get me wrong, I’m not an alcoholic. I just have two or three glasses after I put Mary down and one or two in the afternoon if I’m off.”

*Health care providers.*

All issues reported that had to do with health care providers had to do with communication, lack of communication or inadequate communication. Martin reported multiple issues with nursing. In referring to staying the night prior to discharge, he said, “Yeah, it felt like I was being tested to see like I a bad parent or I was a good parent. I felt like [hospital name] did not trust me, like some of the nurses ganged up and told them ‘On let’s see how good they do here.’” While he didn’t cite an additional specific issue with nursing, he also said, “… but some of them like other nurses was kinda ticked off, like it was real easy for them to tick.” In reference to physicians, he complained, “…They come in, they go in there, they’re tellin’ the nurses, go on the computer and then they tell you some big words and then go on to the next…when the doctor told me my symptoms my son had, I did not understand a word he said. I had to aks a nurse.”

Carla and Luis both addressed a shut down in communication with the physician(s) and nurses caring for Rosa. Carla said, “Doctor say if Rosa’s heart stop, we should no bring her back. We say no. Doctor no talk to us no more, he say he can do nothing…so they put tube in stomach so Rosa can eat. Doctor no talk to us more, nurses no talk to us, just tell us how to feed and take care of tube.” In reference to discontinuation of life support Luis reported “I say God no want this. Doctor say God no want any child suffer. I say God no want me to kill my child. He walk away then.” He also discussed Carla’s fear of the aide who helps care for Rosa.

She afraid of aide. She say aide blame her for Rosa. She afraid to go out... She afraid aide do something to Rosa. No reason for her to feel that way. She say aide like doctor, she say aide think Rosa be better dead. She say aide not nice to her. She say one time aide no
suction Rosa and Rosa choke. She hear on baby monitor went up and aide not there. Aide say she in bathroom. But Carla no forgive. She call agency, that aide never come back, but she afraid the same.

Debbie and Carla both voiced concerns regarding lack of communication during the postpartum period. Carla reported, “When Juan and Maria (her other children) born nurses and doctor spend time talking to me about how they doing, not now. They just come in, don't talk, just ask about my pain and bleeding, then leave. They no ask about Rosa.” Debbie mirrored these comments, “My doctor never talked to me. I kept asking and asking what happened and he always evaded the question. The nurses in labor and delivery were very nice to me, but the nurses on the … floor just kind of came in, asked how I was feeling, but when I started to talk about Stevie, they didn’t stay long.”

Others.

Random comments by strangers and others were viewed as emotionally painful by some participants. Carla stated, “People mean: doctors, nurses, people on street, like they mad at me…Most time just stare. Some say, ‘poor baby.’ This one lady she say, ‘that poor baby should die, we all pay for her.’” Kathy reported “It’s been a challenge. People tend to be rude and ignorant… My own mother says I was cursed [with a child who has a disability] because I am gay, let alone wanted to have a child.”

Theme 4: Outside of Reality.

This theme addressed dreams, daydreams, wishes, denial, feelings of being overwhelmed as well as the voices of two participants who expressed elements consistent with paranoia. Three subthemes included: “Dreams and wishes;” “blinded by the situation;” and “the world is against me.”
Dreams and wishes.

This subtheme addressed actual dreams as well as daydreams and wishes. Martin and Kathy discussed true dreams/nightmares regarding their children. Martin: “I had a dream where I lost him. She [Lisa] was cryin’, my mom was cryin’, everybody was just cryin’ around him and then I was just sittin’ there like (pause) not carin’. In my dream I was just not carin’ that he’s gone… Like, I walked away from [hospital], I walked away from her, I walked away from everybody. I was isolated, everything.” Kathy’s nightmare takes a more abstract turn “It’s the same thing all the time. Everything is fine, the rush me in for the section and instead of a baby, they hand me this monster, then I turn into a bigger monster. They put me in jail and people start stoning me.”

Debbie and Nina both spoke of the immediate post-partum period. Debbie described, “I really didn’t feel like I had a baby at that point…I don’t know, kind of like I was having a bad dream, that someone had taken my baby away.” In a sense, this was true. Nina referred to fear, “Doctor come talk very fast. We so scared. It feel like a bad dream.”

Blinded by the situation.

This subtheme addressed denial, and self-admitted lack of recognition. In introducing me to her daughter, Carla stated, “See how she smiles and laughs when I call her name.” The investigator noted no change in facial expression, no laugh, no smile. Luis refers to his wife’s belief in Rosa’s abilities; “Make me sad, she think Rosa laugh, but Rosa no laugh. She think Rosa see, but doctor say Rosa’s brain can no see.” Kathy admits (in response to the investigator’s observation of her support system) “Maybe I’m just so in the middle of things I don’t see that. I don’t know.”
The world is against me.

Two participants, one with self-admitted mental health issues and the other with apparent depression expressed paranoia or feelings of persecution. Kathy was frustrated with the level of support she could receive for her daughter. “Sometimes I think that I can’t get more because I’m gay, that for some people, I deserve this. It was bad enough when I was just gay, now I’m gay with a disabled child.” Martin stated:

One slow mistake and everybody’s attacking us… once he got home, it was like everything was startin’ to crawl back up, appointments back and forth, um welfare, social security, money, it was like all this stuff just attacking me at one point….because welfare told me that the baby don’t gain weight cause the welfare finds out so if the baby’s not gainin’ weight then the WIC is gonna tell welfare. Welfare’ll tell DYFS [Department of Youth and Family Services]. DYFS is gonna come, take my son or [hospital name] is gonna come take my son. Somebody’s gonna come and take him just because he’s underweight… I don’t know. It was like it felt like at that time that [hospital name] was just tryin’ to just tryin’ to like get people for their kids.

Theme 5: Lemonade from Lemons.

Most participants did not identify positive themes. Two parents exhibit true signs of bon-adaptation, while a third is working toward it. Luis identifies how positively he has now been able to cut bills. “Well, not all bad (voice perky) we cut bills really good. Look not one light on. I fix refrigerator last month, no call someone to fix. I fix much here.” Nina is truly trying to give back to society at this point. “I tell priest that if something happen somebody’s baby, I help however I can. I help mother, Juan help father. We try give back. I take Nita with me, tell other mother how sick she was, give hope.” Debbie wants to work to have her voice heard, “Sometimes I think about writing a book about the experience, so that maybe somebody will hear me.”
The interview process itself was identified by two parents as being currently beneficial. Toward the end of the interview, Melissa stated, “I feel pretty good right now, more energized than I’ve felt in a long time. You know I almost canceled on you.” When the investigator told Melissa that she was glad that she didn’t cancel, Melissa replied, “Me too.” Luis also identified an improvement, “In three years I no tell people what I tell you today. Is good, I have energy go back and do more.”

**Theme 6: If Only…: The Desires of Parents.**

With every interview, a natural question after hearing things that weren’t as optimal as desired was “What can we do better for parents like yourself?” This question grew from “Do you have any questions I can help you with?” This was only asked if dictated by the preceding portion of the interview and based on the principles of Heideggerian phenomenology. Martin voiced his thoughts in terms of preventing problems,

I think like what y’all should do is like when parents come and then [it’s their] first child, I think like y’all should just, like try to have like respect, but like don’t show ‘em too much happiness. If it’s your like first child and you’re in the NICU, nine outa ten those are a couple things that lead to suicidals…I don’t know, like when people first have they children and they get sent to the NICU, try to like be emotional, give advice, like not just, not just sit there and then walk away…Like some parents need somebody to talk to…They need guidance, like they need like conversation, they don’t just need “Hi, how ya doin”? Good morning. It’s a beautiful day.” No, they need like, like my son he has this, like what can we do like to make him feel better? Or is there anything we can do? Like, those are questions I wanted answers to, but none of ‘em could’ve answered to it.

Carla simply stated, “Be nice, talk, ask what can do. Don’t tell what to do.” Luis provided a little more insight. “I think people should listen and ask more, like you, not just tell what to do. In three years I no tell people what I tell you today. Is good, I have energy go back and do more.” Kathy desired society change, “… be more accepting of different kinds of people,
different religions, sexual differences, different abilities. Do other people say this?” As a physician, Melissa had some very specific recommendations.

Have more nurse practitioners like yourself for kids as sick as Mary…it was really easy for me to see the difference in the care and the communication. We really didn't talk to the attending very much, but it didn't matter. I think it would be good for a resident to work alongside the practitioner to learn about this complex care. I think the residents should see them in follow-up along with the practitioner. The most important thing would be for residents to sit with practitioners when they speak with families, they would learn so much. I took lessons from the way they spoke with me back to my own patients.

Jim also voiced a specific request, “I know that there aren't many parents like me, but I think it would be a good idea to have a support group organized maybe at the follow-up clinic, so we can see what other parents are doing. I've looked for one, found some on line stuff, but it wasn't very good.” Nina offered thoughts for both the delivery room and intensive care experiences.

I think the worst was when Nita born. I so scared, nobody talk to me, just to each other. Juan could no understand, I too scared. Juan try to help me, but not good enough… Juan very scared. Nobody talk to him when working on baby. He think she dead. He say she looked dead. He no tell me this til after Nita home. (Investigator: … you're saying it would help to have someone to explain things to you while things were going on?) Nina: Oh yes!

Like Melissa, she offered a suggestion for nurse practitioners. “I think you need to teach other doctors how to talk to parents. When I watch that family next to us, it seem nobody talk to them, like you talk to us. You help us very much.”

4.4.4 Summary of Qualitative Findings

A long-awaited child is about to be born. Parental hopes and dreams abound. Then, the unthinkable happens. The anticipated joyous occasion is marred by the birth of an infant who
has HIE. The birth experience, post-partum experience, hospital and post-hospital courses are not without their effect on the parents.

The qualitative strand of this study uncovered six major themes. Unmet Expectations addressed issues from the peri-partum period to present day and addressed issues such as the rush into an emergency cesarean section, watching their own child’s resuscitation, the neonatal intensive care unit, nursing and medical communication, missed milestones and life changes. The Source of My Strength revealed support systems from family to God to one’s own self. It further addressed a show of strength to negative experiences. Life in the Negative addressed negative behavior from a variety of sources, including the participant, health care providers, strangers. It also addressed wishes for harm to their child or themselves, which was often met with resultant feelings of guilt or shame. Outside of Reality addressed actual dreams and nightmares as well as feelings of the lived experience not being real. It also revealed cases of viewing one’s child as having greater abilities than actually existed. These first four themes revealed issues in the day to day lives of these parents that have been considered to be challenging or difficult. The fifth theme, Lemonade from Lemons uncovered positive adaptations to an otherwise negative experience. It revealed instances of bon adaptation, such as giving back to the community. The final theme, If Only… The Desires of Parents delineated what parents would like to have been different in their experience and what they would like to see changed in the future.

A child is born, the nightmare begins. Emergencies, resuscitations, separation, unkind words, developmental challenges, physical disabilities, the loss of oneself. Whether a positive or negative outcome, parents cannot help but be changed.
4.5 Mixed Methods Analysis

Quantitative data and qualitative data were collected concurrently. In accord with mixed methods convergent design, the qualitative data was analyzed independently and prior to the analysis of the quantitative data. Once these data sets were analyzed, the results from the two methods were explored (Bazeley, 2009; Bekhet & Zauszniewski, 2012; Casey & Murphy, 2009; Creswell & Plano-Clark, 2011). All participants within the qualitative strand completed the same surveys as in the quantitative strand. This allowed for a one to one comparison of the data obtained from the surveys from all participants and allowed for a rudimentary evaluation of the similarity of participants within the qualitative strand to the overall sample. The initial exploration included rereading the interviews with quantitative surveys and findings in mind. Qualitative data was recoded with the subjects of the quantitative strand: Impacts on self, spouse/partner, siblings, family; stress; depression; and coping were derived from the individual questions on each survey for the quantitative data. The researcher quantified some of the qualitative data, as recommended by Creswell and Plano Clark (2011) by tallying statements consistent with impact, stress, depression, and coping based on statements consistent with those parameters. These data were then analyzed using SPSS 20. The density of statements consistent with depression, impact of the child’s neurologic disability, stress, and problem and emotion-focused coping were tabulated. In addition, the quantitative scores of the sample as a whole were compared with the quantitative scores of those participants who also participated in the qualitative strand of the study. This allowed for comparison of the two sets of participants and revealed areas of both convergence and divergence (Table 4.15).
### Table 4.15

**Summary Table of Interview and Survey Data**

<table>
<thead>
<tr>
<th>Survey Subject</th>
<th>Quantitative Survey Results</th>
<th>Applicable Qualitative Subject Matter/Themes</th>
<th>Qualitative Survey Results</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stress</strong></td>
<td></td>
<td>Unmet Expectations</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Range Total Stress: 77-144</td>
<td>Feeling under attack by health care</td>
<td>Range Total Stress: 53-150</td>
</tr>
<tr>
<td></td>
<td>Mean Total Stress: 116.95</td>
<td>Delivery Experience</td>
<td>Mean Total Stress: 99.8</td>
</tr>
<tr>
<td></td>
<td>Mean Percentile: 99</td>
<td>Child not meeting expectations</td>
<td>Mean Percentile: 77</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Life in the Negative</td>
<td>Density: 66 Statements</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Life changes/relationship issues</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Negative Behavior (health care providers</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>and others</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Feelings of helplessness</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Concern/worry over partner</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Finances</td>
<td></td>
</tr>
<tr>
<td><strong>Impact</strong></td>
<td>Range of Total Impact: 0-94</td>
<td>Unmet Expectations</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean Total Impact: 39.86</td>
<td>Limitation of family activities</td>
<td>Range of Total Impact: 0-37</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Loss of freedom due to child’s needs</td>
<td>Mean Total Impact: 13.38</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lack of fairness to spouse/other children</td>
<td>Density: 14 statements</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Loss of previous life/life style</td>
<td></td>
</tr>
<tr>
<td><strong>Depression</strong></td>
<td>Range PHQ: 0-6</td>
<td>Unmet Expectations</td>
<td>Range PHQ: 0-6</td>
</tr>
<tr>
<td></td>
<td>Mean PHQ: 2.33</td>
<td>Related to child’s neurologic outcome</td>
<td>Mean PHQ: 2.11</td>
</tr>
<tr>
<td></td>
<td>Percent Depression: 42.9</td>
<td>Life in the Negative</td>
<td>Percent Depression: 44.4</td>
</tr>
<tr>
<td></td>
<td>Major Depression: 12.2</td>
<td>Hatred of child’s life and own life</td>
<td>Major Depression: 11.1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Wanting to die/wanting child to die</td>
<td>Density: 16 statements</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lack of romantic interest</td>
<td></td>
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</table>
Table 4.15 (contd.)

**Summary Table of Interview and Survey Data**

<table>
<thead>
<tr>
<th>Survey Subject</th>
<th>Quantitative Survey Results</th>
<th>Applicable Qualitative Subject Matter/Themes</th>
<th>Qualitative Survey Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coping</td>
<td></td>
<td>The Source of My Strength: From Within</td>
<td></td>
</tr>
<tr>
<td>Problem Focused</td>
<td>Range: 0-1.98</td>
<td>Just keep going</td>
<td>Range: .79-1.71</td>
</tr>
<tr>
<td></td>
<td>Mean: 1.10</td>
<td>Preparing for future</td>
<td>Mean: 1.04</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Taking charge of finances</td>
<td>Density: 22 statements</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Taking charge of situation</td>
<td></td>
</tr>
<tr>
<td>Coping</td>
<td>Emotion Focused</td>
<td>The Source of My Strength: From Without</td>
<td></td>
</tr>
<tr>
<td>Emotion Focused</td>
<td>Range: .54-1.73</td>
<td>Alcohol</td>
<td>Range: .79-1.73</td>
</tr>
<tr>
<td></td>
<td>Mean: 1.04</td>
<td>God</td>
<td>Mean: 1.13</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Counseling</td>
<td>Density: 29 statements</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Emotionally addressing behavior</td>
<td></td>
</tr>
</tbody>
</table>
Stress was a significant issue within both strands of the study. Qualitative participants made between three and fourteen statements of stress during their interviews. Spearman’s rho revealed that total stress scores were well correlated with the number of statements of stress, \( r_s = -0.04, n = 9, p = .915 \). Total stress scores for in-person participants ranged between 53 and 150, whereas in quantitative participants scores ranged between 77 and 144. A Wilcoxon Signed Ranks Test was completed revealing a significant difference between in-person and on-line total stress scores as reported on the PSI-SF, \( z = -1.94, p = .048 \) with a small to moderate effect size \( (r = .29) \). Despite the fact that the statements of stress and stress scores for in-person participants were well-correlated, when the Mann-Whitney U was conducted, it was found that there was a significant difference between the scores of qualitative versus quantitative participants with quantitative participants \( (Md = 115, n = 38) \) exhibiting significantly higher stress scores than participants who were also qualitative participants \( (Md = 100, n = 9) \), \( U = 87.00, z = -2.72, p = .023, r = .16 \). Both the mean and stress scores within the quantitative strand were higher and within the range of what was considered to be high stress (Abidin, 2012). However, it is noted that two participants from the qualitative strand scored greater than the 99\(^{th}\) percentile for stress. Both of these parents described their children as having severe disabilities.

Qualitatively, stress issues identified during the interviews surrounded both the initial hospitalization and present-day child-related issues; as well as finances, life changes, feelings of helplessness, worry or concern over the participant’s spouse as well as issues related to the health care system, as seen in Table 4.15, above. Differences between the qualitative and quantitative participants are most likely secondary to sampling differences. Qualitative participants were selected by convenience, whereas participants who only completed on-line quantitative surveys were self-selected. It is possible that self-selected individuals may experience more parenting
stress. For example, participant number 9 (qualitative) exhibited a very low stress score, it is possible that she may not have chosen to participate in an on-line survey. In addition, qualitative participants may have exhibited lower stress scores due to their participation in the qualitative interviews with the investigator prior to completing the quantitative surveys, which may have provided a somewhat therapeutic effect and may have skewed the quantitative results.

The impact of neurologic disability was over two times greater in the quantitative strand than within the qualitative strand. Qualitative participants made between zero and six statements of their children’s impact on either the child, the parent, the spouse, the siblings, life activities, or the families’ life styles. Likely secondary to the same sampling and procedural issues as with parenting stress, the scores for purely quantitative participants were significantly higher than qualitative. This was revealed when the Mann-Whitney U was conducted; qualitative (Md = 9.50, n = 9) and quantitative participants (Md = 43.50, n = 50), U = 52.50, z = -3.058, p = .002, r = .433, for a medium – large effect size. This significant difference may be not only related to sampling issues, but also to the scale itself. It was anecdotally noted that four of the nine participants in the qualitative strand of this study asked questions in regards to the ICNDS due to a lack of understanding of the survey. This may have been due to an element of cognitive challenge as in participants one and two, or a lack of complete fluency in English in participants five and six, despite being able to read and converse in English. It is also interesting to note that there was no obvious correlation between the total impact scores, with the exception of the three participants who had an impact score of zero, one of whom made only three statements, which reflected the impact on that individual. The qualitative respondent who had the highest impact score of 37, made only two statements regarding the impact on herself. The participant who
made the most statements of impact, four concerning his family and one concerning his spouse had an impact score of 15.

During the quantitative analysis, it was found that neurophysiologic disabilities held greater impact for participants than epilepsy, cognition, and behavior. When analyses, using the Mann-Whitney U were conducted based upon participant type, both cognition and neurophysiologic disabilities were found to be significantly different. On-line participants scored significantly higher (Md = 12.00, n = 39) than qualitative participants (Md = .00, n = 8) in terms of the impact of cognitive challenges U = 31.50, z = -3.606, p = .000, r = .259 for a small to medium effect size. Neurophysiologic challenges were also significantly higher in the on-line participants (Md = 17.00, n = 39) than in qualitative participants (Md = 8.00, n = 8,) U = 82.00, z = -2.099, p = .036, r = .306 for a medium effect size. This difference likely is representative of a difference in participants based upon self-selection as opposed to convenience sampling and is consistent with the differences in the PSI-SF which similarly revealed greater stress in on-line participants. Statements consistent with impact of neurophysiologic disabilities and cognitive challenges included, “Try to get help when you stay in the building like four or five hours. It’s crazy,” “Is too hard to do with Rosa,” “Is very hard for my Carla. She here all the time. She no go out too much. Just church and doctor. She very sad. Sometime she no want get out of bed. She can no work anymore.” It is noted that no comments were made regarding the impact of any challenges upon the child, himself.

Depression rates were higher than national averages in both groups with participants within the qualitative strand having scores consistent with depression in 44.4%. This is consistent with the on-line sample who had scores consistent with depression in 40% of participants. In order to test the accuracy of this statement, a Mann-Whitney U test revealed no
significant difference in the depression levels of qualitative participants (Md = 1.00, n = 9) and on-line participants (Md = 2.00, n = 42), U = 189.00, z = -.468, p = 1.00, r = .00. Major depression was present in one individual who participated in the qualitative strand, while six participants in the on-line survey, had scores consistent with major depression. Statements consistent with depression included wishes of self-harm or death for the child, loss of romantic interest, woe over the child’s neurologic status and statements of hatred of life. These findings indicate that the PHQ-2 is a keen and useful measure of depression for this cohort and that depression is an issue of great importance for these families.

Coping was evaluated in terms of the use of problem- and emotion-focused coping mechanisms. There was no significant difference in the use of either emotion or problem-focused coping mechanisms between qualitative participants and on-line participants. The Mann-Whitney U was used to compare emotion-focused coping techniques on surveys completed by both qualitative (Md = 1.024, n = 9) and on-line participants (Md = 1.070, n = 40), U = 154.00, z = -.671, p = .502. Problem-focused techniques were similarly evaluated with qualitative (Md = 1.052, n = 9) and on-line participants (Md = 1.095, n = 40), U = 161.00, z = -.491, p = .624.

Statements consistent with the use of emotion-focused mechanisms included references to God, support from family and friends, emotional outbursts and the use of alcohol. Survey questions in relationship to each of these specific mechanisms were few, therefore, it is deemed difficult to draw any conclusions regarding these specific emotion or problem-focused strategies. Statements consistent with the use of problem-focused mechanisms included continuing on, planning for the future and taking charge of both personal situations and finances.

With this in mind, areas of convergence included stress, depression and coping. The highest degrees of convergence occurred in terms of depression. The areas with the most
significant divergence were impact of neurologic disability, impact of cognitive challenges, and stress. These findings indicate two primary study related issues. The first is a sampling issue, already alluded to, in which it would appear that self-selection for on-line participants yielded participants who may be more greatly affected by issues of parenting a child who had HIE. The second is that issues that were brought to light on surveys were not always discussed during open ended interviews.

In addition, multiple statements were made by participants in the qualitative strand that were not covered by the questions within the quantitative strand. These covered six primary areas. The first was Health care communication problems. Four parents made a total of 11 statements of communication difficulties. One parent made six statements. That individual was cognitively, psychologically and socio-economically challenged. Problems voiced related to both the initial hospitalization and during follow-up and could be drawn back to his lack of understanding and presumably the lack of adequate communication to ensure understanding. One parent of a neurologically devastated child, made three statements which addressed the initial hospitalization only. These issues related to the physician’s request to discontinue life support and the parent’s perception that he did not respect their religious preferences in this matter. The spouse of this parent made one similar statement. The fourth parent addressed current communication issues which involved her dissatisfaction with the medical team and their description of her child as having a mild disability as opposed to her description of no disability.

Communication problems with individuals other than health care providers included current issues with a grandmother, work colleagues, strangers and prejudice within society at large. There were three comments in regard to positive communication experiences. Two of these addressed advanced practice nurses. One recommended that advanced practice nurses
teach communication skills to resident physicians. One stated great appreciation for words of hope and efforts to communicate with her husband, who could not speak English. The other positive statement was from a father who appreciated his landlord for decreasing his rent since he was a good tenant.

Four participants made 13 statements that reflected anger and frustration, fear for their children’s lives and guilt. Concern regarding the participants’ partners was voiced. Two participants expressed five statements which reflected concern for their partner’s well-being while the third expressed concern that her spouse was avoiding the situation. Three participants expressed pride in ability to cut costs, that his son has never done without necessities, and that her son was over eight pounds.

The next step in this analysis process was to look at the delineated qualitative themes in terms of the quantitative data. In order to do this, each individual question from the PSI-SF and the WCQ was looked at in terms of that question’s fit with the themes.

The first theme addressed was Unmet Expectations and was addressed by 12 questions within the PSI-SF that addressed the child not meeting parental expectations. Scores could range from 12 to 60, with higher scores indicating greater parenting stress related to unmet expectations. Scores ranged from 15 – 54, with a mean of 41.29, indicating that unmet expectations in regard to the child were relatively high. Unmet expectations were then evaluated in conjunction with the PPDD by means of the Kruskal-Wallis Test. While not statistically significant, it appeared that parents who perceived their children to have severe disabilities identified more frequently with statements of unmet expectations in terms of their child, (n = 48, \( \chi^2 = 3.982, \) df 3, \( p = .263 \)). Qualitatively, this was exemplified by Melissa, who exhibited a score
of 54, has a daughter who she perceives as being severely disabled and lamented at length over the challenges of getting her daughter ready for the day and the life changes she has had to make.

The second major theme addressed was entitled, The Source of My Strength. This theme was able to be linked with the WCQ. It was possible to evaluate the relationship between the sub-themes as delineated in the qualitative strand. “I get my strength from within” included “Taking the bull by the horns” or taking charge of a situation and was addressed by 11 questions in the WCQ where scores ranged from zero to three with a possible high score of 33, with higher scores indicating more frequent usage of these coping mechanisms. Actual scores ranged from zero to 24, with a mean of 13.86, indicating that this mechanism was used some of the time. A review of the data revealed that all but one of the respondents affirmed that they used this mechanism at least some of the time. When these scores were evaluated along with the PPDD, by means of the Kruskal-Wallis test, it was found that parents of children who were perceived to have severe disabilities identified with questions which indicated that they took charge of situations more frequently, (n = 49, $\chi^2 = 8.200$, df 3, p = .042). Qualitatively, this was exemplified by Debbie who “practiced” blocks with her son, rather than played.

The other source of strength identified as being from within included finding strength from within one’s self. At times that activity took an unrealistic turn, as when Carla tells herself that her daughter smiles and laughs. This positive illusion provided a needed image that allowed Carla to cope as well as she could. Other times, parents would give themselves words of encouragement, as when Michael told himself that he knew his son would “pull in.” Thirteen questions from the WCQ were reflective of finding strength within one’s self. The range of potential scores was zero to 39. In this sample scores ranged from 4 to 26 with a mean of 13.88, indicating that these methods were used by all of the respondents at least some of the time. A
Kruskal-Wallis test revealed that there was no relationship between the use of this mechanism and the PPDD, (n = 49, $\chi^2 = .406$, df 3, p = .939). This may indicate that strength from within one’s self may be a pre-existing character trait, for example, if one was raised in a home of faith, it is familiar to the individual and may therefore be called upon in times of need. If one was raised in a home where they were taught to look on the positive side, similar mechanisms may be used. According to Garungaard, Andersen and Skov (2011), some parents may create positive illusions. In this situation, parents perpetually formulated and maintained their ability to tap into their supports by means of cognitive appraisal. This may be envisioned as finding the silver lining and is referred to as “resource-creation” and is exemplified by Carla’s ability to see Rosa as smiling or laughing.

Another source of strength or coping was escapism. This could include sleep, alcohol, drugs or other methods used to avoid the problem. Thirteen questions on the WCQ addressed escapism in various forms, including primarily sleep, but also with 2 questions addressing substance use. Potential scores ranged from zero to 39, while actual scores ranged from 4 to 26, with a mean of 13.88, indicating that this method was used by all respondents some of the time. However, with a paucity of questions addressing substance use, it is suspected that no specific statements may be made as to actual use of this method of escapism. As with some of the quantitative testing, parents who described their children as having moderate disabilities used this particular coping mechanism more than others. While not statistically significant, there was a tendency toward significance (n = 49, $\chi^2 = 6.518$, df 3, p = .089). See Table 4.16.
Table 4.16

<table>
<thead>
<tr>
<th>PPDD</th>
<th>N</th>
<th>Mean Rank of Escapism</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>16</td>
<td>23.75</td>
</tr>
<tr>
<td>Mild</td>
<td>17</td>
<td>27.00</td>
</tr>
<tr>
<td>Moderate</td>
<td>9</td>
<td>33.04</td>
</tr>
<tr>
<td>Severe</td>
<td>4</td>
<td>28.38</td>
</tr>
</tbody>
</table>

Sources of strength were also identified as coming from God and coming from others. God as a source of strength was addressed by only two questions on the WCQ. Therefore, possible scores ranged from zero to six and was equal to the range of scores. Twenty-one of 49 participants had scores of zero. For those who did identify God as a source of strength, n = 28 with a mean score of 3.18 indicating that for those who identified God as a source of strength, His use as a coping mechanism was used a moderate amount of time. When evaluating the use of God as a coping mechanism based on the PPDD, it was found that individuals who identified their children as having severe disabilities used God as a coping mechanism more frequently than others (Table 4.17). However, the Kruskall Wallis test revealed that this use was not statistically significant (n = 49, $\chi^2 = 2.923$, df 3, p = .404).

Table 4.17

<table>
<thead>
<tr>
<th>PPDD</th>
<th>N</th>
<th>Mean Rank of Escapism</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>16</td>
<td>23.88</td>
</tr>
<tr>
<td>Mild</td>
<td>17</td>
<td>21.91</td>
</tr>
<tr>
<td>Moderate</td>
<td>9</td>
<td>28.38</td>
</tr>
<tr>
<td>Severe</td>
<td>4</td>
<td>32.50</td>
</tr>
</tbody>
</table>

The aid and assistance of others as a source of support has long been identified. Participants identified family members, friends, therapists and a health care provider as a source of support. The coping questionnaire contained four questions which addressed other individuals as sources of support. Scores could range from zero to twelve, with a scored range of one to nine.
with a mean of 5.43, indicating that when this mechanism of support was used, it was used with moderate frequency. There was no relationship between the use of other people as a support system with the PPDD.

Life in the negative addressed a variety of experiences, wishes, dreams that were painful or caused an element of shame as well as actions that were potentially harmful. It also addressed negative behaviors or the perceptions of negative behaviors by others. It was exemplified when Luis spoke of wishing that his daughter had died, when Kathy spoke of her dream of both she and her daughter being monsters and when Carla and Melissa spoke of unkind comments made by strangers. There were 22 questions on the stress survey and two on the coping questionnaire which were related to this theme. Possible scores for these questions could range from 22 – 116. Scores for 48 participants ranged from 30 to 95 with a mean of 64.1, indicating that most participants experienced a moderate amount of stress and spent energy coping with negative experiences. The Kruskal-Wallis test further revealed that the degree of stress and coping with negative experiences was positively correlated with the PPDD (n = 48, $\chi^2 = 9.596$, df 3, p = .022). See Table 4.18.

<table>
<thead>
<tr>
<th>PPDD</th>
<th>N</th>
<th>Mean Rank of Escapism</th>
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</thead>
<tbody>
<tr>
<td>None</td>
<td>16</td>
<td>17.53</td>
</tr>
<tr>
<td>Mild</td>
<td>17</td>
<td>23.75</td>
</tr>
<tr>
<td>Moderate</td>
<td>11</td>
<td>31.50</td>
</tr>
<tr>
<td>Severe</td>
<td>4</td>
<td>36.25</td>
</tr>
</tbody>
</table>

The qualitative theme, “Lemonade from lemons” referred to participant statements of positivity in terms of life experiences, how they were coping or a positive benefit of an experience. This could be identified with five questions from the WCQ. Total scores could range from zero to 15. The 49 participants scored between zero and nine with a mean score of
3.78 and a median of 4.00, indicating that participants tended to use some type of positivity some of the time. It may be noted that only three participants did not identify the use of positivity in any way for coping. However, the Kruskal-Wallis test revealed that there was no correlation between the PPDD and the use of positivity (n = 49, χ² = 2.88, df 3, p = .578).

“Outside of reality” addressed dreams, fantasies and thoughts that were not otherwise grounded in fact. This was addressed by only two questions on the WCQ, thus scores could range from zero to six. Scores ranged from zero to six with a mean of 3.63 and a median of 4.00, indicating that participants did tend to use some element of a leave from reality in coping with life situations. It is noted that six of 49 (12.2%) of participants did not report the use of any mechanism outside of reality in coping with life situations. Coping mechanisms outside of reality were then evaluated in terms of the PPDD. While not statistically significant by means of the Kruskal Wallis test (n = 49, χ² = 6.10, df 3, p = .107,) parents of children who had moderate disabilities demonstrated greater use of coping mechanisms outside of reality (Table 4.19).

<table>
<thead>
<tr>
<th>PPDD</th>
<th>N</th>
<th>Mean Rank Outside of Reality</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>14</td>
<td>22.04</td>
</tr>
<tr>
<td>Mild</td>
<td>17</td>
<td>20.38</td>
</tr>
<tr>
<td>Moderate</td>
<td>12</td>
<td>32.13</td>
</tr>
<tr>
<td>Severe</td>
<td>4</td>
<td>21.88</td>
</tr>
</tbody>
</table>

4.5.1 Summary of Mixed-Methods Findings

Mixed-Methods analysis was conducted in three phases. The first looked at the quantitative data then linked it with qualititative statements. The second phase looked at qualitative themes, linking those themes with quantitative findings based upon the individual questions within each survey. Finally, areas of convergence and divergence were sought and
qualitative statements and themes which were not covered within the quantitative strand were identified.

The quantitative strand evaluated stress, depression, coping and the impact of having a child with a neurologic disability. The stress scores of parents who participated in the qualitative strand were compared with the stress scores of on-line participants. While the stress scores were somewhat lower in those participants who completed the interview, this difference was not statistically significant with both groups exhibiting high levels of parenting stress. Qualitatively issues of stress shared with the investigator during the interviews included issues surrounding the delivery experience, feeling under attack by health care, finances, life changes and relationship issues, feelings of helplessness, concern or worry over one’s partner and a child not meeting parental expectations.

Depression rates were higher than national averages in both groups with participants within the qualitative strand having scores consistent with depression in 44.4%. This is consistent with the overall sample who had scores consistent with depression in 43% and the scores of on-line participants who had scores consistent with depression in 40%. Qualitatively, statements consistent with depression were related to the child’s neurologic outcome, lack of romantic interest, wanting to die or wishing that his or her child either had died or would die.

The impact of neurologic disability was significantly greater in on-line participants than within the qualitative participants. Qualitatively, issues brought up within this category included limitation in activities, loss of freedom, lack of fairness to family and loss of previous life/life style including career changes.

As all participants used some method to deal with stress, coping was evaluated based upon the vocalization or the identification of the use of problem or emotion focused techniques
on the WCQ. There was no significant difference in the use of either emotion or problem-focused coping mechanisms between the two groups. Statements consistent with the use of emotion-focused mechanisms included references to God, support from family and friends, emotional outbursts and the use of alcohol. Statements consistent with the use of problem-focused mechanisms included continuing on, planning for the future and taking charge of both personal situations and finances.

The second phase of analysis involved evaluation of the qualitative themes based upon questions in the quantitative surveys. The first theme evaluated was “Unmet expectations.” It was found that unmet expectations in regard to the child were relatively high. While not statistically significant, the ranks indicated that parents who perceived their children to have severe disabilities identified more frequently with statements of unmet expectations in terms of their child. Parents voiced other unmet expectations, which were not evaluated in the surveys, such as care during the labor and post-partum periods, as well as unexpected life changes.

The second theme was entitled, “The Source of My Strength,” which was then broken down into sub-themes based upon both the source and the type of strength attained. Strength could be sourced from within the individual by means of several internal mechanisms. The first involved taking charge of a situation and was entitled “Taking the Bull by the Horns.” All but one of the participants surveyed reported that they used this mechanism at least some of the time; with parents of children with severe disabilities using this mechanism more frequently than parents of children with less severe challenges. The second mechanism of finding internal strength was simply finding a support within oneself by means of positive self-talk, at times using positive imagery which created an image of the situation, which was not necessarily accurate in the eyes of outsiders, but was found beneficial to the individuals involved. This was
exemplified when Carla spoke of how her daughter, Rosa, laughed and smiled when this was not something that she was able to do. These methods were used by all of the respondents at least some of the time; however, there was no relationship between the use of this mechanism and the perceived levels of disability.

A third mechanism within strength from within addressed a coping mechanism, which may be considered as a negative coping mechanism, as it did not address the issue of concern. Escapism could include sleep, alcohol, drugs or other methods used to avoid the problem. It was found that this method was used by all respondents at least some of the time. As with some of the quantitative testing, parents who described their children as having moderate disabilities used this particular coping mechanism more than others, although this tendency was not statistically significant.

Strength could also be found from without the individual. God was identified as a source of strength by just over half of participants and was used a moderate amount of time. When evaluating the use of God as a coping mechanism based on the PPDD, it was found that, while not statistically significant, individuals who identified their children as having severe disabilities tended to use God as a coping mechanism more frequently than others.

The aid and assistance of others as a source of support has long been identified. Participants identified family members, friends, therapists and a health care provider as a source of support. It was found that when this mechanism of support was used, it was used with moderate frequency. There was no relationship between the use of other people as a support system with the PPDD.

Life in the negative addressed a variety of experiences, wishes, dreams that were painful or caused an element of shame as well as actions that were potentially harmful. It also addressed
negative behaviors or the perceptions of negative behaviors by others. It was found that most participants experienced a moderate amount of stress and expended energy in coping with negative experiences. It was further found that the degree of stress and coping with negative experiences was significantly positively correlated with the PPDD.

Parents of children who had HIE experience a myriad of experiences and emotions, some of which are related to the PPDD. However, much of what was voiced in the qualitative strand was not able to evaluated by the quantitative measures. Similarly, the quantitative strand uncovered issues which were not brought up by qualitative participants. Particular issues regarding communication, labor care and postpartum care as well as care for the infant in the intensive care and follow-up care environments were not evaluated on the surveys. It appears that the most informative instruments that were consistent in both qualitative and quantitative strands were the PHQ-2 and the PSI-SF. The ICNDS and the WCQ were not as beneficial as the issues which parents brought up during the qualitative strand did not coincide with the questions on those to surveys as well.

In conclusion, areas of convergence, such as stress and depression were well enhanced by parental statements during interviews, allowing the researcher to gain a deeper understanding of the guilt, pain, and taxes on parents of children who had HIE, particularly when resultant disabilities are great. Areas of divergence indicate that neither the quantitative surveys nor open ended interviews were adequate to capture issues of importance in these areas. Finally, there were numerous issues, particularly in terms of communication, which were qualitatively revealed, but were not addressed on surveys. Certainly, these important findings, in terms of the mixing of the qualitative and quantitative strands opens doors for future research.
CHAPTER FIVE

DISCUSSION

5.1 Introduction

“The presence of a disabled child causes profound changes in the family. The impact of anxiety and depression on parents and on their quality of life are considerable. This is a situation that involves an adaptation process” (Thabet et al., 2013).

Your baby is about to be born. Anticipations are high. Then, the bottom falls out. A team of people rush into your sanctum, taking your baby, doing things to him, then whisking him away, maybe or maybe not letting you see him. The next time you see your baby, he’s cold, almost naked, and attached to multiple pieces of equipment. You can barely breathe. This isn’t a baby. This isn’t your baby. The days go on. You try to pump breast milk, but you can’t. You are told that your baby may have problems, perhaps significant problems over the coming years. This cannot be happening, but you go on. The pain of missed milestones is met by stares or comments from others. You quit your job, money is tight, you have a stranger in your home, you rush to multiple appointments. This cannot be your life, but you go on. And no one understands.

This exploratory, mixed methods study used a convergent parallel design in order to explore the experiences, perceptions, feelings, and self-identified needs of parents who have a child who had HIE in the neonatal period. Non-parametric testing and t-tests were used to analyze the quantitative portion of the study. Several significant findings were revealed. Notably, parents of children who were described as having severe disabilities reported a somewhat lesser degree of impact upon the family unit than those with moderate degrees of disability, although both were greater than parents of children described as having no or mild disabilities. This sample also exhibited significantly high levels of stress and depression. Social support was the
most frequently used coping mechanism. It was further appreciated that more emotion-focused mechanisms were used by parents who perceived their children to have a moderate impairment.

Using a Heideggerian phenomenological approach to inquiry allowed six major themes related to the phenomenon of being the parent of a child who had hypoxic-ischemic encephalopathy to reveal themselves. Analysis of the interviews revealed that remote experiences continued to be present in the minds of participants. Focus was often on issues of communication. Finally, a mixed methods analysis, using a convergent, parallel design was undertaken. Areas of both convergence and divergence were appreciated. Furthermore, both strands yielded data that were not appreciated in the other. The most significant convergent findings addressed both stress and depression. The most significant divergent finding addressed issues of communication. These above findings are discussed in terms of professional and lay literature and related to the Resiliency Model of Stress, Adjustment and Adaptation. In addition, study limitations, implication for health care delivery and education, health care policy and future research are proposed.

5.2 Discussion and Interpretation of Findings

5.2.1 Quantitative

Several research questions were used to guide this portion of the study. The first was: What is the relationship between the parentally perceived degree of disability and the impact of childhood neurologic disability as measured by the Impact of Childhood Neurologic Disability Scale (ICNDS)? The parentally perceived degree of disability is important because one may only accurately assess parental perceptions from parents. Parental perceptions of a child’s disabilities may differ from the measured degree of disability, and as parents are the focus of this study, their perceptions are vital in the exploration of their issues. There is a paucity of literature addressing
the parentally perceived degree of disability in concert with the medically described degree of disability. However, in their study of stress in mothers of children with intellectual disabilities, Hassall, Rose and McDonald (2005) concluded that parental perceptions influence parental stress levels. It has also been found that parents of children with juvenile arthritis view their children as more vulnerable and report a lower health related quality of life (Haverman et al., 2014). More closely related to correlations of the medically described versus the parentally perceived degree of disability; Chong, Mackey, Broadbent and Stott (2011) found that for children who were less severely affected, there was poor correlation between the parentally perceived walking abilities of their children and the measured abilities of those children. In this sample, five of seven parents described their children as having a less significant disability than described in the medical record, thus validating the use of the PPDD. Perhaps most importantly, it has been found that while the psychological severity of a disability, such as occurs with emotional/behavioral function, self-esteem, mental health, and behavior, has been found to be significantly predictive of stress, the physical severity of the disability was not (Giovagnoli et al., 2015; Peer & Hillman, 2012). This finding may explain why parents who viewed their child as having a moderate level of disability experienced more significant findings of impact than those who viewed their children as having severe disabilities.

The ICNDS explored the effect of behavior, cognition, neurophysical disabilities and epilepsy in the target child on members of the family and the child. The developers of the ICNDS (Camfield et al., 2003) intended its use for parents of children with not only epilepsy, but with a variety of neurological disorders. However, it was not validated for more than parents of children with epilepsy with or without other neurologic disorders. In this sample, few parents reported that their children had a seizure disorder. Furthermore, a few parents did not complete
the survey. There may have been several reasons for this: 1) survey burden in that there were four surveys plus demographic and intake questionnaires; 2) the layout of the survey may have been a challenge for some participants, with four of the nine qualitative participants asking for help in understanding how to fill out the survey; 3) some parents may have perceived that the survey was not applicable “enough” to them. Despite these possible impediments to the instrument, itself, some important findings were revealed. There was a moderate positive correlation between the total impact of neurologic disability and the PPDD. Interestingly, parents of children who were perceived to have moderate degrees of disability exhibited higher impact scores than those who were reported to have severe disabilities. There may be several reasons for this: 1) some children who may have been medically described as having severe disabilities, were described by parents as having moderate disabilities; 2) children described as having severe disabilities are often less verbal and less mobile, which was anticipated to lower behavioral issues, thus lowering the total impact. This is consistent with the findings of Peer and Hillman (2012) and Giovagnoli et al. (2015) who found greater impact from psychological severity of disability, such as behavior than from physical disability. When the sub-realms of behavior, cognition, neurophysical, and epilepsy were evaluated, it was found that only neurophysical disabilities were positively correlated with the PPDD. Furthermore, older parents and parents with greater incomes reported greater impacts. This may be due to greater physical care requirements on older parents who may not be as physically able to lift and move their child. This coincides with the age of the child. While not statistically significant (p = .052,) parents of older children also reported a greater impact, again likely secondary to increased physical needs. Greater impact in parents with higher incomes may be related to a change in lifestyle. There is no literature addressing this factor.
The second research question was: Do parents of children with HIE exhibit more stress than parents of children who do not have disabilities? It was addressed by the Parenting Stress Index – Short Form. Parenting stress was found to be a significant issue for participants, with 71% of parents scoring at the 85th percentile or greater for total stress. Lima, Cardosa and Silva (2016) found similarly high stress levels, requiring professional intervention in 31.8% of parents of adolescents with cerebral palsy. They found that the main stressors were the level of motor and behavioral issues. Using the ABCX model of adaptation, a precursor to the Resiliency model used in this study, the researchers found that the strongest mediating factors in managing this stress were family resources, such as support systems and the family perceptions of the stressor of having a child with CP. Giovagnoli et al. (2015) identified child behavioral and emotional issues as the greatest stressor for parents of children with autism spectrum disorders. Similarly, Lima and colleagues found that there was no association between the degree of stress and the child’s physical impairments.

The third research question was: Do parents of children with HIE meet criteria for depression as measured by the Patient Health Questionnaire II (PHQ-2)? Depression was a prominent finding in this study, with levels higher than those in the general population and almost twice the norm in women. Similar findings were made by Veisson (1999), Thabet and colleagues (2013) and Resch, Elliott, and Benz (2012) who found high levels of depression (19-57%); and Fernandez-Alcantara and colleagues (2015), who’s qualitative study revealed depression and findings consistent with chronic sorrow, citing sorrow and desperation, particularly in women. Similarly, Vickers (2005) qualitatively identified long term, chronic grief in working mothers from the life changing experiences of their children’s challenges which
impacted all aspects of life. They expressed grief-associated depression with deep and pressing sorrow.

The final quantitative question was, “What coping mechanisms are used by parents of children with HIE, as measured by the Ways of Coping Questionnaire (WCQ)? Coping was evaluated based upon the use of emotion versus problem-focused mechanisms, as well as the use of those mechanisms based upon a variety of factors. In this study, the use of problem and emotion-focused mechanisms were not significantly different. Thabet et al (2013), however found that 68% of parents used emotion-focused versus 32% using problem-focused mechanisms. They further found that the use of emotion-focused mechanisms was used more frequently by parents in lower socioeconomic situations and with lesser education. This is consistent with parents in this study, who were found to use more emotion-focused mechanisms if they were in a lower income bracket. Also, consistent with this study’s findings, problem-focused mechanisms were used more frequently by fathers than mothers.

5.2.2 Qualitative

The research question guiding this portion of the study was: What is the lived experience of parents of children who had HIE? It is recognized that the all characteristics of this phenomenon may not necessarily have been manifested in the findings of this study. However, the findings have revealed some important issues for these families, which have the potential to be improved upon in order to improve the care received by such families.

The lived experience in the eyes of this study’s participants were both varied and similar. Some participants experienced unique issues, such as personal impairments or a request to discontinue support. These unique issues were deemed unlikely to reach saturation, unless particularly sought. They provide seed for future research, but at the same time will be discussed
in terms of the researcher’s perceptions, as consistent with Heideggerian phenomenology. This being understood, both these and all of the other participants voiced a variety of issues based upon their lives which are reflected in six themes.

**Theme 1: Unmet expectations.**

Welcome to Holland

… When you're going to have a baby, it's like planning a fabulous … trip to Italy. You buy… guidebooks and make your wonderful plans. The Coliseum, the Michelangelo… It's all very exciting. After months of … anticipation, the day finally arrives… later, the plane lands. The stewardess… says, "Welcome to Holland." "Holland??" you say. "What do you mean, Holland?" … I'm supposed to be in Italy. All my life I've dreamed of going to Italy. But there's been a change in the flight plan. They've landed in Holland and there you must stay. The important thing is that they haven't taken you to some horrible, disgusting, filthy place... It's just a different place. So you must go out and buy a new guidebook. And you must learn a whole new language. And you will meet a whole new group of people you would never have met. It's just a different place. It's slower paced than Italy... But after you've been there…, you look around, and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts. But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life you will say, "Yes, that's where I was supposed to go. That's what I had planned." The pain of that will never, ever, go away, because the loss of that dream is a very significant loss. But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland (Kingsley, 1987).

Every parent either verbally or tacitly expressed verbalizations of some type of unmet expectation either in terms of his/her child, the delivery experience, their or their partner’s care, or their life situation. Grief may follow the loss of the idealized or healthy child and may be of greater significance for some parents than the death of that child due to lifelong challenges (Chiambretto et al., 2010; Collings, 2008; George et al., 2007; Godress et al., 2005; Worthington,
It describes the mental suffering or distress over an affliction or loss and may be envisioned as a deep, at times heartbreaking distress caused as if the individual was bereaved.

**My child is not what I expected.**

Kupfer (1982), the mother of a child with disabilities, relates a story of another mother in her book, *Before and After Zachariah*, “Of course it is horrible when a child dies. It is one of the worst things that can happen – for the parent to outlive the child…but at least the act, the death, is an ending, a finality. And the parents’ wounds can begin to heal.” Carla and Luis expected to have a beautiful healthy daughter to make their family of five. Instead, the unexpected happened, their daughter experienced a perinatal hypoxic-ischemic insult which left her neurologically devastated. This led to Carla’s perpetual state of grief, consistent with chronic sorrow. Eakes et al., (1998) describes chronic sorrow as the ongoing disparity following a loss and characterized by both pervasiveness and permanence. Prior to Rosa’s discharge from the hospital, Carla asked her husband to put away all the toys that their daughter would never be able to use. She was tearful throughout most of the interview.

Grieving individuals experience fatigue, loneliness, anxiety, somatization, guilt, anger, fear, and denial (Barr & Cacciatore, 2008; Cowles, 1996; Jacob, 1993). In her grief in regards to Rosa’s disabilities, Carla exhibits anxiety, anger, fear, and denial. She exhibits fear and anxiety in regards to leaving Rosa alone with an aide and anger when she addressed the woman who stated that her child “should die” Similarly, Melissa’s anger is likely related to grief over her child and her own life course and was obviated in a shopping mall in response to perceived rudeness. She ended up giving the woman a lecture on her daughter and her story, ultimately telling this woman, in no uncertain terms, that she should be more compassionate and even helpful. In addition, Carla exhibited denial, a form of positive reappraisal, but also an emotion-
based or negative coping mechanism (Lazarus & Folkman, 1984) when she tells the investigator and presumably herself that her daughter can see, smile, and laugh.

While Carla merely stated that Rosa is not like her other children, Martin compared Eddie to both himself and other children. Hayman (2012) describes this as a relatively normal act which is always based upon behavior. However, she cautions against making comparisons, as it fails to allow the parent to “see who they (children) truly are and what they need in order to grow.” In a household with challenges and a child who is less likely to develop in a typical manner, this parental behavior, which may have been meant to provide a description to the researcher, may in fact create more issues. If it continues as Eddie grows, particularly if the parents have additional children who are more likely to develop in a typical manner or if continued comparisons are made between Eddie and his cousins, behavioral issues, emotional issues, resentment, depression and other negative sequelae could occur (Jenson & McHale, 2015).

*My life is not what I expected because of my child.*

In addition to grieving the loss of a healthy child, unmet expectations also address parental life changes. Kathy grieves the loss of her profession. I love Kristin, I just hate her life, and I guess I hate mine too. I want my life back. I want to go back to work again.” Melissa discussed how her marriage was in a sad state and that Mary’s needs for physical care were so significant that she had to decrease her work hours. Dellve et al. (2006) studied 244 parents of children with rare diseases. They found more parental stress in mothers than fathers, as well as with a comparison group of mothers. They found that this stress was related to feelings of incompetence, role restriction, social isolation, problems with spousal relationships, and health problems. Following an intervention, working mothers were found to have decreased fatigue,
improve spousal support, increased coping knowledge, improved compliance with therapists, and decreased physical strain. It may therefore be expected that an inability to work or the necessity to decrease one’s work may create additional strain, decreased coping, decreased spousal support and increased fatigue in the mother of a child with a disability as evidenced by Kathy and Melissa.

More recently Wei and Yu (2012) found that parents of children with multiple disabilities were more likely to be unmarried by the time the child grew to adolescence compared with the parents of children with learning disabilities, alone. Melissa discussed her marriage, “My marriage is on the rocks…I think my husband works so much just so he can avoid being home…he’s probably having an affair… I don’t really care. I can’t even tell you the last time we had sex. Oh well, I don’t even want it anyway.”

Caicedo (2014) 84 families (47% Hispanic,) finding issues of fatigue, frustration, anxiety, anger, helplessness, hopelessness and isolation to be prevalent in her sample of caregivers of high needs children. Melissa described frustration with some of the care burden for Mary, “…I get up at five…to get her bathed…she’s so stiff…I can hold her on the seat…as I bathe her…I get her dried and dressed…I do chest PT. I put her into her chair and strap her in. I give her her meds…her feeding, so that she’s done in time to go to medical day…The bus comes at 8:30…when she gets home I have to get her cleaned up again…” She further describes her frustration, “She cries, she screams. I know she’s in pain from all the spasticity, but she can’t tell me.”

Vickers (2005) interviewed nine working mothers of children with disabilities. They identified long term, chronic grief from the life changing experiences of their children’s challenges which impacted upon all aspects of life. They expressed grief-associated depression
with deep and pressing sorrow. Depression appears to be apparent in Carla. She cried through much of the interview. In addition, her husband stated, “She very sad. Sometime she no want get out of bed. She can no work anymore.” Carla also exhibits denial, an emotion-focused coping mechanism, when she tells the investigator that Rosa sees, smiles, and laughs. Denial has been described in grieving individuals (Barr & Cacciato, 2008; Cowles, 1996; Jacob, 1993). In 1991, Phillips interviewed three mothers. While two mothers had chronic sorrow, one did not. The researcher noted that this mother was in complete denial of her child’s disability, making her incapable of appreciating the loss. While Carla exhibits an element of denial in terms of some of her daughter’s challenges, it was not as all-encompassing as in the mother described by Phillips. She recognizes that her daughter does not look the same as she once did and that others view her as fragile, “But not like when she baby. Then people hold her, love her. They don’t anymore. She no look the same. (Rosa is limp and obviously microcephalic) I think people afraid they hurt her by accident.”

*My/our delivery experience as not what I expected.*

While all parents desire a normal labor and delivery experience, none of these parents were able to experience it. For some the unexpected delivery experience remains profound. It is clear from Lisa’s description that her birth experience was not what she expected. “That was most scary because it’s like, I think they like cuttin’ your whole part… I was trying, and trying, and trying to push, but it didn’t work, so they said we had to do the C-section …I felt everything. It was so painful. I felt the tugging and pulling. It was like hours, literally crying and I fell asleep crying. I didn’t wake up til I felt like they was like already stitchin’ me up.” Giving birth is a frightening experience for the laboring woman (Bewley & Cockburn, 2002; Lyberg & Severinsson, 2010; Maestas, 2002; Scarborough, 2001). Pain and uncertainty combined with
loss of control are contributors. These factors may make the delivery experience traumatic. Similarly, Nina describes her unexpected birth experience, including her husband’s perspective. Unfortunately, the investigator was not able to interview Juan, as he spoke little English. It is possible, that Juan’s lack of English proficiency may have contributed to the issues with communication during this time. However, Nina was fluent in English and remembers little other than pain and being told that they had to get the baby out.

Juan tell me Juanita not breathe… They use forceps… so much pain… I just remember doctor saying that have to get baby out, have to get baby out… Nobody talk to him (husband) when working on baby. He think she dead.”

Nina’s description is congruent with Beck’s (2004a) work with mothers who had traumatic birth experiences. Presumably, this may also exist in fathers, as seen in both Juan and Martin. One of her themes addressed inadequate communication with clinicians. In a recent study of parents who had a child with a disability, 62% of respondents stated dissatisfaction with the medical team (Thabet, 2013). There is a marked paucity in the literature in terms of parental responses following witnessing their own child’s resuscitation in any setting. McGahey-Oakland, Leider, Young and Jefferson (2007) interviewed ten family members of children resuscitated in the emergency department. Seven of whom were present during the resuscitation, with each stating that being present would have been beneficial. They uncovered five themes: 1) It’s my right to be there; 2) Connection and comfort makes a difference; 3) Seeing is believing; 4) Getting in; and 5) Information Giving. Most of the literature in this area, however, addressed perceptions of members of the health care team in regards to parental presence rather than the parental perceptions. Clearly, more knowledge in this area is needed.

Martin expected more contact with his son at birth, “I was only angry because I couldn’t touch him… they took him outa her, then hauled him off. All we seen was his hair, we didn’t see
his face, we didn’t see his hands, we didn’t see his feet. All we seen was his hair inside a box.”

Similarly, Debbie recalls seeing Stevie for the first time, “Well, when I finally got to see him it was awful. He was white as chalk. He had two tubes in his throat, they had IVs in his belly, a catheter in his penis.”

_The care for myself and my child was not what I expected._

Most of the issues of care expressed by the participants had to do with communication; either it was perceived as inadequate or unwelcome. Martin expected better communication, “When the doctor told me my symptoms my son had, I did not understand a word he said. I had to ask a nurse.” Beck (2004a) interviewed mothers who had traumatic birth experiences. Presumably, this may also exist in fathers. One of her themes addressed inadequate communication with clinicians. Issues with communication have been cited as sources of stress for parents (Quittner et al., 2010; Smith et al., 2001). Similarly, Carla remembered, When Juan and Maria (her other children) born nurses and doctor spend time talking to me about how they doing, not now. They just come in, don't talk, just ask about my pain and bleeding, then leave. They no ask about Rosa.” Wofford, Wofford and Bothra (2004) qualitatively explored patient complaints about physician behaviors. They found that disrespect was the most commonly identified complaint, followed by disagreements regarding care expectations, inadequate information, distrust, perceived unavailability, interdisciplinary miscommunication and misinformation. While issues of disrespect were not made in actual verbiage, Luis and Carla repeatedly reported a “shut-down” in communication when they chose to not discontinue life support. Repeated attempts by the physician to address their decision were perceived as an affront to their religious convictions and beliefs. As Luis described, “I say God no want me to kill my child. He walk away then.” Martin expressed that he felt that he was being judged by
nursing. “Yeah, it felt like I was being tested to see like I a bad parent or I was good parent. It felt like [hospital name] did not trust me, like some of the nurses ganged up…”

Both Martin and Debbie describe issues with care in follow-up. Debbie felt as if her perceptions did not matter, “I try to explain…what he’s like at home, but I don’t know if they really hear me…they tell me that he’s not doing this or he’s not doing that… I just want them to understand that Stevie is completely normal.” Martin lost confidence in the medical team. He expected his son to gain weight. Rather than give the gastrostomy feeds as directed, possibly due to a misunderstanding in how to manage these, he fed his child orally. As his son was not gaining weight adequately, he fed him large volumes. Fortunately, there were no obvious deleterious effects reported.

What did I do? I stop listenin’ to them. I started feedin’ him regular food… regular milk and I told the doctor, “I’m not listenin’ to what you say cause what I did it already…so I tell him what I give the baby, he was like, “oh none of this is good for the baby.” … but I didn’t see what he gave the baby gain weight, gainin’ weight, cause all he wanted to do was just give the baby straight Enfamil, no ingredients, no cereal, no nothing…”

**Theme 2: My Source of Strength.**

The Resiliency Model of Family Stress, Adjustment and adaptation identifies social support and family resources as significant factors in the adaptation to crisis, such as occurs when a child is ill or disabled (Robinson, 1997). Family resources include such factors as finances, belief systems, previous experiences with crisis, previously used coping mechanisms and individual and family strengths.

*I get my strength from without.*

Martin identified his therapist and his past in a residential facility as his primary sources of strength, “I talked to my therapist…we was in a program… they taught me anger
management. I graduated anger management. They taught me something true.” His partner, Lisa, identified her mother, “I started cryin’ my mom had to come to the hospital and calm me down…” Sadly, neither of these parents identified each other as a source of strength, unlike Carla and Luis. Carla simply says “…he my strength…” Luis admires Carla’s strength and faith, particularly when confronted about discontinuing life support for Rosa, “Carla say ‘no’, she strong woman. She say God have reason for this…” Debbie identified her mother as a source of daily support, “I call my mother all the time…I cry. She’s always there for me. She reminds me to take care of myself.”

Nina identified her large and extended family as getting her through the crisis. She also identified the nurse practitioner caring for her daughter, reminding herself that the investigator (in the early days of her daughter’s life) told her that babies could adapt better than adults. “I hang on to that a lot…”

From the times prior to the evolution of monotheistic beliefs, a higher power has been sought by many. Whether an individual or society was concerned about health, crops, or wars, God has been viewed as a source of both strength and comfort. The degree of religiosity often waxes and wanes for many individuals, frequently coming to the forefront during times of crisis. Four of nine participants identified God as a source of strength.

Martin, despite his simplicity, viewed God as responsible for supporting him, “you gone through too much here, I’ll throw a little hand and like God gave me his little finger.” Carla described her experience with Rosa’s doctor in response to a discussion of discontinuation of life support. Wearing God as her armor, “We say no, God no want this. Doctor say God decide, but we stopped it… Doctor say to leave tube out, let Rosa die. We say no, God no want this. Doctor say God decide, but we stopped it. We say no. Doctor put tube back.” While Luis is faithful in
his belief in God, he expresses guilt in his question of his faith. “I tell priest I think doctor right. I
guilty for thinking this.”

Nina Jubilates, “We thank God every day. We go to church together. We praise God. We
ask him to help babies. We ask him protect you and doctors, nurses who save Nita.” She and her
husband then take this one step further by giving back. They work with their priest to identify
families in need of support for a child with illness or disabilities, then go to that family to offer
additional support.

While only families of the Catholic faith identified God as a source of support during this
study, God or some higher power has been used as a source of support for those of many belief
systems. Speraw (2006) qualitatively explored the spiritual experiences of parents of children with
disabilities. She discerned four themes: 1) parents and caregivers believed that their children were
spiritually connected to God, 2) those connections to God were often unrecognized or devalued, 3)
parents did not receive support in their children’s religious education, and 4) parental experiences
of faith were impacted by the response of the religious community to their children. These themes
were identified in families of multiple faiths. Unfortunately, her themes are primarily negative.
She noted that few participants identified that their children were valued by their faith
communities. While the families interviewed in the current study all had children who were quite
young, themes one and four could be identified. Carla and Luis refuse to discontinue life support
based upon their belief that Rosa is connected to God in terms of God’s desire for Rosa to live.
Carla received weekly phone calls from her priest, who also prayed for Rosa, Luis received
support, encouragement and prayers from his priest, and Nina worked with her priest in terms of
identifying families to whom she could be helpful. Rigler (2016) described the religious
community as a source of support for families in need. This could be found in terms of physical
support in meeting needs, such as the provision of food; spiritual support in terms of prayers, phone calls; and emotional support as when religious leader or community member provides an outlet for the person in need. The response of their religious communities provided a source of strength which provided the needed energy to go on for Carla; and to expand and share for Nina. Only time will tell if Speraw’s themes two and three will become an issue for Rosa, Luis and Nina. Although Martin did not identify his membership within a faith based community to this researcher, it is apparent that he carries some image of God as a support.

**I get my strength from within.**

This subtheme addressed the parent finding a source of strength within him or herself; whether it was telling oneself words of encouragement, using a positive illusion, or choosing to take charge of a situation. Most parents found some strength from within themselves. The two who didn’t, interestingly, were on both ends of the spectrum. Kathy who has a daughter with severe disabilities and came across as quite depressed and in need of support; as opposed to Nina, whose daughter has the mildest of challenges, came across as the complete opposite of Kathy in terms of disposition, and has numerous family members and her faith to support her. It is suspected that Kathy, who comes across as depressed and overwhelmed has depleted her internal coping mechanisms. Nina on the other hand, has so much family support and a daughter with only minimal challenges, it is likely that she has not needed to tap deeply into her internal resources for her own support and instead is able to provide that needed resource to others. This is consistent with bon-adaptation. She has used positive reappraisal, finding something positive within her negative experience, thus aiding in acceptance and creating a positive outlook (Cheshire et al., 2010a).
While one customarily would view taking charge of a situation as a problem-focused coping mechanism, Carla and Melissa used it in a manner consistent with emotion-focused coping, when they vent their anger toward offending individuals. Emotion-focused coping has been viewed as a negative coping mechanism, however when viewed through the lens of the Resiliency Model, it is neither positive or negative. Instead the usefulness of the mechanism, in this case, venting, may be considered successful when it improves ultimate adaptation. This is appreciated during Melissa’s interview when she received an apology from the offending party and then told me, “I felt pretty good about it… I took charge of it. I actually felt like my old self.”

Martin took charge of a situation when he abandoned the prescribed feeding regimen for his son. He perceived a problem, inadequate weight gain. He came up with a plan and then acted upon it. For Martin, positive results were achieved, thus reinforcing a take charge attitude for the care of his son. He believed he was doing what was in his son’s best interest and was fortunate that there were no obvious deleterious effects on his son. At the time of the interview, it was clear that Martin did not appreciate the potential for a negative outcome based on his actions. “What did I do? … I started feedin’ him regular food, I started to give him regular milk early and I told the doctor, “I’m not listenin’ to what you say cause what I did it already.”

Luis and Jim want nothing more than to do the best they can for their families. They both use problem-focused coping mechanisms, augmented by positive reinterpretation. Folkman and Lazarus (1985) state that positive reinterpretation may augment problem focused coping by enabling revision of plans or activities. In this situation, Luis simply stated, “Well not all bad (voice almost sounds perky). We cut bills really good. Look, not one light on (said with sense of pride) I fix refrigerator last month, no call someone to fix. I fix much here.” If he did not have the stressor of a decrease in income, he might not have utilized this mechanism. Similarly, Jim
anticipates physical challenges in the future for both himself and his wife. He talked his wife into moving to a ranch house, “… no steps to deal with for when it gets hard.” His wife, Debbie, also uses a problem-focused method. She is determined to help Stevie be “completely normal… I spend every waking moment with him; doing his therapy, playing with blocks. He's going to catch up just fine…So we come home and practice. Like after his last visit we came home and practiced blocks til he needed to nap. Interestingly she changes her verbiage slightly so that instead of playing blocks he is now “practicing” blocks. Miller et al. (1992) found that the problem-focused mechanism of responsibility taking was highly correlated with psychological distress. Debbie is taking responsibility for her son’s failure to meet milestones. At the same time, however, this may also be viewed as planful problem solving which was found to be negatively correlated with psychological distress. More information would be needed to determine if her efforts are more in line with helping her son to gain skill, i.e. planful problem solving, or if her practicing blocks with her son is more enmeshed with her own self-esteem as a mother, in which cased it would be viewed as taking responsibility.

**Theme 3: Life in the Negative.**

This theme addressed a variety of experiences, wishes, dreams that were emotionally painful or caused an element of shame and actions that were potentially harmful. It also addressed negative behaviors or the perceptions of negative behaviors by others.

**The negative wish.**

This subtheme specifically addressed wishes of harm to the participant or the participant’s child. In a parent pamphlet by United Cerebral Palsy (Burdicko et al., 2013) parents are told that resentment of this “thing” happening in your family is normal. They are told a story of a parent, “There were days when I think I actually hated her for making my life so
difficult…” While Kathy and Luis say outright that they wished that their daughters had died and Melissa says that she thinks it would have been better had her daughter not been cooled as she probably would have died, it is not out of a sense of cruelty, rather it comes from a place of pain and anguish, as heard when Luis says, “Sometime, I wish Rosa no live, God forgive me. Not fair to Carla Luis, or Maria… I wish doctor one night take Rosa off breathing machine and just tell us she go to God.” Kathy tells the investigator, “Sometimes I wish Kristin had just died, then I get mad at myself. Don’t get me wrong, I would never act on that wish…” News reports tell of situations where parents have killed their disabled children. The news describes these cases as “tragic, but understandable” with prosecutions being dropped at times, due to the degree of parental stress (S. E. Smith, 2015). While Kathy is clear to tell the investigator that she would not act on that wish, Kristin is young and her needs will not decrease. As she grows, providing physical care will become more challenging. This is Kathy’s cry for help. It is difficult to find literature regarding a parent’s wish for their child to die or to have died, one does occasionally see a wish that a child with a significant life-affecting issue had not been born (Rapp, 2012). Similarly, Melissa wishes that Mary had not been cooled, with the thought that she otherwise would not have survived, only to suffer. Peteet et al. (2010) address threats of self-harm in response to coping with the illness of a loved one. Kathy stated that she wished someone would just “kill her.” This type of comment is categorized by the authors as a “wish,” as it does not express a specific intent or plan and is not deemed to be as significant a threat of self-harm as a specific plan, such as “I plan to kill myself when Susie dies.”

**Negative behavior.**

This subtheme addressed specific behaviors of the participants. It also looked at negative behaviors and the perceptions of negative behaviors by health care providers and others. Both
Kathy and Melissa used alcohol to numb themselves a bit. This is an emotion-based or negative coping mechanism, specifically categorized as escape-avoidance, which according to Miller, et al. (1992) is highly correlated with psychological distress.

Carla and Luis both addressed a shut down in communication with the physicians and nurses caring for Rosa when the discussion of discontinuation of life support was broached. Carla reported, “…we say no. Doctor talk to us no more…nurses no talk to us, just tell us how to feed and take care of tube.” Luis reported, “I say God no want me to kill my child. He walk away then.” While this story does not include the physicians’ and nurses’ perspectives, it is clear that the parents expressed a sense of abandonment when they were not in agreement with discontinuation of support. Again, there is a paucity of literature from the parents’ perspectives in these types of discussions and only a smattering from physicians. A study in the Netherlands (van der Heide et al., 1998) found that discontinuation of support only occurred when both parents and physicians were in agreement. This appears to be true today in the United States as well. What seems to be in question is the communication that occurs, particularly when the family and the medical team are not in agreement. It would appear that once Carla and Luis were clear in their desire to continue support, there was an inability for the physician to move on.

It would be beneficial to have the physicians’ perspectives on these dialogues.

In the best of situations, these discussions are difficult to undertake. Harrison, Evan, Hughes, Yazdani, Federman, and Harrison (2014) identified a need for a level of comfort in terms of conversations regarding end of life care. The American Academy of Pediatrics addresses principals in the care for such children and families, including: respect for the dignity of patients and families, access to appropriate palliative care, support for caregivers, respect and empathy while maintain meaningful communication, and others (Anonymous, 2000). It would
appear that the ability to maintain meaningful communication fell short in this situation. This is possibly secondary to a lack of comfort in the discussion of such topics by the medical and nursing staff. Granted, this discussion should never be “comfortable,” rather it is painful to the core of the care community. It is not simply a matter of failing to save the child or viewing oneself as a failure for not being able to save the child. It is more likely a matter of empathizing and sympathizing with the pain of the family. The communication skills needed for these difficult discussions can be both taught and learned. However, when one is in the business of saving lives, it is often on the lower end of the priority list compared with learning a new technique for saving life.

Carla and Debbie also give voice to feelings of abandonment during the post-partum period. Carla reported, “When Juan and Maria (her other children) born, nurses and doctor spend time talking to me about how they doing, not now. They just come in, don’t talk, just ask about my pain and bleeding, then leave. They no ask about Rosa. Debbie mirrored these comments, “My doctor (obstetrician) never talked to me. I kept asking and asking about what happened and he always evaded the question… but the nurses on the … floor just kind of came in asked about how I was feeling, but when I started to talk about Stevie, they didn’t stay long.”

Talking about a child in the neonatal intensive care unit possibly with neurologic damage, may be anticipated to be uncomfortable for nurses as well as physicians. The obstetrician in this case may feel responsible on some level for the child’s problems. In addition, post-partum nurses and obstetricians more often deal with happy outcomes. Again, communication and skill development in communication would likely be beneficial.

Random comments by strangers and others were viewed as emotionally painful by some participants. Carla stated, “People mean: doctors, nurses, people on street, like they mad at
me…Most time just stare. Some say, ‘poor baby.’ This one lady she say, ‘that poor baby should die, we all pay for her.’” Kathy reported “It’s been a challenge. People tend to be rude and ignorant… My own mother says I was cursed (with a child who has a disability) because I am gay, let alone wanted to have a child.” These types of comments have occasionally been reported (Koshti-Richman, 2009). Luis reports that his wife, Carla is afraid of the aide caring for Rosa. “She say aide like doctor, she say aide think Rosa be better dead. She say aide not nice to her.”

As appalling as some of this behavior is, it is not unique. In her blog, a woman relates a story of her experience in a pediatrician’s office. The author is the mother of a child with autism. In the pediatrician’s office, another woman goes into a dissertation on how children with disabilities, specifically autism, should not be placed in the same class rooms as “Normal” children. This discussion went on for some time, despite the author of this blog telling the “ignorant woman” that her child had autism and the positive aspects of children who are developing typically being in the same class as children who have challenges. Unlike Carla and Melissa, this mother says nothing, being so upset that she left the pediatrician’s office without even being seen (Roussel, 2012).

Theme 4: Outside of Reality.

This theme addressed dreams, daydreams, wishes, denial, feelings of being overwhelmed as well as the voices of two participants who expressed elements consistent with paranoia. Three subthemes included: “Dreams and wishes;” “blinded by the situation;” and “the world is against me.”
Dreams and wishes.

Two parents described actual dreams. One need only to think of Golda telling Tevye, in *Fiddler on the Roof*, “Tell me what you dreamed and I’ll tell you what it meant,” to know that dream interpretation is inexact and as variable as the dreamers and interpreters themselves. However, some work has been done in dream interpretation. Martin relates, “I had a dream where I lost him. She was cryin’, my mom was cryin’, everybody was just cryin’ around him and then I was just sittin’ there like (pause) not carin’. In my dream I was just not carin’ that he’s gone... Like, I walked away from [hospital], I walked away from her, I walked away from everybody. I was isolated, everything.” It is possible that this dream reflects Martin’s fears of losing Eddie. His lack of caring may be a subconscious effort to protect himself from the pain of that loss, yet at the same time, he walks “away from everybody.” This may reflect possible inconsolability over such a loss. While the culture is different, some of the constructs may be quite relevant in this situation. Nations (2013) discussed maternal dreams of dead babies as a means of alleviating the trauma of that death. In Martin’s case, it would appear that he is trying to protect himself from that trauma in an anticipatory fashion.

Kathy dreams that she gives birth to a monster, becomes a monster and is then stoned. By this time, we know that Kathy is depressed, engages in self-harming behavior, has been left by her partner and has been shamed by her mother. Britton (2015) looked at Mary Shelley’s story of *Frankenstein*. In this classic tale, Victor Frankenstein creates the “creature,” who horrifies him, leading to his ultimate rejection of the creature, who is now referred to as the monster. The parallel between the creation of the creature and a child with disabilities is clear. Interestingly though, it is believed that the story is related to Shelley’s loss of her own mother after she was born and then the subsequent loss of her own child, which made her feel rejected as
a child and to be thought of as a monster. Kathy also speaks of being stoned in her dream. This was also seen in the story of Frankenstein, when the townspeople reacted to the creature in fear. In addition, Kathy had a strong religious upbringing. She spoke of “Catholic guilt.” It is well known that stoning was a common form of punishment during the time of Jesus, it is therefore reasonable to expect that Kathy was aware of this ancient punishment. Looking at this from Kathy’s perspective, she gave birth to a child with significant disabilities, a.k.a. a monster. If she delivers a monster, then she must be a monster, deserving of a monster’s punishment.

**Blinded by the situation.**

This subtheme addressed denial, and self-admitted lack of recognition. In introducing me to her daughter, Carla stated, “See how she smiles and laughs when I call her name.” The investigator noted no change in facial expression, no laugh, no smile. Wortman (2004) describes this as a form of positive reinterpretation or positive illusions, however, it is used in a negative manner, i.e. denial of a difficult reality. Luis refers to his wife’s beliefs in Rosa’s abilities; “Make me sad, she think Rosa laugh, but Rosa no laugh. She think Rosa see, but doctor say Rosa’s brain can no see.”

Kathy admits (in response to investigators observation of her support system) Kristin’s challenges: seizures, not walking or talking and grunting. Faerstein (1986) found that while mothers in her cohort used problem-focused coping, which was viewed as effective in obtaining services for their children with learning disabilities, this method was abandoned when directly involved with their children. The mothers reported using more defensive, emotion-focused approaches, such as denial. In 1950, parental grief in relation to disability was first described in the medical literature. Boyd (Fotheringham & Creal, 1974) addressed this issue in a paper presented to the Bergen-Passaic Unit, New Jersey Parents’ Group.
for Retarded Children,” where he described the grief work of these parents. The first stage identified was denial of a problem. As time is a markedly variable component of the grieving process, Carla’s denial of some of Rosa’s disabilities may indicate that Rosa remains in the early stages of grief. Barr and Cacciatore (2008,) Cowles (1996) and Jacob (1993) further found denial within grieving individuals. It has already been noted that Carla likely remains in a state of chronic sorrow, although this was not specifically studied. Furthermore, in emotion-focused coping, an individual may find himself using denial or displacement. Emotion-focused coping may also be termed, avoidance or negative coping. The Resiliency Model looks at coping as neither positive nor negative; rather it is the success in coping that contributes to the ultimate degree of adaptation (Kishore, 2011). The question remains as to how successful Carla’s denial is at this point. It is likely that believing that Rosa responds to her, allows Carla to get through life, identifying a positive response which is needed to form the attachment between parent and child. It has been found that infant response predicts attachment (Braungary-Reiker et al., 2014), she may be simply doing what she can to remain attached to her daughter.

In looking a step beyond infantile issues of responsiveness, Svensson, Eriksson and Janson (2013) found several qualitative themes believed to be contributors to parental abuse of children with disabilities. The most applicable theme was entitled, “Emotional demands in precarious situations between parent and child.” While Melissa, Kathy, Luis and Carla all had multiply disabled children, none of them indicated past or future desires to cause harm, despite the fact that there were wishes for their children to not live. Carla is likely promoting an attachment to her daughter which, in addition to her generally warm nature, would likely be beneficial in preventing negative behavior toward Rosa. Melissa and Kathy both speak of struggles which may be referred to as emotional demands. The authors describe these demands
as creating anger, frustration, or a feeling of being powerless spurred by care giving activities such as giving medications or treatments and showering. The elevated demands of a child with multiple disabilities creating these feelings were believed to be linked to a lack of energy with a subsequent loss of control. Melissa’s description of showering Mary may also relate to this type of stress. While neither of these women voiced intent or desire to cause harm, they both voiced fatigue and a feeling of lack of control. The stage has been set, placing both women at risk for committing an abusive act, by the very nature of their situations, but stayed by the success of their coping abilities.

The world is against me.

Martin and Kathy both exhibit feelings of persecution or paranoia. Martin has a self-identified psychiatric history with bipolar disorder. Kathy speaks of being belittled by her mother because of her sexual orientation, being told that she was being punished for that by having a child with a disability. She states, “Sometimes I think that I can’t get more because I’m gay, that for some people I deserve this…” Martin’s statement is just as pronounced,

“One slow mistake and everybody’s attacking us… because welfare told me that the baby don’t gain weight cause the welfare finds out so if the baby’s not gainin’ weight then the WIC is gonna tell welfare. Welfare’ll tell DYFS. DYFS is gonna come, take my son or [hospital name] is gonna come take my son. Somebody’s gonna come and take him just because he’s underweight…It was like it felt like at that time that [hospital name] was just tryin’ to just trying’ to like get people for their kids.”

Johnson, Jones, Lin, Wood, Heinze and Jackson (2014) found that shame amplified the association between stress and paranoia. They concluded that shame creates a vulnerability for paranoia and conversely that resistance to shame or a lack of shame where others might experience it, could be a marker for resilience. Kathy has been shamed in her life and while she
doesn’t report that she feels shamed, she exhibits paranoia, specifically in the area in which she has been shamed, her sexual orientation. Martin further does not vocalize being shamed, however, he does discuss an insecure upbringing, “Through my whole life I been in and out of people houses… I was never spoiled. I was never, I was the only child that could say I was never spoiled. It was hard for me when I was growin’ up.” He did not go into more detail; however, one can surmise that finances were an issue, perhaps not having what other children had, i.e. a steady home. He spoke of his grandmother, not his mother or father. One then questions what his upbringing entailed. In combination with Martin’s mental health history, it is understandable where feelings of paranoia may come into play.

**Theme 5: Lemonade from Lemons.**

Most participants did not identify positive themes. Two parents exhibit true signs of bon-adaptation, while a third is working toward it. Luis identifies how positively he has now been able to cut bills. “Well, not all bad (voice perky) we cut bills really good. Look not one light on. I fix refrigerator last month, no call someone to fix. I fix much here.” Nina is truly trying to give back to society at this point. “I tell priest that if something happen somebody’s baby, I help however I can. I help mother, Juan help father. We try give back. I take Nita with me, tell other mother how sick she was, give hope.” Debbie wants to work to have her voice heard, “Sometimes I think about writing a book about the experience, so that maybe somebody will hear me.” Lazarus and Folkman (1984) address various degrees of successfulness in coping with positive outcomes being called “bon adaptation,” a term borrowed by the Resiliency Model. McCubbin, Balling, Possin, Friedich, and Byrne (2002) evaluated resiliency in the face of childhood cancer. They identified a variety of internal family strengths at play in this situation, some of which included:
• Support from the health care team. This was identified by Nina when she referred to reminding herself of the nurse practitioner telling her that babies can adapt better than adults and holding her hand when she cried

• Support from extended family. Nina has a large extended family, sharing with the investigator how they were so supportive to her

• Support from the community. Carla, Luis and Nina all identified their church communities as a source of support. While Carla and Luis remained entangled in continued grief and Carla remaining depressed, Nina reported strength from this source, such that she was able to give back to the community.

• Support from the workplace. While things remained difficult for Luis, he identified his coworkers as modifying their schedules so that he could take Rosa to her clinic visits, “If can trade shift, good, if not, must take time off, no pay. Most of time can trade, people try to help when can.

The interview process itself was identified by two parents as being beneficial. At the beginning of the interview Melissa voiced anger at both her husband and her situation. Toward the end of the interview, Melissa stated, “I feel pretty good right now, more energized than I’ve felt in a long time. You know I almost canceled on you.” When the investigator told Melissa that she was glad that she didn’t cancel, Melissa replied, “Me too.” Luis also identified an improvement, “In three years I no tell people what I tell you today. Is good, I have energy go back and do more.” One of the particularly notable features of phenomenology is that the act of participation may serve to validate a difficult experience for the participant and may, in and of itself have therapeutic benefit (Drury et al., 2007; Munhall, 2007).
Theme 6: If Only… the Desires of Parents.

All of the desires voiced by parents centered around communication. Martin alluded to feeling disrespected when he recommended that health care providers should have respect, but not too much “happiness.” Carla simply stated, “Be nice, talk, ask what can do. Don’t tell what to do.” Luis provided more insight, “I think people should listen and ask more, like you, no just tell what to do.”

Families who stated that they were cared for by nurse practitioners reported positive interactions, with recommendations for education and training. Kathy stated, “Communication was pretty good. I think that’s because Kristin had a nurse practitioner instead of a resident.” As a medical professional, Melissa’s comments are reinforcing to the role of advanced practice nurses. She recommended, “Have more practitioners like yourself for kids as sick as Mary…Don’t get me wrong, I don’t think there were any blatant mistakes, but it was really easy for me to see the difference in the care and the communication… I think it would be good for a resident to work alongside the practitioner to learn about this complex care. I think the residents should see them in follow-up along with the practitioner. The most important thing would be for residents to sit with practitioners when the speak with families…I took lessons from the way they spoke with me back to my own patients.” Nina also offered advice for an educational role for nurse practitioners, “I think you need to teach other doctors how to talk to parents. When I watch that family next to us, it seem nobody talk to them like you talk to us.” While parents made some comparisons between physicians and advanced practice nurses in terms of communication. There is a paucity of literature exploring this phenomenon, however Kilpatrick, Jabour and Fortin (2016) interviewed parents and patients who were cared for by a variety of nurse practitioners, including neonatal. They described many interactions with physicians as being “rushed or pressured,” whereas
practitioners were viewed as liaisons who understood their concerns and could address them either independently or with the physician. In addition, participants identified several strategies employed by nurse practitioners which they valued: 1) asking the patient’s or parent’s opinion; 2) asking if they were in agreement with the plan; and 3) interest in the patient or family’s impression of a situation. Perhaps most importantly, the presence of the practitioner as an integral part of the medical team was viewed as providing cohesion and coordination within that team.

Armentrout and Cates (2011) interviewed parents who experienced death of their children within the newborn intensive care unit. They identified provider communication that was perceived both positively and negatively. For example, parents valued being able to ask questions and talk about their experiential feelings. They desired to be spoken with compassionately with acknowledgement of their pain and person to person rather than in a hierarchical manner. Signs of personhood within the provider were viewed as very meaningful; such as a tear or a hand squeeze. Dissatisfaction occurred when there was a perception of avoidance or lack of support. Even a provider’s inability to find the right words were perceived in a negative manner. While this study evaluated parents of children who died, it is likely that the responses may be similar to those of parents who are being told that their child may or will have brain damage.

Anecdotally, this investigator recently spoke with a mother of a critically ill newborn in her role as a neonatal nurse practitioner. The mother asked to speak with her and then asked if she could request that the resident not care for her child. While this was a newer member of the house staff, he was smart, personable, and caring. Upon further inquiry, the mother reported that she felt that she did not get enough information from the resident, that she felt like he was holding something back. This practitioner explained to the mother the roles of the various medical providers in the unit, including that communication is one of the hardest skills to learn. The
practitioner further enabled the mother to take a stronger role by asking for more information if she felt she wasn’t getting everything she needed, adding that the nurse practitioner team and neonatal attending physicians were also available. She then spoke with the resident, explained the conversation and offered recommendations for how to improve his communication. This was well received. Later in the day, the resident spoke with this mother and according to her, things went positively.

Nina’s response to asking what health care providers could do better began with a retelling of her delivery story, “…nobody talk to me, just to each other. Juan could no understand… Nobody talk to him when working on baby. He think she dead…” To this, the investigator said, “You’re saying it would help to have someone to explain things to you while they were going on?” Nina emphatically replied, “Oh yes!” To make this more of a challenge Juan did not understand English well. DuBard and Gizlice (2008) found that individuals with a Spanish-language preference are particularly vulnerable within the health care system due to a decreased access to care. If one does not understand what is being said, access to care and access to understanding that care once it is obtained is diminished. Mothers who experienced traumatic births were interviewed by Beck (2004a). She uncovered four themes which identified issues that could be addressed by nursing and medicine, two of which are applicable in this description. The first described a perception of a lack of caring for the laboring woman, associated with feelings of abandonment, loss of dignity, and depersonalization. The second addressed a perception of inadequate communication, with clinicians speaking with other clinicians leaving the mother out of the experience.

Jim sought support, “I know that there aren’t many parents like me, but I think it would be a good idea to have a support group organized, maybe at the follow-up clinic, so we can see
what other parents are doing. I’ve looked for one, found some on line stuff, but it wasn’t very good.” Kingsnorth, Gall, Beayni and Rigby (2011) qualitatively reported several benefits to a parent-led support group. These included new knowledge acquisition and increased future planning. In addition, they also benefitted from the social support created by participating in the group.

5.2.3 Mixed-Methods

Areas of convergence within the mixed-methods analysis included stress, depression and coping, while areas of divergence included the impact of childhood neurologic disability and communication issues, which were not addressed in any of the surveys. The latter indicates that neither the quantitative surveys nor open ended interviews were adequate to capture issues of importance in these areas.

The PSI-SF was found to be a good instrument to evaluate issues of parenting stress in this sample and has been used in studies of similar populations (Almogbel, Goyal, & Sansgiry, 2017; Lima et al., 2016; Valicenti-McDermott et al., 2015). Statements consistent with stress were most often found within the themes, “Life in the Negative” and “Unmet Expectations.” High levels of stress were found in both surveys and in interview data. Qualitatively issues of stress shared with the investigator during the interviews included issues surrounding the delivery experience, feeling under attack by health care, finances, life changes and relationship issues, feelings of helplessness, concern or worry over one’s partner and a child not meeting parental expectations. The stress of parenting a child with a disability has been recognized for close to one hundred years when an authority in the Canadian Department of Health in the 1920s was believed to have said that it was worse for parents to have to raise a child with an intellectual deficit than for that child to have died. While familial emotions regarding their children were
rarely mentioned, it was also recognized that the burden was so great that it could lead to the break-down of the family unit (Strong-Boag, 2007). The majority of studies evaluated depression based on the stress of caring for a child with a disability. One of the earlier studies addressing this construct was conducted in 1982, (Breslau) which found significantly higher levels of depression and anxiety in mothers of children with disabilities as opposed to children without disabilities. Stress was linked with depression by Chen and Lukens (2011) found that parents of children with disabilities exhibited more depressive symptoms, with grief and stress being the greatest risk factors for depression.

Depression scores were high in this sample, with depression in women being present at approximately twice the rate as seen in the general population and were most often appreciated within the theme, “Life in the Negative.” Statements consistent with depression were made by about half of the qualitative participants which addressed hating one’s life, missing the time when life was better before the child was born, precise statements of being depressed, wishes for self-harm, lack of interest in sexual relations, as well as observed crying through much of an interview. These statements primarily fell into the theme of Life in the Negative. It is interesting to note however that statements of significant depression were quite pronounced in some individuals, but were not as high as one might expect on the PHQ-II. For example, Carla had a PHQ-II score of 3, consistent with depression, but not a major depression. This may be due to being able to voice her feelings prior to filling out the survey and perhaps feeling better than she had at the beginning of the interview. It is also possible that she intentionally did not answer honestly, the interview was conducted on a bad day, when perhaps life seemed more negative than she customarily perceived, or perhaps that she was in denial of her own feelings, just as she was in denial of her daughter’s disabilities. On the other hand, Kathy scored a 6 on
the PHQ-II, consistent with major depression. and verbalized multiple depressive statements, including thoughts of self-harm.

Statements of both stress and depression within the interview process informed the quantitative findings, thus validating the importance of both of these concepts in this sample. An example of this is demonstrated in Kathy who made a statement of stress in regards to other people’s behavior being rude and ignorant and then later also stating that she feels like an outsider, a statement consistent with depression. Her stress level was greater than the 99th percentile and her depression score was consistent with a major depression. Additionally, she reported that she felt better, “like my old self,” when she used an emotion-based coping mechanism by verbally addressing the woman who she perceived as rude.

Coping was quantitatively evaluated by means of the WCQ and qualitatively was found within the theme, “The Source of My Strength.” Whether coping came from within one’s self or from another source, the Resiliency Model of Family Stress, Adjustment and Adaptation addresses inherent coping abilities as a contributing factor to mal-adaptation, adaptation, and bon-adaptation. The concept of coping (Lazarus, 1984) relates well to the Resiliency Model of Family Stress, Adjustment and Adaptation. A hierarchy of response mechanisms is delineated and aligned with the successfulness of various family characteristics within the Resiliency Model.

Taking charge of a situation or “Taking the Bull by the Horns,” a problem-focused coping mechanism was used by all but one of the 51 total participants at least some of the time. Qualitatively, it was exemplified by Debbie practicing blocks with her son, Martin changing his son’s dietary regimen, and Luis when he began to fix various things to save money. Minnes, Perry and Weiss (2015) identified parent coping variables as the greatest predictor of gain in a
negative situation as well as of parental distress. These parents who took charge of situation demonstrated a feeling of empowerment in having an element of control over their situations. Parental empowerment, in particular was identified as a strong predictor of parental gain and a strong negative predictor of parental distress and can be linked with bon-adaptation, as when Nina began to give back to families within her church; adaptation, as when Jim convinced Debbie to move to a single level home; or maladaptive, as when Kathy begins drinking.

There was no difference in the use of problem- versus emotion-focused coping mechanisms between qualitative and on-line participants. It is possible that this is due to coping mechanisms being a learned and inherent quality to which individuals resort during times of stress. It is part of the cache of resources available to individuals referred to within the Resiliency Model of Family Stress, Adjustment and Adaptation as resources. As inherent qualities within individuals, little change may be expected in the use of these mechanisms.

The greatest area of divergence between on-line and qualitative participants was in terms of issues of communication. As there were no questions on the survey which addressed communication, it was impossible to have any convergence. However, as this issue was in the forefront for almost all qualitative participants, addressing it is vital. Most qualitative statements arose from the theme, “Life in the Negative,” with a few being noted in “If Only…The Desires of Parents.” All issues reported that had to do with health care providers had to do with communication, primarily lack of communication or inadequate communication with a few positive statements regarding positive experiences. Martin reported multiple issues of trust with nursing, “Yeah, it felt like I was being tested to see like I a bad parent or I was a good parent. I felt like [hospital name] did not trust me.” In reference to physicians, he complained, “…when the doctor told me my symptoms my son had, I did not understand a word he said. I had to ask a
nurse.” Carla and Luis both addressed a shut down in communication with the physician(s) and nurses caring for Rosa. Carla said, “Doctor say if Rosa’s heart stop, we should no bring her back. We say no. Doctor no talk to us no more…” Debbie and Carla both voiced concerns regarding lack of communication during the post-partum period. Carla reported, “They just come in, don't talk, just ask about my pain and bleeding, then leave. They no ask about Rosa.” Debbie mirrored these comments, “My doctor never talked to me. I kept asking and asking what happened and he always evaded the question. The nurses on the … floor just kind of came in, asked how I was feeling, but when I started to talk about Stevie, they didn’t stay long.” Jones, Taylor, Watson, Fenwick and Dordic (2015) described a disconnect between nurses and parents of preterm infants in the neonatal intensive care unit with parents at times describing an inability to engage with the nurses caring for their infants. Wigert, Dellenmark and Bry (2013, 2014) studied parents of infants in the NICU from both qualitative and quantitative perspectives. They found that only about 50% of parents felt that either physicians or nurses were able to appreciate their emotional status. Most concerning was that a lack of communication or perceived communication led to feelings of loneliness and abandonment, as well as a feeling of being excluded from parenting. Fisher and Broome (2011) recommended a caring and inclusive approach with families, such that families could feel nurtured and cared for, as well by means of creating an interpersonal relationship.

In addition, random comments by strangers and others were viewed as emotionally painful. Carla stated, “People mean: doctors, nurses, people on street, like they mad at me…” Kathy reported “It’s been a challenge. People tend to be rude and ignorant…” Infanticide of infants with disabilities was proposed by Ernst Haeckel in 1870 in his book, *The Natural History of Creation* (Weikert, 2004). This became the fuel for the development of eugenics and Hitler’s
atrocities in Europe. Toward the end of the 19th century, state schools appeared, the term, “idiot,” was commonplace. Darwin’s theories were becoming known. A child with a disability was a problem within the family and the result of sinful, diseased parents. It is understandable that families in the 19th and 20th centuries passed these stigmatizing responses on to future generations.

At the dawn of the twentieth century being “normal” became increasingly important. Imperfections were something to be fixed or discarded (Strong-Boag, 2007). Despite advances being made in the acceptance of individuals with physical and/or cognitive differences, bias has continued to be appreciated toward individuals with disability, including thoughtless comments, bullying and shunning (Koshti-Richman, 2009; McMurray & Thompson, 2016; Raffalli & Pomeroy, 2016; Wilson & Scior, 2015).

Positive statements of communication had to do with the communication style of nurse practitioners with Nina stating that she clung to works of encouragement made by the practitioner caring for her daughter and Melissa recommending the use of more practitioners for children as sick as Mary and further stating that she took lessons of communication by the practitioners back to her clinical practice. It cannot be determined if such statements were made because the investigator is a nurse practitioner, but it is encouraging to know that there were positive communication experiences for some of these parents.

5.3 Limitations of the Study

Perhaps the greatest limitation within this study was in the number of potential informants who declined to be interviewed. It is not a surprise that a parent may not desire to take part in what may be emotionally painful. While many potential participants provided contact information, they often declined the interview or would not return phone calls. The
stories of these individuals may have been insightful. In addition, there was an inadequate sample of on-line participants to achieve adequate power. There may be a variety of reasons for this. Addressing painful emotions is never an easy task, even in the best of situations. Reaching out to a parental support sight on line may be considered one of simply support or helpful advice, but not necessarily an activity where an individual may choose to address difficult feelings. This may be supported in part by the fact that none of the on-line participants expressed interest in taking part in an interview. While some parents did choose to fill out surveys, they may be thought of as a specific subset: they have access to a computer and possess internet skills, they may be more literate than individuals who do not choose to participate; or they have a child who the parents view as having a minimal or no level of disability, negating their need or desire to seek on-line support.

One limitation of this study is that qualitative participants filled out the surveys after the completion of the interview, which may have had an element of therapeutic benefit. Heideggerian phenomenology permits the researcher to use reciprocity with the participant to develop an almost conversational aspect to the interview, which is believed to be vital to the understanding of the phenomenon and specifically useful in terms of caring encounters (Dowling, 2005; Mackey, 2005). However, it is believed by the researcher that the interview experience may have been helpful in terms of comfort, thus the participant may have had a different point of view when the surveys were completed.

Perhaps the most confounding limitation of this study had to do with qualitative participant recruitment. While multiple families coming through the doors of the follow-up sites would have met criteria, many did not voice interest. This occurred despite the fact that the researcher presented herself to the health care providers and clerks on a regular basis. Pamphlets
were in multiple areas. Additionally, while many parents were identified by health care providers with information in the parents’ handwriting provided to the researcher, they often either declined the interview or would not return phone calls. The particulars of these individuals and their stories may have been insightful. No respondents to the on-line surveys agreed to be interviewed. This may have been secondary to a potential loss of anonymity that would occur off line. Only parents of children under five years of age were interviewed. It is believed that either once the child is older if his/her challenges are minimal, they may not be on the minds of parents or if the disabilities are severe, the parents may be more fatigued and entrenched in care giving.

Despite a varied population at the study institution, only Caucasian and Hispanic families agreed to participate. This left out an important conglomerate of African American families and others, whose views may have been quite helpful.

5.4 Conclusions

Parents of children who had HIE make up a unique population, heretofore under-studied. This study has uncovered issues of stress and depression at high rates, seen more often in parents of children perceived by their parents to have moderate or severe disabilities. It has shown that daily life for the family has been impacted. Furthermore, that coping appears to be based on past, learned techniques, not differing based on parentally perceived degree of disability. In addition, it has highlighted issues of communication with both the nursing and medical teams as well as societal stigmatization. Parents have described being avoided or abandoned not only in general, but also when their goals were not in line with the medical team. On the contrary, some parents identified the nurse practitioner as particularly beneficial in terms of communication. In conclusion, implications for further research, education and practice are plenty.
5.5 Implications and Recommendations

5.5.1 Implications for Research.

Despite the birth of a newborn requiring resuscitation being considered traumatic, there is no literature which specifically addresses HIE or birth asphyxia in relationship to PTSD or acute stress disorder, thus making it a fertile area for future research. Studies addressing the initial hospital care from prior to delivery through the neonatal intensive care experience through follow-up care need to evaluate communication and the perceptions of communication. It is likely that some care providers are not comfortable in situations with potentially negative or even devastating outcome. Studies evaluating education programs for medical, nursing, and therapy providers in terms of communication, such that improved communication may affect some of the negative emotions, such as stress and depression, might be appreciated. Evaluation and augmentation of cultural competency of care providers for such families, understanding that being the parent of a child with disabilities is its own, culture may be undertaken.

5.5.2 Implications for Practice.

Perhaps the single most comment by parents when asked what we as health care providers could do for them, was to listen. While provision of information and physical care is vital, it has been shown that actively listening to what parents have to say and asking them what is on their minds can be beneficial in terms of reducing feelings of abandonment and being ignored by health care providers (McMurray & Thompson, 2016; Raffalli & Pomeroy, 2016; Wigert et al., 2013, 2014). It has been recommended that staff be cognizant of parental presence, avoiding personal conversations, particularly when those conversations delay care. Enabling parents to parent has been viewed as vital in this difficult situation, particularly as physical contact is extremely limited during the perinatal and cooling periods (Heringhaus, Blom, &
Wigert, 2013). Even helping a parent to change a diaper during this difficult time provides that opportunity. It has also been recommended that if possible, a member of the resuscitation team be available during the resuscitation to communicate with parents in real time.
CHAPTER 6
MANUSCRIPTS

Parents of Children Who Had Hypoxic-Ischemic Encephalopathy: A Mixed-Methods Exploratory Study: Part 1, Qualitative Strand

This manuscript is being submitted to “Advances in Neonatal Care.” The author guidelines require AMA formatting; therefore, this chapter is presented according to AMA formatting requirements. Tables are to be submitted in a separate document, but for the purposes of this chapter, they are submitted within the text.

Abstract

**Background:** There is scant literature addressing the parents of children who had hypoxic ischemic encephalopathy (HIE), therefore only inferences may be made as to variables that affect their perceptions of their experiences.

**Purpose:** The purpose of this study was to uncover the lived experiences of parents of children who had HIE, in order to better care for them and thus, their families.

**Methods:** A parallel, convergent mixed-methods design was used to explore experiences and perceptions of these parents regarding their experiences and life changes. Quantitative surveys addressing impact of family, stress, depression and coping were completed by 51 parents, 9 of whom participated in a single qualitative interview using Heideggerian phenomenology. For the purposes of this manuscript, only the qualitative findings will be discussed.

**Results:** Qualitative results yielded six themes: *unmet expectations, the source of my strength, life in the negative, outside of reality, lemonade from lemons, and the desires of parents.* Parents expressed unmet expectations from the time of their labor and delivery experience through present challenges. Family, God and professionals were identified by parents as providing
strength. While few parents identified positive aspects of the experience, almost all voiced clear desires regarding the care they received.

**Implications for Practice:** Health care providers have a significant role in aiding parents with the challenges of parenting a child who had HIE.

**Implications for Research:** Further research aimed at parental needs throughout the caring process may provide clinicians with methods by which more supportive care may be provided.

**Key Words:** Hypoxic-Ischemic Encephalopathy, Parents, Disability, Stress, Family, Coping. Depression, Mixed-Methods, Heidegger
BACKGROUND: “The act of birth does occasionally imprint upon the …nascent infantile organism very serious and peculiar evils.”\(^{1(p243)}\) HIE affects between 1 and 8 of 1,000 births in the United States.\(^2\) While hypothermic therapy has improved outcomes, disability remains high and death is not uncommon.\(^3\) Survivors exhibit a full range of sequelae.\(^4–12\) Seizures, cerebral palsy, and behavioral and cognitive challenges occur.\(^5,7–11\) Even in those who are “typically” developing; learning, memory and fine motor skills may be lacking.\(^12\)

Grief over the loss of the idealized child has been linked with long-term health effects on parents.\(^13–15\) Posttraumatic stress disorder, grief, depression, stress and ill health have been described in parents who had traumatic deliveries and within the neonatal intensive care unit.\(^16–21\) There are few studies which address parents of children who had HIE, with no studies found that describes their feelings or concerns from the perinatal period through childhood.

As a unique population, this creates a significant gap in the literature making this study both timely and necessary. By understanding the experiences of these parents, we in health care may be better able to provide the care and support needed to improve their overall lives.

MATERIALS/SUBJECTS AND METHODS

Study Design: A parallel, convergent mixed-methods design was used to explore experiences and perceptions of parents who have a child who had HIE. The qualitative strand used a Heideggerian phenomenological methodology, guided by a single research question: “What is the lived experience of parents of children who had HIE?”

Setting: The qualitative strand of this mixed-methods study was conducted in the homes of 9 parents in Northeastern United States, who were part of the larger study (n=51).

Sample Selection: Inclusion criteria included: being the birth parent of a child who had HIE, 18 years of age or older, literate in English, and had a child less than 18 years old, born between 35
and 43 weeks gestation. Exclusion criteria included: parents of children with congenital anomalies or were no longer living, or parents who required that they be interviewed together.

Following IRB approval from the primary study hospital and the investigator’s university, fliers were placed in pediatric, pediatric neurology, neonatal follow-up clinics and community businesses. Potential participants contacted the investigator by placing an index card in a locked box or by calling or emailing the investigator. Sampling was by convenience, assurances of confidentiality were made, and written consent was obtained from all participants. At the onset of the interview, respondents were reminded that they could stop the interview at any time. In addition, the consent form contained supportive web sites and of the availability of counseling from the follow-up clinics.

Methods: Prior to the interview, participants completed a demographic form and intake questionnaire. Heideggerian phenomenology was the method of inquiry. As an interpretive approach, it assumes that perceptions provide us with evidence of “being” in the world. Data collection and analysis occurred concurrently until saturation occurred. Data saturation refers to the point in data collection, after which no new information emerges. According to Heidegger, member checking negatively affects findings, as the context of the interview is changed, thus threatening the rigor of the study. For this reason, validations and questions requiring more detail were addressed during the interview. In addition, data obtained from earlier interviews prompted probing questions in subsequent interviews. A conversational style of interviewing is encouraged as reciprocity is vital to the understanding of the phenomenon.

Interviews were open-ended and began with the question, “Will you please tell me what it is like for you to be (child’s name) mother (or father)?” Follow-up and clarifying questions were addressed during the interview in order to elicit a deeper understanding of the phenomenon.
Participants were allowed an uninterrupted opportunity to express themselves. Interviews lasted between 40 and 120 minutes. At times, supportive statements were made. This proved effective in encouraging further dialogue. As the participants shared their stories, an in-depth understanding of their contexts was revealed, aiding in the revelation of their individual realities.

**DATA ANALYSIS:** Prior to analysis, the researcher addressed her “fore-structures” or preconceptions in terms of how they may have colored data interpretation. While it is impossible to lay aside all presuppositions, biases and preconceptions were checked to minimize their effects. This researcher maintained a diary which included her reflections of interviews, notes, memos, participants, and her own feelings. The researcher could then look upon her fore-structures, which may have impacted the understanding of that data and take them into account. Lindseth and Norberg refer to this as “bracketing our judgments.”

Audiotapes were immediately transcribed verbatim by the researcher and entered into NVIVO 10, using pseudonyms. After transcribed data was checked for accuracy, memos and field notes were added. The Heideggerian researcher is taught to “lose oneself” in the data, allowing the thoughts to just come together. In addition, the researcher re-listened to the taped interviews to better appreciate inflection, emotion, and the informants’ story intents. This comprised the first steps of analysis and created a “naïve” understanding. The initial naïve understanding contained 46 meaning units, which were compressed into 12 subthemes and 9 themes. Repeating this process ultimately led to the six final themes and relevant subthemes.

The following phase of analysis is a structural thematic analysis. In this phase meaning units, which may contain multiple, seemingly inconsequential (by either the content or the informants’ inflections) statements were identified. The text was then reread with these units and described in common language. The units were then sorted and condensed into subthemes,
at times discarding insignificant units. This process was repeated to create themes. The researcher then returned to the naïve understanding to determine if these themes were in agreement. When the thematic analysis was in disagreement, the text was reread and a new naïve understanding was created. This process was repeated until both the naïve understanding and thematic analysis were aligned. After theme development, in order to understand family efforts, the Resiliency Model of Family Stress Adjustment and Adaptation\textsuperscript{32,33} was used to help understand parental efforts, both conscious and subconscious, to cope with their individual situations.

It is at this point that the researcher returned to the research question and preunderstandings. Reflection upon the research question, preunderstandings, and the text, allowed the investigator to achieve a deepened understanding of the text.\textsuperscript{31} This led the researcher to the final phase of analysis, where further interpretation of being the parent of a child with HIE was sought through the experiences of other parents in similar, albeit differing challenges with their children, as well as through the lay literature. The goal at this point was for the researcher to gain insight into the varying “truths” about the phenomenon.

**RESULTS**

**Sample Description:** The qualitative sample consisted of 9 parents, identified by pseudonyms, 7 of whom were recruited from the primary study hospital, while 2 were from recruited via fliers posted in community businesses, all of whom participated in the quantitative strand of the study (Table 1).
Table 1. Participant Characteristics (N = 9)

<table>
<thead>
<tr>
<th>Name</th>
<th>Education</th>
<th>Employment</th>
<th>Marital Status</th>
<th>Children</th>
<th>Age</th>
<th>Perceived Degree of Child’s Disability</th>
<th>Background</th>
</tr>
</thead>
<tbody>
<tr>
<td>Martin</td>
<td>Some HS</td>
<td>Unemployed</td>
<td>Living together</td>
<td>1</td>
<td>11 Mos.</td>
<td>Moderate</td>
<td>Cognitive and mental health issues</td>
</tr>
<tr>
<td>Lisa</td>
<td>Some HS</td>
<td>Unemployed</td>
<td>Living together</td>
<td>1</td>
<td>11 Mos.</td>
<td>Mild</td>
<td>Cognitively impaired</td>
</tr>
<tr>
<td>Debbie</td>
<td>College</td>
<td>Unemployed</td>
<td>Married</td>
<td>1</td>
<td>18 Mos.</td>
<td>Mild</td>
<td>Chronic health condition</td>
</tr>
<tr>
<td>Jim</td>
<td>College</td>
<td>Employed</td>
<td>Married</td>
<td>1</td>
<td>18 Mos.</td>
<td>Mild</td>
<td>Chronic health condition</td>
</tr>
<tr>
<td>Carla</td>
<td>HS</td>
<td>Unemployed</td>
<td>Married</td>
<td>3</td>
<td>11 Mos.</td>
<td>Moderate</td>
<td>From Honduras</td>
</tr>
<tr>
<td>Luis</td>
<td>HS</td>
<td>Employed</td>
<td>Married</td>
<td>3</td>
<td>11 Mos.</td>
<td>Severe</td>
<td>From Honduras</td>
</tr>
<tr>
<td>Kathy</td>
<td>Master’s</td>
<td>Unemployed</td>
<td>Single</td>
<td>1</td>
<td>3 years</td>
<td>Severe</td>
<td>Identified as homosexual</td>
</tr>
<tr>
<td>Melissa</td>
<td>Doctorate</td>
<td>Employed</td>
<td>Married</td>
<td>1</td>
<td>4 years</td>
<td>Severe</td>
<td>Medical background</td>
</tr>
<tr>
<td>Nina</td>
<td>HS</td>
<td>Unemployed</td>
<td>Married</td>
<td>2</td>
<td>19 Mos.</td>
<td>None</td>
<td>From Honduras</td>
</tr>
</tbody>
</table>
A Heideggerian phenomenological approach was used which revealed 6 major themes and a variety of subthemes, which were reflective of the life experiences of these parents (Table 2).

<table>
<thead>
<tr>
<th>Table 2. Major Themes and Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Unmet Expectations</strong></td>
</tr>
<tr>
<td>My Child is not What I Expected</td>
</tr>
<tr>
<td>My Life is not What I Expected Because of My Child</td>
</tr>
<tr>
<td>My/Our Delivery Experience was not What I Expected</td>
</tr>
<tr>
<td>The Care for Myself and My Child was/is not What I Expected</td>
</tr>
<tr>
<td><strong>The Source of My Strength</strong></td>
</tr>
<tr>
<td>I get my Strength from Beyond Myself</td>
</tr>
<tr>
<td>I get my Strength from Others</td>
</tr>
<tr>
<td>I get my Strength from God</td>
</tr>
<tr>
<td>I get my Strength from Within</td>
</tr>
<tr>
<td>Positive self-talk</td>
</tr>
<tr>
<td>Taking the Bull by the Horns</td>
</tr>
<tr>
<td><strong>Life in the Negative</strong></td>
</tr>
<tr>
<td>The Negative Wish</td>
</tr>
<tr>
<td>Negative Behavior</td>
</tr>
<tr>
<td>My Own</td>
</tr>
<tr>
<td>Health Care Providers</td>
</tr>
<tr>
<td>Others</td>
</tr>
<tr>
<td><strong>Outside of Reality</strong></td>
</tr>
<tr>
<td>Dreams and Wishes</td>
</tr>
<tr>
<td>Blinded by the Situation</td>
</tr>
<tr>
<td>The World is Against Me</td>
</tr>
<tr>
<td><strong>Lemonade from Lemons</strong></td>
</tr>
<tr>
<td><strong>If Only…The Desires of Parents</strong></td>
</tr>
</tbody>
</table>

Parental focus was most often on unmet expectations and issues of communication. Most participants shared issues that addressed their views of the child, their lives, the medical community, and society. There were two interviews in which the researcher was asked about her own experience. Heidegger views this as beneficial, viewing the respondent and researcher as partners on a two-way street. Seeking or questioning is cognitively guided by what is sought and is congruent with Heidegger’s concept of “being.” The researcher sought to understand the participants’ life experience. Some respondents sought to understand the
researcher’s perspectives. Answering these questions honestly and succinctly is believed to have augmented the responses from the participants, who then knew that the researcher understood some of their personal reality.

**Theme I. Unmet Expectations.** Having a child who had HIE was frequently met with an element of dismay. All participants identified some unmet expectations.

**Subthemes**

1. *My Child is Not What I Expected,* addressed differences in the child. Carla stated, “She can no do like my other children.” Kathy stated, “She’s three… doesn’t walk...”

2. *My Life is Not What I Expected Because of My Child* addressed sadness and frustration regarding life changes and was exemplified by Melissa, “My marriage is on the rocks, my career is on the rocks, I resent Mary and I hate myself...” and then addressing her daughter’s care burden, “…I get up at five...to get her bathed...she’s so stiff... I do chest PT. I put her into her chair... give her her meds...her feeding... go to medical day... get her cleaned up again.”

3. *My/Our Delivery Experience Was Not What I Expected* addressed an often-shattered dream of a positive delivery experience. Most responses had to do with lack of contact, fear, pain, and communication. Martin: “I was angry... all we seen was his hair inside a box.” Nina related fear in her story of her daughter’s resuscitation, “Juan (who did not speak English) tell me Juanita not breathe.... He say you put tube in mouth. He hear you call orders...Another doctor come running in...People calling out, counting...Nobody talk to him (husband)... He think she dead.”

4. *The Care for Myself and My Child Was/is Not What I Expected* addressed disappointment in the care, or often lack of care, received from the health care team.
Debbie complained, “My doctor never talked to me…he always evaded the question” and in the post-partum unit, “The nurses … when I started to talk about Stevie, they didn’t stay…”

Theme II. The Source of My Strength. With so many unmet expectations from multiple fronts, this theme focused on the identification of supports.

Subthemes

1. *I Get My Strength From Beyond Myself,* was subdivided into two smaller categories: *I Get My Strength From Others* and *I Get My Strength From God.* Martin spoke with his therapist. Lisa cried to her mother. Nina identified her family and this investigator, “My mother, abuela, sisters…One would stay every night…I remember you say you (this investigator) worry about brain, but babies can adapt better than adults. I hang on to that.” Luis related, “I talk to priest…I tell priest I think doctor right (for requesting discontinuation of support) … He tell me to keep pray…” Nina jubilates, her daughter is doing well. “We praise God…We ask him protect you and doctors, nurses who save Nita.”

2. *I Get My Strength from Within* addressed how some parents found strength and coping from within themselves and included two smaller categories: in *Positive Self Talk,* Debbie encouraged herself, “He’s going to catch up just fine.” In *Taking the Bull by the Horns,* Rosa seemed to come to life, “Most time just stare. This one lady say, “That poor baby should die…” I say, “You want me to wish on your baby!” Jim works to make their future secure, “I work a lot of overtime…I want to be prepared.” Debbie is determined to help Stevie be “normal;” “I spend every… moment with him; doing his therapy, playing with blocks.”
Theme III: Life in the Negative. Negative experiences were discussed by most participants and addressed wishes and dreams that were painful, potentially harmful behaviors, and the hurtful behavior of others.

Subthemes

1. The Negative Wish was reflective of the pain of the family and child. Luis lamented, “I wish Rosa no live… I wish doctor take Rosa off…” Kathy stated, “I wish someone would kill me…I wish Kristin had died.”

2. My own, referred to negative behaviors or negative coping techniques. Melissa stated, “I’m not an alcoholic. I just have 2 or 3 glasses after I put Mary down and 1 or 2 in the afternoon…”

3. Health care providers addressed behaviors arising from the health care community. Martin: “It felt like I was being tested…” Carla addressed a shutdown, “Doctor say if Rosa’s heart stop, we should no bring her back. We say no. Doctor no talk to us no more…”

4. Others made up the final subtheme. Random comments were emotionally painful. Carla reported a stranger on the street saying, “That poor baby should die…” She since has not taken Rosa for a walk.

Theme IV. Outside of Reality. This theme addressed dreams, daydreams, denial and feelings of persecution, all in an attempt to deal with their difficult reality, and was brought to light by 4/9 participants.

Subthemes

1. Dreams and Wishes. Martin dreamed of his son’s death, relating how while everyone was crying, he walked away. Kathy, in an apparent expression of guilt: dreamed that
she delivered a monster, “then I turn into a…monster… people start stoning me.”

She also related, “You know I dreamed of having a family…now everything is ruined.

2. *Blinded by the Situation*, addressed denial and lack of recognition, used in an attempt to deal with painful truths. In introducing me, Carla said, “Ola’ Rosa, my beautiful baby. See how she smiles and laughs...” Rosa was unmoving, drooling, and limp.

Kathy admits (to observation of her support systems) “Maybe I’m just so in the middle of things I don’t see that.”

3. *The World is Against me*, focused on feelings of persecution. Martin, feeling insecure, “Somebody’s gonna come and take him just because he’s underweight.”

Kathy complained, “Sometimes I think I can’t get more because I’m gay.”

**Theme V. Lemonade from Lemons:** Theme 5 identified positive aspects of the parental experiences. Two parents exhibit bon-adaptation, (refers to coming out of a situation better than how one went into it,) a third is working toward it, while others identify positivity in other aspects. Luis proudly stated, “We cut bills... I fix refrigerator..., no call someone...” Nina is giving back. “I tell priest that if something happen somebody’s baby, I help… give hope.” For others, the interview was identified as beneficial. Melissa stated, “I feel pretty good… more energized than…in a long time.” Luis, smiling stated, “I no tell people what I tell you today. Is good...”

**Theme VI. If only...The Desires of Parents:** In this theme, parents offered their desires, based upon what they expressed was lacking in their experience of having a child who had HIE. Carla and Luis recommended that health care providers should be sensitive, listen, and ask questions rather than assume. Kathy, who expressed being persecuted because of her sexual
identify, desired societal change. Melissa recommended “Have more nurse practitioners... residents [should] sit with practitioners when they speak with families.” Nina similarly stated, “I think you need to teach other doctors how to talk with parents.”

**DISCUSSION**

This study has provided health care providers with new knowledge regarding a heretofore understudied population. As a unique population who anticipates the birth of a healthy new family member, who then is affected by an unthinkable, possibly devastating event, their emotions and coping are challenged. The birth may often be traumatic, both in process and the aftermath of a possibly witnessed resuscitation. The aftermath may include confusing or seemingly unfeeling communications by the hospital staff and sights of what may appear to be a cold, dead baby. Most importantly, in many cases, parental lives are forever changed. The pain of missed milestones is mourned. The child is met by stares or comments from others, money becomes tight, and it often seems that no one understands.

While all characteristics of this phenomenon may not have been manifested, important issues were revealed in this study. Every parent described *unmet expectations*, which describes a loss of something anticipated. That loss is still felt and therefore may be described as grief. As demonstrated in other studies, grief may follow the loss of the idealized child. 13,36–38 Grieving individuals experience fatigue, loneliness, anxiety, somatization, guilt, anger, fear, and denial. 39–41 Denial is a form of positive reappraisal, but also an emotion-based coping mechanism which may be used to deal with that grief. 42 It provides an individual with the ability to formulate an image which allows one to cope by means of cognitive reappraisal of an otherwise painful situation. 43,44

*Unmet expectations* also addressed life changes. Parental stress has been found in
association with feelings of incompetence, role restriction, social isolation, relationship, and health problems. An inability to work or to decrease one’s work may create additional strain, decreased coping, decreased spousal support, and increased fatigue. Wei and Yu found that parents of children with multiple disabilities were more likely to be unmarried by the time the child grew to adolescence. Fatigue, frustration, anxiety, anger, helplessness, hopelessness, and isolation are prevalent in caregivers of high needs children.

These parents did not have the expected, joyful delivery of their dreams. For some, the experience remains profound. Pain, uncertainty, and loss of control contribute to fear, which may make delivery traumatic. Inadequate communication is not uncommon in perceived traumatic births. There is scant literature in regards to parental responses following the witnessing of their child’s resuscitation. However, it has been found that in parents of children resuscitated in the emergency room, parents generally felt that their presence was beneficial. Communication is impaired when there is a language barrier. Individuals with a Spanish-language preference are vulnerable due to decreased access to care, which includes understanding. Mothers who experienced traumatic births were interviewed by Beck. She uncovered four themes, the most applicable addressed inadequate communication.

In a study of parents who had a child with a disability, 62% reported dissatisfaction with the medical team. Specific issues included disrespect, disagreements regarding care, distrust, perceived unavailability, miscommunication, and misinformation. Physician communication, particularly when conveying difficult news may be as difficult for the physician to provide as for the parent to hear. This is likely due to a disconnect between the culture of being a healer and the culture of being the parent of a child with a disability, with neither fully appreciating the other’s point of view. Clever and colleagues found that only 33% of their sample of over
3,000 patients rated attending communication as excellent on four factors: treating the patient on an equal level, encouraging the patient to ask questions, letting the patient tell their story, and discussing therapeutic options.

The Resiliency Model identifies social support and family resources, such as beliefs, prior experiences, and individual and family strengths as factors in adaptation. God has been identified as a source of strength and comfort for many. Religiosity often waxes and wanes, frequently coming to the forefront during crisis. Speraw explored the spiritual experiences of parents of children with disabilities, finding that parents believed that their children were connected to God. The response of the clergy and spiritual community were instrumental in that connection or lack of connection, when there was a lack of acceptance of the child.

Most parents found strength within themselves. However, when disability is significant and supportive resources are low, the lifelong caregiving burden can lead to grief, chronic sorrow and depression. Suicidal ideations are often reflective of depression; however, they may also indicate challenges in coping with the illness of a loved one. On the other side of the spectrum, some are able to use positive reappraisal, finding something positive within a negative experience, creating a positive outlook and thereby seeing themselves as better for the experience, at times giving back to society.

Taking charge of a situation is usually a problem-focused coping mechanism, however it may also be used as emotion-focused, such as when a person vents anger toward an offending individual. Emotion-focused coping is neither positive or negative. Instead its usefulness is based upon ultimate adaptation. Problem-focused mechanisms may be augmented by positive reinterpretation, which heightens problem focused coping by enabling revision of plans or activities, such as reducing household expenditures. The problem-focused mechanism of
responsibility taking is highly correlated with psychological distress. However, it may also be viewed as planful problem solving which is negatively correlated with psychological distress.

*Life in the Negative* addressed experiences, wishes, dreams or actions that were emotionally painful or potentially harmful, as well as negative behaviors by others. In a pamphlet by United Cerebral Palsy, parents are told that resentment of this “thing” happening in your family is normal. News reports tell of situations where parents have killed their disabled children. These cases are described as “tragic, but understandable” with charges being dropped or reduced at times, due to the degree of parental stress. While there is scant literature regarding a parent’s wish for their child to die or to have died, one does occasionally see a wish that a child had not been born. Threats of self-harm have also been reported.

Negative behaviors addressed both behaviors and perceptions of negative behaviors. Substance use is an emotion-based negative coping mechanism, specifically escape-avoidance and is highly correlated with psychological distress. Random comments were painful and have been reported. In her blog, a mother of a child with autism tells of her experience in a pediatrician’s office. Another mother ranted about how children with autism should not be placed in the same class as “Normal” children. Despite the author telling the woman that her child had autism and the positive aspects of children who are developing typically being in the same class, the offending woman continued. This mother said nothing, leaving the pediatrician’s office without being seen.

Communication regarding bad outcomes or limitation of care may be viewed negatively. A study in the Netherlands found that discontinuation of support only occurred when parents and physicians were in agreement. What is in question is the communication that occurs when the family and the medical team are not in agreement. The American Academy of Pediatrics
addresses the care for such children and families, including: respect, dignity, appropriate palliative care, support for caregivers, and empathy while maintaining meaningful communication. Talking about a child in the neonatal intensive care unit with possible neurologic damage may be uncomfortable for nurses, physicians, and parents alike, as in discussions of end of life.

*Outside of Reality* often addressed dreams. Dream interpretation is inexact, but some work has been done. Maternal dreams of dead babies have been described as a means of alleviating the trauma of that death. Children with disabilities may be viewed as monsters, even by their parents. In *Frankenstein*, Victor Frankenstein creates the “creature,” who horrifies him, leading to his rejection of the “monster.” The parallel between the creature and a child with disabilities is clear and according to the author, is likely related to family tragedies within Mary Shelley’s own life.

Blinded by the situation addressed denial, and lack of recognition. Denial may be illustrated as seeing a child with a disability as being more able than he actually is. This is a positive illusion, however in this situation, it is used in a negative manner, i.e. denial of a difficult reality. Faerstein found that while mothers of children with disabilities often used problem-focused coping, which was effective in obtaining services, they also reported using more defensive, emotion-focused approaches, such as denial. The Resiliency Model views coping as neither positive nor negative; rather it is its success that contributes to the degree of adaptation. As infant response predicts attachment, a parent may believe that a child is responding positively to him or her, when there is no such response. This belief is necessary for the parent to form an attachment to the child.
Emotional tension between parent and child are believed to contribute to abuse of children with disabilities, perhaps even wishing that a child would die. The authors describe anger, frustration, or a feeling of powerlessness, spurred by care giving, leading to a lack of energy with a subsequent loss of control. This may be seen in situations with child behavioral issues, high care burden, or additional stressors within the home.

*The World is Against Me* described feelings of persecution. The parents in this study who exhibited feelings of persecution have been shamed in their lives in terms of insecure upbringings or personal factors. Shame amplifies the association between stress and paranoia, creating a vulnerability for paranoia and conversely, that resistance to shame could be a marker for resilience.

*Lemonade from Lemons* addressed positive outcomes, which are consistent with bonadaptation. There are a variety of internal family strengths at play in resiliency, some of which include: support from the health care team, family, and community. In addition, participation in a phenomenologic interview may serve to validate a difficult experience for the participant and may, in and of itself, have a therapeutic benefit.

*If Only…The Desires of Parents* addressed the voiced statements of what parents would have liked to have happen or happen in the future. All voiced desires centered around communication. Families who stated that they were cared for by nurse practitioners reported positive interactions, with recommendations for education and training. Practitioners were viewed as liaisons who understood and addressed their concerns. Several strategies employed by nurse practitioners were valued: 1) asking the patient’s or parent’s opinion; 2) asking if they were in agreement with the plan; and 3) interest in the impression of a situation. The practitioner was viewed as providing cohesion and coordination. Parents of children who died in the neonatal
intensive care unit identified positive and negative communication. Parents valued being able to ask questions and talk about their feelings. They desired to be spoken to with compassion, acknowledgement of their pain and person to person. Signs of personhood, such as a hand squeeze were viewed as very meaningful. While this study evaluated parents of children who died, the responses may be similar to those of parents of children in serious situations.

**Limitations of the Study:** The greatest limitation in this study was in the number of potential informants who declined to be interviewed. It is not a surprise that a parent may not desire to take part in what may be emotionally painful. While many potential participants provided contact information, they often declined the interview or would not return phone calls. The stories of these individuals may have been insightful. Only parents of children under five years of age were interviewed. It is believed that either once the child is older, if his/her challenges are minimal, they may not be on the minds of parents or if the disabilities are severe, the parents may be more fatigued and entrenched in care giving. Only Caucasian and Hispanic families agreed to participate. This left out an important conglomerate of African American families and others, whose views may have been helpful. In addition, there were many potential informants who did not speak English, their views may have been beneficial.

**Implications for Research.** There is no literature which specifically addresses HIE in relationship to stress of any kind, none which addresses long-term issues and minimal literature addressing short-term issues, thus making it a fertile area for future research. Studies addressing the hospital care from prior to delivery through the neonatal intensive care experience and follow-up need to evaluate communication and perceptions of communication. Further evaluation of the delivery, neonatal intensive care, and pediatric follow-up experiences is warranted from the parent, as well as the provider perceptions. Studies evaluating education
programs in communication for health care providers, such that minimization of negative emotions might be appreciated. Evaluation and augmentation of cultural competency of care providers may be undertaken, understanding that being the parent of a child with disabilities is its own culture. In addition, research is needed in parental perceptions of witnessing their child’s resuscitation. New instruments may be developed which target this unique population, which may include interview guides and/or new, more focused surveys. Most importantly, it would be particularly beneficial to use multiple centers from which to obtain participants. This would allow more confidence in statements as to this population’s experiences and needs.

**Implications for Practice.** It has been shown that actively listening to what parents have to say and asking them what is on their minds is beneficial in reducing feelings of abandonment by health care providers. 84–87 It has been recommended that staff be cognizant of parental presence, avoiding personal conversations, particularly when those conversations delay care. Enabling parents to parent has been viewed as vital, particularly as physical contact is extremely limited during the perinatal and cooling periods. 88 It is recommended that a member of the team be available during the resuscitation to communicate with parents in real time.

**Conclusions:** Parents of children who had HIE make up a unique, understudied population. This study revealed the stories of 9 parents who exhibited stress, depression, and various coping challenges in dealing with their delivery experience and children of varying disability levels. Perhaps most importantly, however, it identified the struggle both from within and without that these parents face every day. Much of what was uncovered is consistent with the struggles identified by parents of children with many challenges. What is unique for these parents is the emergent delivery experience. These findings add to the research available pertaining to the specific needs of parents of children who have experienced HIE. Furthermore, this study has
highlighted issues of communication with both the nursing and medical teams as well as societal stigmatization. Some parents identified negative issues related to the health care team while others reported the nurse practitioner as particularly beneficial in terms of communication.

By knowing the stress and emotional distress in these parents, targeted interventions may come forth to reduce emotional and thereby physical maladies. If parents have fewer physical and emotional consequences, target children and parents may experience a decrease in health care expenditures. Being able to show an improvement in health by providing appropriate emotional, financial, and physical support with potential decreased expenditures for a fragile population enables nurses and policy makers to lobby for increased support for this group.
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This manuscript is being submitted to “Advances in Neonatal Care.” The author guidelines require AMA formatting; therefore, this chapter is presented according to AMA formatting requirements. Tables are to be submitted in a separate document, but for the purposes of this chapter, they are submitted within the text.

Abstract

BACKGROUND: There is scant literature addressing the parents of children who had hypoxic-ischemic encephalopathy (HIE), therefore only inferences may be made as to parental issues.

PURPOSE: The aim of the quantitative and mixed-methods strands of the study were to evaluate issues of stress, depression, coping and impact of childhood neurologic disability in parents of children who had HIE.

METHODS: A parallel convergent mixed methods design was used to explore experiences, perceptions and feelings of parents who have a child who had HIE. The quantitative strand addressed 4 research questions which addressed the above stated purpose. The qualitative and quantitative strands were then explored seeking areas of convergence and divergence.

RESULTS: The total impact of disability and the parentally perceived degree of disability were positively correlated. Parents exhibited significant stress with 31.4% participants scoring above the 99th percentile. Of the women, 16.3% exhibited scores consistent with major depression. These were well enhanced by parental statements. Areas of divergence indicated that neither the quantitative surveys nor open ended interviews were adequate to capture issues, such as
communication between parents and health care providers, which was qualitatively revealed, but
was not addressed on surveys.

**IMPLICATIONS FOR PRACTICE:** Health care providers have the opportunity to discern
issues of concern in order to develop methods to aid parents with the challenges of parenting a
child who has had HIE.

**IMPLICATIONS FOR RESEARCH:** Further research aimed at assessing and addressing
parental needs and concerns may provide clinicians with methods by which more supportive care
may be provided.

**Key Words:**

Hypoxic-Ischemic Encephalopathy, Parents, Disability, Stress, Family, Coping,
Depression, Mixed Methods, Heidegger
BACKGROUND: Hypoxic-ischemic encephalopathy (HIE) affects 1 - 8 of 1,000 births in the United States. Stressors and medical issues create challenges. Posttraumatic stress, grief, depression, stress and ill health have been described with emergent deliveries and within the neonatal intensive care unit. While hypothermic therapy has improved outcomes, disability remains high and death is not uncommon. Seizures, cerebral palsy, behavioral and cognitive challenges occur. Even in those who are “typically” developing; learning, memory, and fine motor skills may be lacking. Grief over the loss of the idealized child has been linked with long term health effects on parents. Depression, stress, and anxiety are prevalent. The Resiliency Model of Family Stress, Adjustment and Adaptation addresses coping abilities as a factor in mal-adaptation, adaptation and bon-adaptation and was the lens through which data was viewed. There is a paucity of literature which addresses these parents, making this study both timely and necessary.

MATERIALS/SUBJECTS AND METHODS

Study Design: A parallel convergent mixed methods design was used to explore experiences, perceptions and feelings of parents who have a child who had HIE.

Research Questions:

1. What is the relationship between the self-rated, parental perception of degree of disability of their child and the impact of childhood neurologic disability?

2. Do parents of children with HIE exhibit more stress than parents of children who do not have disabilities?

3. Do parents of children with HIE meet criteria for depression?

4. What coping mechanisms are used by parents of children with HIE?
**Setting:** The quantitative strand was conducted via online support groups. Qualitative interviews were conducted in the homes of parents in Northeastern United States, who also filled out the surveys.

**Sample Selection:** Inclusion criteria included: being the birth parent of a child who had HIE, 18 years of age or older, able to speak and write in English, and had a child less than 18 years old, born between 35 and 43 weeks’ gestation. Exclusion criteria included: parents of children with congenital anomalies or were no longer living. Invitations to participate in the quantitative strand were posted on parent support web sites, which were devoid of identifiers, ensuring confidentiality and inferring voluntary consent. All forms and data were stored in locked file cabinets.

**Sample Description:** The quantitative sample consisted of 51 parents, 9 of whom also participated in the qualitative strand. A description of participants was compiled (Table 1) and the parentally perceived degree was obtained from the intake questionnaire (Table 2).
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<th>Quantitative</th>
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<td>n</td>
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<td>2</td>
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<tr>
<td>Other</td>
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<td>7</td>
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</table>
MEASURES

Methods: Parental perception of their child’s disability was surveyed on the intake form using four levels of disability: none to severe. The Impact of Childhood Neurologic Disability Scale (ICNDS) has Cronbach’s α of 0.92 and a test-retest reliability of 0.89. The Parenting Stress Index-Short Form (PSI-SF) has high reliability with alphas being close to .90 and provided normative data to which comparisons could be made. The Patient Health Questionnaire II (PHQ-2) has a high diagnostic accuracy with an area under the curve of 0.90 for a major depressive disorder and 0.89 for any depressive disorder. The Ways of Coping Questionnaire (WCQ) has an internal consistency for each subscale yielding a Cronbach α between 0.60 and 0.93.

Statistical Analysis: Medical records were available for 5 children (7 parents) and were compared with the parentally perceived degree of disability (Table 3).

<table>
<thead>
<tr>
<th>Disability</th>
<th>Parentally Perceived</th>
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<tbody>
<tr>
<td></td>
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<tr>
<td>None</td>
<td>15</td>
</tr>
<tr>
<td>Mild</td>
<td>18</td>
</tr>
<tr>
<td>Moderate</td>
<td>12</td>
</tr>
<tr>
<td>Severe</td>
<td>4</td>
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</table>

### Table 3. Comparison of Parentally and Medically Described Degree of Disability (N=7)

<table>
<thead>
<tr>
<th>Parent</th>
<th>Parentally Described</th>
<th>Medically Described</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Moderate</td>
<td>Moderate</td>
</tr>
<tr>
<td>2</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td>3</td>
<td>Moderate</td>
<td>Severe</td>
</tr>
<tr>
<td>4</td>
<td>Severe</td>
<td>Severe</td>
</tr>
<tr>
<td>5</td>
<td>None</td>
<td>Mild</td>
</tr>
<tr>
<td>6</td>
<td>None</td>
<td>Mild</td>
</tr>
<tr>
<td>9</td>
<td>None</td>
<td>Mild</td>
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</table>
The perceived degree of disability and impact of childhood neurologic disability was investigated using Spearman’s rho, then further analyzed by the Kruskal-Wallis. A series of t-tests analyzed parenting stress. Descriptive statistics, one-sample t-tests and Spearman’s rho were used to analyze depression. Coping was analyzed using a Friedman test, paired-sample t-test, and Mann-Whitney U. SPSS 20 was used for all statistical analysis. Qualitative data was analyzed using NVIVO 10.

**Mixed methods analysis:** Qualitative data was analyzed independently and prior to the quantitative data. The results were then explored. Side by side comparisons were made. The interviews were reread with surveys in mind. The density of statements was tabulated. Scores of on-line and in-person participants were compared. Wilcoxon Signed Ranks test was used to evaluate issues of stress. The Mann-Whitney U evaluated ICNDS, PHQ-2 and WCQ scores.

**RESULTS:**

**Quantitative Findings.**

**Question 1.** *What is the relationship between the self-rated parental perception of degree of disability of their child and the impact of childhood neurologic disability?* There was a moderate positive correlation between the total impact of disability and the parentally described degree of disability, \( r_s = .348, \ n = 50, p = .013 \). Parents who described their children as having a severe disability exhibited less impact upon the family, with only neurophysiologic disabilities being significant (Table 4).
These data were then analyzed based upon demographic variables using the Kruskal-Wallis.

Older parents and parents having greater incomes reported a greater impact (n = 47, $\chi^2 = 9.793$, df 4, p=.044; n = 47, $\chi^2 = 11.989$, df 5, p = .035, respectively). Child age approached significance (p = .052,) with parents of older children reporting a greater impact.

**Question 2. Do parents of children with HIE exhibit more stress than parents of children who do not have disabilities?** The percentiles of Parent-Child Dysfunction were examined, finding that the mean percentile was 88.98 with a range of 24 - >99. Sixteen of 51 (31.4%) participants scored greater than the 99th percentile for parent child-dysfunction, indicating very high stress levels, with instrument recommended intervention (Table 5).

<table>
<thead>
<tr>
<th>Subrealm</th>
<th>N</th>
<th>Rs</th>
<th>Sig</th>
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<td>Behavior</td>
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<td>-.580</td>
<td>.695</td>
</tr>
<tr>
<td>Cognition</td>
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<td>.092</td>
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<tr>
<td>Neurophysical</td>
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<td>.433</td>
<td>.002*</td>
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<tr>
<td>Epilepsy</td>
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<td>.157</td>
<td>.308</td>
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**Table 5. Parental Stress Based on the PSI-SF (N = 50)**

<table>
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<tr>
<th>Domain</th>
<th>n</th>
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<th>SD</th>
<th>t</th>
<th>Sig</th>
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<td>Child</td>
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<td>37.80</td>
<td>7.87</td>
<td>-3.74</td>
<td>.000*</td>
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<td>13.38</td>
<td>.000*</td>
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<td>Total Stress</td>
<td>47</td>
<td>112.51</td>
<td>22.73</td>
<td>10.17</td>
<td>.000*</td>
<td>1.48</td>
</tr>
</tbody>
</table>

**Question 3. Do parents of children with HIE meet criteria for depression?** Depression was appreciated in 22/51 (43%,) with the scores of 7 (13.7%) participants consistent with major depression. A one sample t-test revealed a significant difference between participants and the general population, (t = -11.607, p < .001, CI: -3.17 - -2.24), with a very large effect size of 1.63. Major depression was found in 7/43 (16.3%) of females. Spearman’s rho revealed that parents who perceived their children as having greater degrees of disability and longer initial
hospitalizations exhibited more depression, \((r_s = .564, n = 51, p < .001; r_s = .316, n = 51, p = .024,\) respectively). Total impact of disability and depression were positively correlated (Table 6).

Table 6. Depression in Parents of Children Who Had HIE (N = 51)

<table>
<thead>
<tr>
<th>Category</th>
<th>n</th>
<th>(r_s)</th>
<th>Sig</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>51</td>
<td>.126</td>
<td>.380</td>
</tr>
<tr>
<td>Age</td>
<td>51</td>
<td>.171</td>
<td>.231</td>
</tr>
<tr>
<td>Income</td>
<td>51</td>
<td>-.184</td>
<td>.195</td>
</tr>
<tr>
<td>Child Age</td>
<td>51</td>
<td>.238</td>
<td>.092</td>
</tr>
<tr>
<td>PPDD</td>
<td>51</td>
<td>.564</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td>Duration of Hospitalization</td>
<td>51</td>
<td>.316</td>
<td>.024*</td>
</tr>
<tr>
<td>Total Impact of Neurologic Disability</td>
<td>50</td>
<td>.304</td>
<td>.032*</td>
</tr>
<tr>
<td>Total Stress</td>
<td>47</td>
<td>.678</td>
<td>&lt;.001*</td>
</tr>
</tbody>
</table>

**Question 4.** *What coping mechanisms are used by parents of children with HIE?* There was no difference between the use of problem- \((M = 1.103, SD = .386)\) and emotion-focused \((M = 1.058, SD = .274)\), \(t (48) = .781, p = .44\) (two-tailed) styles. Problem-focused coping was used more by males (Md = 1.355, n = 8) than females (Md = 1.052, n = 41), \(U = 66.00, z = -2.651, p = .008, r = .38,\) for a small to moderate effect size. Those with higher incomes or more children used more problem-focused techniques. Parents of children perceived to have a moderate disability used more emotion-focused (Table 7).
<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Emotion Focused Mean Rank</th>
<th>$\chi^2$</th>
<th>Sig</th>
<th>Problem Focused Mean Rank</th>
<th>$\chi^2$</th>
<th>Sig</th>
</tr>
</thead>
<tbody>
<tr>
<td>Income (thousands)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;$25</td>
<td>8</td>
<td>28.63</td>
<td>1.254</td>
<td>.870</td>
<td>20.56</td>
<td>9.971</td>
<td>.041*</td>
</tr>
<tr>
<td>25-50</td>
<td>9</td>
<td>21.22</td>
<td></td>
<td></td>
<td>18.33</td>
<td></td>
<td></td>
</tr>
<tr>
<td>50-75</td>
<td>11</td>
<td>24.45</td>
<td></td>
<td></td>
<td>20.41</td>
<td></td>
<td></td>
</tr>
<tr>
<td>75-100</td>
<td>10</td>
<td>23.60</td>
<td></td>
<td></td>
<td>26.45</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;100</td>
<td>10</td>
<td>25.10</td>
<td></td>
<td></td>
<td>35.75</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of Children</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One</td>
<td>21</td>
<td>19.48</td>
<td>6.939</td>
<td>.031*</td>
<td>16.93</td>
<td>11.751</td>
<td>.003*</td>
</tr>
<tr>
<td>Two</td>
<td>18</td>
<td>26.72</td>
<td></td>
<td></td>
<td>30.75</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Three or more</td>
<td>10</td>
<td>33.50</td>
<td></td>
<td></td>
<td>31.60</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PPDD</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>14</td>
<td>22.36</td>
<td>8.604</td>
<td>.035*</td>
<td>18.61</td>
<td>4.671</td>
<td>.198</td>
</tr>
<tr>
<td>Mild</td>
<td>17</td>
<td>18.12</td>
<td></td>
<td></td>
<td>24.35</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate</td>
<td>12</td>
<td>32.67</td>
<td></td>
<td></td>
<td>30.21</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Severe</td>
<td>4</td>
<td>28.75</td>
<td></td>
<td></td>
<td>22.75</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
In order to evaluate the specific techniques used, relative scores were calculated based upon the number of questions in each category, scored 0 to 3, reflecting not used to used a great deal. The Kruskal-Wallis evaluated these techniques according to demographic variables.

Confrontive coping refers to mechanisms which address taking charge of a situation and was associated with the number of children, $\chi^2 (3, n = 49), p = .042$. Those with 3 or more used more confrontive techniques (Md = 1.08) than those with 1 child (Md = .667) or 2 children (Md = .833). The data were re-analyzed, combining severe and moderate disability, $\chi^2 = 8.409, p = .015$. In this case, the median for the moderate to severe disability group was (Md = 1.625), indicating that confrontive mechanisms were used to a moderate degree. There was a trend toward significance according to age, $\chi^2 (3, n = 48) = 6.739, p = .081$, with those in the 46-55 year age group using these techniques more frequently (Md = 1.333) as opposed to 18-25 year olds (Md = .667), 26-35 year olds (Md = .667), and 36-45 year olds (Md = .917).

A trend was appreciated in the use of escape and avoidance techniques, such as substance use, sleeping or excessive working, by income, $\chi^2 = 7.41, p = .116$. Those with the lowest incomes used these techniques more frequently (Md = 1.938) as opposed to those with higher incomes which ranged between 1.125 to 1.375. Parents who perceived their children to have greater degrees of disability used more escape-avoidance techniques, $\chi^2 = 8.536, p = .036$.

Positive appraisal is the evaluation of something in one’s life and, either consciously or subconsciously, viewing it with positivity, which enhances the successfulness of coping. It was associated with the presence of a relationship (Table 8) and the number of children, $\chi^2 (3, n = 49) = 11.214, p = .004$. Parents with 3 or more children recorded a higher median score (Md = 1.07) than those with 1 (Md = .429) or 2 children (Md = .929), meaning that parents with more children used positive appraisal more often.
Table 8. Relationship Status and Positive Reappraisal (N = 51)

<table>
<thead>
<tr>
<th>Relationship</th>
<th>N</th>
<th>Mean Rank</th>
<th>Median</th>
<th>χ²</th>
<th>Sig</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>21</td>
<td>29.90</td>
<td>.857</td>
<td>11.729</td>
<td>.019*</td>
</tr>
<tr>
<td>Unmarried in Relationship</td>
<td>6</td>
<td>28.50</td>
<td>1.143</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>9</td>
<td>27.72</td>
<td>.857</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>1</td>
<td>19.00</td>
<td>.571</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>12</td>
<td>13.13</td>
<td>.357</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Distancing behaviors remove an individual from something perceived as negative. They were used more frequently by males (Md = 1.083, n= 8) than females (Md = .667, n = 41), U = 76.50, z = -2.391, p = .016, r = .34), consistent with a very large effect size.

Mixed-Methods Findings.

Quantitative and qualitative data were collected concurrently. The results from the two strands were explored. Interviews were reread with quantitative findings in mind. Some qualitative data was quantified by tallying statements consistent with impact, stress, depression, and coping. The scores of the on-line sample were compared with the in-person. Areas of convergence and divergence were revealed. Qualitative themes and subthemes are presented in table 9.
Side by side comparison of the two data sets were made (Table 10).

<table>
<thead>
<tr>
<th>Table 9. Major Themes and Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Unmet Expectations</strong></td>
</tr>
<tr>
<td>My Child is not What I Expected</td>
</tr>
<tr>
<td>My Life is not What I Expected Because of My Child</td>
</tr>
<tr>
<td>My/Our Delivery Experience was not What I Expected</td>
</tr>
<tr>
<td>The Care for Myself and My Child was/is not What I Expected</td>
</tr>
<tr>
<td><strong>The Source of My Strength</strong></td>
</tr>
<tr>
<td>I get my Strength from Beyond Myself</td>
</tr>
<tr>
<td>I get my Strength from Others</td>
</tr>
<tr>
<td>I get my Strength from God</td>
</tr>
<tr>
<td>I get my Strength from Within</td>
</tr>
<tr>
<td>Positive self-talk</td>
</tr>
<tr>
<td>Taking the Bull by the Horns</td>
</tr>
<tr>
<td><strong>Life in the Negative</strong></td>
</tr>
<tr>
<td>The Negative Wish</td>
</tr>
<tr>
<td>Negative Behavior</td>
</tr>
<tr>
<td>My Own</td>
</tr>
<tr>
<td>Health Care Providers</td>
</tr>
<tr>
<td>Others</td>
</tr>
<tr>
<td><strong>Outside of Reality</strong></td>
</tr>
<tr>
<td>Dreams and Wishes</td>
</tr>
<tr>
<td>Blinded by the Situation</td>
</tr>
<tr>
<td>The World is Against Me</td>
</tr>
<tr>
<td><strong>Lemonade from Lemons</strong></td>
</tr>
<tr>
<td><strong>If Only... The Desires of Parents</strong></td>
</tr>
<tr>
<td>Survey Subject</td>
</tr>
<tr>
<td>----------------</td>
</tr>
<tr>
<td>Stress</td>
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<tr>
<td>Impact of</td>
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<tr>
<td>Disability</td>
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<tr>
<td>Depression</td>
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<tr>
<td></td>
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<tr>
<td></td>
</tr>
<tr>
<td>Survey Subject</td>
</tr>
<tr>
<td>----------------</td>
</tr>
<tr>
<td>Coping</td>
</tr>
<tr>
<td>Problem-focused</td>
</tr>
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<tr>
<td></td>
</tr>
<tr>
<td>Coping</td>
</tr>
<tr>
<td>Emotion-focused</td>
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</tbody>
</table>
Stress: A Wilcoxon Signed Ranks Test revealed a significant difference between the in-person and on-line total stress scores as reported on the PSI-SF, \( z = -1.94, p = .048 \) with a small to moderate effect size (\( r = .29 \)). While most of the PSI-SF scores were lower, multiple statements of stress were made. On-line participants (Md = 115, n = 38) exhibited significantly higher scores than in-person (Md = 100, n = 9), \( U = 87.00, z = -2.72, p = .023, r = .16 \), however, the in-person participants’ scores were well correlated with the number of stress statements made, \( rs = -.04, n = 9, p = .915 \). The mean scores for total stress for on-line participants were higher and within the range of what was considered to be high stress.\(^{34} \) Two in-person participants, who described their children as having severe disabilities, scored greater than the 99\(^{th} \) percentile. Qualitatively, verbalized stress issues fell into the themes of Unmet Expectations, *Life in the Negative*, and *Outside of Reality*, thus informing the quantitative findings.

Impact of Disability: In-person participants made between 0 and 6 statements of their children’s impact on either the child, themselves or their families, which was identified within the theme, Unmet Expectations, particularly in the subtheme, *Life is not What I Expected Because of my Child*. The Mann-Whitney U revealed a significant difference between in-person (Md = 9.50, n = 9,) on-line participants (Md = 43.50, n = 40), \( U = 52.50, z = -3.058, p = .002, r = .433 \), for a medium – large effect size.

Cognitive challenges impacted on-line (Md = 12.00, n = 39) more than in-person participants (Md = .00, n = 8), \( U = 31.50, z = -3.606, p = .000, r = .259 \) for a small to medium effect size. Neurophysiologic challenges created greater impact in on-line (Md = 17.00, n = 39) than in in-person participants (Md = 8.00, n = 8,) \( U = 82.00, z = -2.099, p = .036, r = .306 \) for a medium effect size.
**Depression:** Depression rates were higher than national averages with in-person participants having scores consistent with depression in 44.4% and 40% in the on-line sample. Statements consistent with depression were found in the themes, Unmet Expectations and Life in the Negative and included wishes of self-harm, death, loss of romantic interest, woe over the child’s neurologic status and statements of hatred of life.

**Coping:** Coping was evaluated based on the use of problem- and emotion-focused styles and found within the theme, The Source of My Strength. There was no difference based on participant type. Statements reflecting the use of emotion-focused mechanisms included references to God, support systems, emotional outbursts and the use of alcohol. Survey questions in relationship to these mechanisms were few, therefore, it is deemed difficult to draw conclusions. Statements consistent with the use of problem-focused mechanisms included continuing on, planning for the future and taking charge of both personal situations and finances.

The qualitative themes were then evaluated in terms of the quantitative data. Questions from the PSI-SF and the WCQ were looked at in terms of each question’s fit with the themes.

**Unmet Expectations** were addressed by 12 questions within the PSI-SF. Scores could range from 12 to 60, with higher scores indicating greater parenting stress. Scores ranged from 15 – 54, with a mean of 41.29, indicating that unmet expectations in regard to the child were moderately high. While not significant, parents who perceived their children to have severe disabilities identified more frequently with statements of unmet expectations, \( n = 48, \chi^2 = 3.982, \text{ df} 3, p = .263 \). This was exemplified by Melissa, who exhibited a score of 54, has a daughter perceived as severely disabled and lamented over her care burden and life changes.

**The Source of My Strength** was linked with the WCQ. *I Get My Strength from Within* included “Taking the bull by the horns” or taking charge and was addressed by 11 questions.
Scores ranged from 0 to 3 with a possible high of 33, with higher scores indicating more frequent use. Actual scores ranged from 0 to 24, with a mean of 13.86, indicating that this mechanism was used some of the time. Parents of children perceived to have severe disabilities identified with questions which indicated that they took charge of situations more frequently, (n = 49, \( \chi^2 = 8.200, \text{df} 3, p = .042 \)). This was exemplified by Debbie who “practiced” blocks with her son.

*Strength from Within* sometimes took an unrealistic turn, as when Carla uses “resource creation” and tells herself that her daughter smiles and laughs. Some parents encouraged themselves. Thirteen questions were reflective of finding strength within one’s self. The potential range of scores was 0 to 39. Actual scores ranged from 4 to 26 with a mean of 13.88, indicating that these methods were used by all respondents at least some of the time. Some parents created positive illusions by perpetually formulating and maintaining their ability to tap into their supports. There was no relationship with any demographic variables, indicating that strength from within may be a pre-existing trait.

God as a source of strength was addressed by 2 questions. Scores ranged from 0 to 6. For those who identified God as a source of strength, n = 28, the mean score was 3.18 indicating that His use as a coping mechanism was used a moderate amount of time. There was no relationship between God and the perceived degree of disability.

In-person participants identified family members, friends, therapists and a health care provider as being supportive. The WCQ contained 4 questions which addressed other individuals as support. Scores could range from 0 to 12, with a scored range of 1 to 9 with a mean of 5.43, indicating that when this mechanism of support was used, it was used with moderate frequency.

*Life in the Negative* addressed experiences, wishes or dreams that were painful or caused shame, potentially harmful actions and negative behaviors of others or the perceptions of such.
It was exemplified when Luis spoke of wishing that his daughter had died, when Kathy spoke of her dream of she and her daughter being monsters and when Carla and Melissa spoke of unkind comments. There were 22 questions on the PSI-SF and 2 on the WCQ which were related. Scores could range from 22 – 116. Scores for 48 participants ranged from 30 to 95 with a mean of 64.1, indicating that most participants experienced a moderate amount of stress and spent energy coping with negative experiences. The Kruskal-Wallis revealed that the degree of stress and coping with negative experiences was positively correlated with the perceived degree of disability (n = 48, χ² = 9.596, df 3, p = .022).

*Lemonade from Lemons* referred to statements of positivity or a positive benefit of an experience. This was identified by 5 WCQ questions. Scores could range from 0 to 15. The 49 participants scored between 0 and 9 with a mean of 3.78 and a median of 4.00, indicating that participants used some positivity some of the time. Qualitatively, this was expressed by Nina, who helped families of ill children from her church.

*Outside of Reality* addressed dreams and thoughts that were not grounded in fact. This was addressed by 2 questions. Notably, 43 of 49 (87.8%) participants reported the use of this mechanism. Scores ranged from 0 to 6, with a mean of 3.63 and a median of 4.00, indicating that many participants used some element of a leave from reality in coping. While not significant, (n = 49, χ² = 6.10, df 3, p = .107,) parents of children with moderate disabilities tended to use these mechanisms more frequently.

*If Only…The Desires of Parents* was not addressed on the surveys. Communication was the greatest area of divergence and found within the themes of If Only… The Desires of Parents, Life in the Negative, and The Source of My Strength. These findings indicate that neither interviews or surveys, alone, were adequate to capture all issues of importance.
DISCUSSION: Having a child with a disability causes profound changes in the family. The impact of anxiety and depression are great and require adaptation.\textsuperscript{36} The Resiliency Model addresses inherent coping abilities as contributing to mal-adaptation, adaptation, and bon-adaptation in response to crisis or stress.

Stress has been found to be linked with the psycho-emotional severity of a disability more than the physical.\textsuperscript{37–39} High stress levels, requiring intervention, have been found in a third of parents of adolescents with cerebral palsy, with the main stressors being motor and behavioral issues.\textsuperscript{40} High levels of stress and depression were found in many respondents. Many of which had to do with communication, which has been cited as a source of stress.\textsuperscript{41}

In the mixed-methods analysis, communication was the greatest area of divergence, simply because it was not on the surveys. Inadequate communication is not uncommon\textsuperscript{42} with disrespect, disagreements regarding care, inadequate information, distrust, perceived unavailability, miscommunication and misinformation being reported.\textsuperscript{43} In a study of parents who had a child with a disability, 62\% reported dissatisfaction with the medical team.\textsuperscript{36} This is consistent with the descriptions of many in-person participants, which most often arose from “Life in the Negative.” A study in the Netherlands\textsuperscript{44} found that discontinuation of support only occurred when parents and physicians were in agreement. What is in question is the communication that occurs when they are not in agreement. Talking about a child in the neonatal intensive care unit with possible neurologic damage, may be uncomfortable, as in end of life discussions.\textsuperscript{45,46} A disconnect can occur between nurses and parents in the neonatal intensive care unit with parents describing an inability to engage staff.\textsuperscript{47} Parents felt that the medical/nursing team was not able to appreciate their emotional status, which led to feelings of loneliness and abandonment, as well as a feeling of being excluded from parenting.\textsuperscript{48,49} The
American Academy of Pediatrics addresses principals in this specialized care, including: respect for dignity, access to appropriate palliative care, support for caregivers, respect, empathy and meaningful communication. \(^{45,50}\) Parents desire to be spoken to with compassion, person to person, and with acknowledgement of their pain. Participants who stated that they were cared for by nurse practitioners reported positive interactions, with recommendations for education and training. \(^{33}\) They have been viewed as liaisons who understood and could address their concerns.\(^{51}\) Parents valued: 1) being asked their opinion; 2) if they were in agreement with the plan; 3) interest in their impression; and 4) being able to ask questions and talk about their feelings. \(^{51,46}\)

Depression in this study was prominent. Consistent with previous studies, \(^{36,52–55}\) depression was greater than in the general population, particularly in females. Parents of children with disabilities exhibit more depressive symptoms, with grief and stress being the greatest risk factors. \(^{20}\) Scores were high and qualitatively appreciated within “Life in the Negative.” Statements of stress and depression, as well as observed behaviors validated the importance of these concepts.

Parents who viewed their child as having moderate disabilities reported a greater impact of neurologic disability upon their and their families’ lives than those who were reported their child to have severe disabilities. Children with severe disabilities may be less mobile, which could decrease behavioral issues, thus lowering impact. The perceived degree of disability may have been lower than the medically defined. Older parents and parents with greater incomes reported greater impacts, possibly due to greater physical care requirements on older parents. Greater impact in parents with higher incomes may be related to a lifestyle change. Qualitatively this included care burden, lack of fairness, and marital and life changes.
The Resiliency Model identifies social support and family resources as factors in adaptation. It is the successfulness of coping that contributes to adaptation. The use of problem- and emotion-focused mechanisms were not different in any groups, indicating that coping abilities may be a pre-existing character trait. Thabet et al, however found that a majority of parents used more emotion-focused mechanisms, particularly in lower socioeconomic groups, as found in this study.

Coping was evaluated by means of the WCQ and qualitatively was found within “The Source of My Strength.” Coping abilities are the greatest predictor of gain in a negative situation as well as of parental distress. Parents who took charge of situations demonstrated empowerment, a strong predictor of parental gain, a strong negative predictor of parental distress and can be linked with bon-adaptation, as in giving back to society; adaptation, as when methods are found to reduce expenditures; or maladaptive, as when mind altering substances are used. Coping mechanisms are learned and part of the cache of resources, within the Resiliency Model.

Problem-focused mechanisms heighten coping by enabling revision of plans or activities. It has been associated with higher levels of adaptation in caregivers of individuals with Rett syndrome, intellectual disabilities, stuttering, and autism. However, it may also create psychological distress by placing stress on the individual trying to improve a situation.

Negative behavior addressed behaviors and perceptions of negative behaviors. Substance use is an emotion-based, negative coping mechanism, specifically, escape-avoidance and is highly correlated with psychological distress. Blinded by the situation addressed denial, and lack of recognition, as a parent views a child as having abilities that he or she does not. This is a positive illusion, used in a negative manner, i.e. denial of a difficult reality. It is successful, as it allows the formation of an attachment with the child. Faerstein found that while mothers
used problem-focused coping, they also used defensive, emotion-focused approaches, such as denial.

Parts of the WCQ and parts of the PSI-SF addressed experiences, wishes, dreams or actions that were emotionally painful or potentially harmful and came to life in the theme, Life in the Negative. In a pamphlet by United Cerebral Palsy parents are told that resentment of this “thing” happening in your family is normal. Tragically, some parents have killed their disabled children. There may be a wish that a child had not been born. Threats of self-harm have also been reported. Physical or emotional demands contribute to parental abuse of children with disabilities, which is mal-adaption. Anger, frustration, or a feeling of powerlessness are spurred by care giving and linked to a lack of energy and loss of control. While no participants indicated a desire to cause harm, there were wishes for their children to not live.

The longed-for, happy delivery experience was ruined for these parents. For some, this is profound. Pain, uncertainty and loss of control contribute to fear, which may make delivery traumatic. There is scant literature in terms of parental responses following witnessing their child’s resuscitation. However, it has been found that in parents of children resuscitated in the emergency room, there was a general feeling that their presence was beneficial.

The greatest areas of convergence were depression and coping, while the greatest area of divergence was communication, which was not addressed in the surveys, indicating that neither the surveys nor open ended interviews were adequate to capture issues of importance in this area.

Limitations of the Study: The greatest limitation within this study was the small quantitative sample size. Parents may not desire to take part in a study that recalls what may be emotionally painful. Reaching out to a parental support site may be emotionally safer. This is supported by the fact that none of the on-line participants agreed to be interviewed. This may also have been
secondary to a potential loss of anonymity. This indicates two issues. The first is a sampling issue, in which it would appear that self-selection for on-line participants yielded more participants who may be more affected by issues of parenting a child who had HIE. The second is that issues which were brought to light in interviews were not always addressed on the surveys. On-line participants may be thought of as a specific subset: they have access to a computer, possess internet skills, may be more literate than those who do not participate; or they have a child who is viewed as having a significant disability, enhancing their need or desire to seek support in a safe, anonymous venue.

Qualitative participants filled out the surveys after the interview, which may have had a therapeutic benefit. Heideggerian phenomenology encourages the use reciprocity to develop a conversational aspect, which is believed to be useful in terms of caring encounters. The interview may have been helpful; thus, the participant may have had a different point of view when the surveys were completed.

Many potential participants did not voice interest in the study. While many provided contact information, they often declined the interview or would not return calls. Only parents of children under five years of age were interviewed. It is believed that either once the child is older, if his/her challenges are minimal, they may not be on the minds of parents or if the disabilities are severe, the parents may be more fatigued and entrenched in care giving. Only Caucasian and Hispanic families agreed to participate. This left out an important conglomerate of others, whose views may have been different.

**Implications for Research.** There is no literature which addresses HIE in relationship to stress or depression, thus making it a fertile area for future research. Studies addressing the hospital care from prior to delivery through the neonatal intensive care experience and follow-up need to
evaluate communication and perceptions of communication. It is necessary to look at the parents of older children, as well as parents from a wider cultural range in order to paint a more complete picture. Studies evaluating education programs in communication for health care providers, such that minimization of negative emotions might be appreciated. Evaluation and augmentation of cultural competency may be undertaken, understanding that being the parent of a child with disabilities is its own culture. Finally, it would be beneficial to study the duration of the benefits of a phenomenological interview process on the participant.

**Implications for Practice.** It has been shown that actively listening to what parents have to say is beneficial in reducing feelings of abandonment by health care providers. 75,76,48,49 It has been recommended that staff be cognizant of parental presence, avoiding personal conversations, particularly when they delay care. Enabling parents to parent is vital, particularly as physical contact is extremely limited during the perinatal and cooling periods.77 It is recommended that a team member be available during the resuscitation to communicate with parents in real time.

**Conclusions:** Parents of children who had HIE make up a unique, understudied population. This study has uncovered issues of stress and depression, seen more often in parents of children perceived to have moderate or severe disabilities. Daily life has been impacted. Coping appears to be based on past, learned techniques. It has highlighted issues of communication with both the nursing and medical teams as well as societal stigmatization. Some parents identified the nurse practitioner as particularly beneficial in terms of communication, as an often more open, welcoming style of communication helps parents to have more of a voice.
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CONSENT TO PARTICIPATE IN A RESEARCH STUDY

TITLE: Parents of Children Who Had Hypoxic-Ischemic Encephalopathy: A Mixed-Methods, Exploratory Study

INVESTIGATOR
Natalene P. Kramer, RN, MSN, CRNP-BC
PhD Candidate
Duquesne University School of Nursing
600 Forbes Avenue
Pittsburgh, Pennsylvania 15282
kramern@duq.edu
Neonatal Nurse Practitioner
Cooper University Hospital
7th Floor Dorrance Building
1 Cooper Plaza
Camden, New Jersey 08103

ADVISOR:
Kathleen Sekula, PhD, FAAN, APRN-BC
Associate Professor
Duquesne University School of Nursing
600 Forbes Avenue
523 Fisher Hall
Pittsburgh, Pennsylvania 15282
sekula@duq.edu
xxx-xxx-xxxx

SOURCE OF SUPPORT: This study is being performed as partial fulfillment of the requirements for the doctoral degree in nursing at Duquesne University.

PURPOSE: You are being asked to help with a research project to learn about parents of children who did not have enough blood flow to the brain or enough oxygen at birth. This may be called hypoxic-ischemic encephalopathy or “birth asphyxia.” You will be asked to fill out several forms about your child, yourself, and being a parent. You will be asked to let me interview you. Your interview will be taped and then written down. It is expected that our meeting will last 1-2 hours. This may later improve health care for other families like your own. These are the only requests that will be made of you.
RISKS AND BENEFITS: There is no more risk in taking these surveys than you have in everyday life. There will be no direct help to you or your child by taking these surveys. This is because you have already had this parenting experience. If you are interviewed, you may feel better just by telling the researcher about your feelings. You may feel that you understand yourself and/or your relationships better. You may feel proud in knowing that you helped us to understand issues experienced by parents such as yourself. This may later improve healthcare for other families like your own. On the other hand, some people may feel more sadness or stress by retelling of their story. If this happens and you want, you may stop the interview. If you want, the investigator will also help you to get counseling services.

COMPENSATION: To thank you for your time and willingness to be interviewed, you will receive a twenty-dollar ($20) WAWA gift card. If you also finish the questionnaires, you will also receive an additional ten-dollar ($10) WAWA gift card. There will be no charge or fee for your being in this project.

CONFIDENTIALITY: Your name will never be on any survey or research tools. You will not be able to be picked out on anything used to understand the data. You will not be able to be picked out in any presentation. All written papers and consent forms will be stored in a double-locked file in the researcher's home. All information that is on the computer will be password protected. Your answer(s) to surveys will only be in summaries mixed in with other people’s answers. All materials will be destroyed three years after the research is finished.

RIGHT TO WITHDRAW: You are under no obligation to participate in this study. You are free to take back your consent at any time.

SUMMARY OF RESULTS: A report of this study will be sent to you, free, if you would like. If you were interviewed, you will be called to make sure that the researcher understood your answers. You will have the chance to fix anything that is different from what you meant.

VOLUNTARY CONSENT: I have read the information above. I understand what I am being asked to do. I understand that being in this study is voluntary. I understand that I may take back my consent at any time, for any reason. On these terms, I agree that I am willing to be in this research project. I understand that should I have any further questions about my participation in this study, I may call the Principal Investigator, Natalene Kramer at XXX-XXX-XXXX, (kramerm@duq.edu,) her advisor, Dr. Kathleen Sekula at XXX-XXX-XXXX, (sekula@duq.edu,) and Dr. Paul Richer, Chair of the Duquesne University Institutional Review Board at XXX-XXX-XXXX.

Participant's Signature Date

Researcher's Signature Date
INFORMED CONSENT AND HIPAA AUTHORIZATION
TO PERMIT THE USE AND DISCLOSURE
OF PROTECTED HEALTH INFORMATION (PHI)
FOR RESEARCH PURPOSES

TITLE OF STUDY: Parents of Children Who Had Hypoxic-Ischemic Encephalopathy: A Mixed Methods, Exploratory Study

PRINCIPAL INVESTIGATOR:
Natalene P. Kramer, MSN, APN-BC, PhD (candidate)

AFFILIATION:
PhD program, School of Nursing, Duquesne University, 600 Forbes Avenue, Pittsburgh, Pa.

FACULTY ADVISOR:
Dr. Sonia Imaizumi, MD, FAAP

DEPARTMENT(S): Pediatrics, Division of Neonatology

PHONE NUMBER(S): XXX-XXX-XXX; XXX-XXX-XXXX

ADDRESS:
Division of Neonatology
7th Floor, Dorrance Building
Cooper University Hospital
1 Cooper Plaza
Camden, NJ 08103

What does the research study involve?
This research will use up to 30 mothers and/or fathers of children who had hypoxic-ischemic encephalopathy (not enough blood flow or oxygen to the brain) at birth. You are being asked to be in this research study because you have a child who had this challenge at birth. There are several reasons for this study. The first reason is to try to understand your experiences and feelings about this time in your life. The second reason is to try to understand how that experience and the experiences of being a parent of a child who had this challenge may or may not make you feel. The third reason for this study is to try to determine what we, as health care professionals may be able to make this parenting experience better for you.
Participating in this research study is strictly voluntary. If you decide to participate you will be asked to do the following:

- Allow the researcher to conduct an audio recorded interview of you at either your home or in the pediatric clinic at Cooper University Hospital.
- Allow the researcher to take notes during the interview.
- Complete two questionnaires which address some general issues about you, your family, and your birth experience.
- Complete several questionnaires which address how your child’s birth and life have affected you and your family.

As the nurse researcher, I will collect the following information from you:

- I will ask you to give me information about yourself, your family, your delivery, and how you may view the challenges your child may or may not have.
- I will ask for permission to get delivery information and medical information about your baby from their medical record in the hospital.
- I will ask for permission to interview you at either your home or in the hospital clinic area.
- I will ask you to fill out several check lists about your feelings.

The following are the names of the forms you will be completing during this study:

- Parent Demographic Questionnaire
- Parent Intake Form
- Impact of Childhood Neurologic Disability Scale
- Parenting Stress Index – Short Form
- Ways of Coping Questionnaire
- Patient Health Questionnaire – 2

You will be in this study from the time you sign this consent and until the questionnaires are returned to the nurse researcher.

You are being asked to be interviewed and to complete the questionnaires just for this research study. This is not a part of routine care. You and your child will receive all of the care that you normally receive even if you choose not to participate in the study.

**What risks are there?**
Completing the questionnaires has no more risk than you have in everyday life.

There will be no direct help to you or your child by taking these surveys because you have already had this parenting experience.
When or after you are interviewed you may feel some sadness or stress by retelling your story. If this happens and you want, you may stop the interview. Doctors, nurses, and social workers will be available if you feel that your emotions are hard to handle.

There is always a risk for loss of confidentiality. Your name will never be on any survey or research tools. Neither you, nor your child will be able to picked out on anything used to understand the data. Neither you nor your child will be able to be picked out in any presentation. All written papers, audio recordings, and consent forms will be stored in a double-locked file cabinet in the researcher’s home. All information that is on the computer will be password protected. Your answers to surveys will only be in summaries mixed in with other people’s answers. All materials, including papers as well as audio recordings will be destroyed three years after the research is finished.

What benefits are there?
There are no direct benefits of being in this study, because you have already had this parenting experience.

When or after you are interviewed, you may feel better just by telling the researcher about your feelings.

You may feel proud in knowing that you helped the researcher to understand issues experienced by parents such as yourself. This understanding may later improve healthcare for other families like your own.

Will your information be kept confidential?
The information collected about both you and your child for this study is called “protected health information” (PHI). It includes demographic information (e.g., you name, address, delivery information, you child’s medical information, your answers to questionnaires, and interview materials.

All of this information is being collected because you are participating in this research study. The information that is collected from you and from your child’s medical records will be used to decide if you qualify to participate in this research and will be analyzed to answer the research questions.

Injury Compensation
Cooper University Hospital and Duquesne University, nor any other agency funding this research project will provide special services, free care, or compensation for any injuries resulting from this research. Treatment for any risks or emotional support will be at your expense and/or paid through your medical plan.
Confidentiality
To help maintain the confidentiality of your study records, information such as your name, your child’s name, and any contact information will be kept separate from your study-related information, which will be given a separate subject number. All documents and audio recordings will be stored in a double-locked file cabinet in the researcher’s home. All information that is on the computer will be password protected. Your answers to surveys will only be in summaries mixed in with other people’s answers. All materials, including papers as well as audio recordings will be destroyed three years after the research is finished. The information from this study may be published in scientific journals or presented at scientific meetings, but neither you nor your child will not be personally identified in these publications and presentations.

By signing this form, you are allowing the following people or groups to have access to the information above (your and your child’s PHI). The research team, which includes the investigator listed on this form and other personnel involved in this specific study needed to analyze data. Cooper’s Institutional Review Board (IRB), and Duquesne University’s IRB, committees that review, approve, and monitor research involving human subjects may look at your study records. All of these people and entities are obligated to protect your and your child’s PHI.

You are also allowing your and your child’s PHI to be shared with other people or groups specified below: Dr. L. Kathleen Sekula, RN, PhD, CRNP-BC, FAAN; Dr. Rebecca Kronk, RN, PhD, CRNP-BC; Dr. Rick Zoucha, RN, PhD, CRNP-BC, CTN, all from Duquesne University, and Dr. Sonia Imaizumi, MD, FAAP from Cooper University Hospital. These nurses and this physician are part of the nurse researcher’s dissertation committee and will be able to see the data that is collected. They will guide and assist the nurse researcher when she analyzes the data. The data that they see will not contain any personal information. They will not be able to identify you to any study materials.

The Office for Human Research Protection (OHRP) is an office that oversees research funded by the federal government and it oversees the IRB at Cooper University Hospital.

The Food and Drug Administration (FDA). The FDA needs to be sure the records are accurate and that the research is done according to FDA regulations.

The sponsor of this study who is paying for the research. The sponsor needs to be sure the records are accurate and will analyze the research data.

Contract Research Organization name. This organization works for the sponsor and has access to your records for the same purposes as the sponsor.
Although these entities listed above have their own confidentiality procedures to protect your and your child’s PHI, they are not covered by the same federal privacy rule (The Health Insurance Portability and Accountability Act of 1996, or HIPAA) that governs healthcare providers and therefore they are not bound to its regulations.

You have the right to limit the use and sharing of your PHI, and you have the right to see your research study records and know who else is seeing them. You will not be allowed to see your health information that is created or collected during the course of the research. After the research is finished, however, you may see this information.

You are authorizing us to use and disclose your PHI until the end of the research study. You may revoke this authorization to use and share your PHI at any time by contacting the principal investigator, in writing, at the address on the front of this form. If you decide not to authorize us to use and disclose your PHI or you revoke this authorization, you will no longer be able to participate in this research study and the use or sharing of future PHI will be stopped. However, the PHI that has already been collected may still be used.

Whom can you contact if you have a question?
If you have any questions about this research, you can contact the principal investigator at the number on the first page. If you have any questions about your rights as a research subject or your rights related to the research use of your PHI, you may contact the Senior Vice President of Academic Affairs at Cooper at 856-963-3835 or the Chairperson of the Duquesne University Institutional Review Board at 412-396-6326. You should also contact the above persons if you believe that you have not been adequately informed as to the risks, benefits, or alternative procedures of this research study, or that you are being pressured to participate in the study against your wishes.

When can your participation be terminated by the investigator?
The investigator may terminate your participation in the study if you are not able to meet with the investigator, despite multiple scheduling attempts.

Are there any other costs?
There are no costs to you for participating in this study.

Will you be paid for participation?
To thank you for your time and willingness to be interviewed, you will receive a twenty-dollar ($20) WAWA gift card. If you also finish the questionnaires, you will also receive an additional ten-dollar ($10) WAWA gift card. There will be no charge or fee for your being in this project.
What will happen if you withdraw?
You may withdraw from the study at any time. Tell the investigator if you want to withdraw from the study. You and your child will still receive all of the care you require while at Cooper.

CONSENT STATEMENT
Participation in this study is strictly voluntary. You do not have to participate.

Your participation and your decision to allow the use of your or your child’s PHI are entirely voluntary. You do not have to participate or let us use your or your child’s PHI. If you decide not to participate or not to let us use your or your child’s PHI or you decide to stop participating or to stop letting us use your or your child’s PHI, it will not affect your treatment or your child’s treatment at Cooper University Hospital. Your doctors will continue to treat you and your child the way they always have.

All of the above has been explained to me. All of my questions have been answered. I can ask questions that I have about the research or about the use and disclosure of my or my child’s PHI at any time. My questions will be answered by one of the investigators listed on the first page of this form.

By signing this form, I agree to participate in this study and I agree to the use and disclosure of my and any child’s PHI for the purposes described above. A copy of this form will be given to me.

Parent Name (printed):______________________________date____________

Parent Signature:_________________________________________date__________

Investigator Signature:________________________________________date__________
APPENDIX B

Participant Recruitment Flier

Are you a parent of a child who didn’t have enough oxygen or blood flow at birth?

If you are the parents of a child less than 18 years old who had a lack of oxygen or blood flow around birth and are willing to volunteer 1-2 hours of your time for either an interview and/or to fill out a questionnaire, please contact me by phone or email and we can arrange a convenient time to meet. Interview participants will receive a $20 WAWA gift card for your help in this study.

I am a nurse researcher looking to understand your experiences and feelings, both then and now. The focus of this study is to understand these experiences and feelings in order to develop ways to help families like yours.

I have provided all contact information below. I look forward to your insight. Thank you for your time and consideration. Please feel free to pass this along to a friend, colleague, or relative.
Appendix C

Tri-fold Flier

Approvals and Support

This study has been approved by the Institutional Review Boards of Duquesne University and Cooper University Hospital.

This study is being supported in part by:

Epsilon Phi Chapter of Sigma Theta Tau International, The Honor Society of Nursing

Duquesne University, Pittsburgh, PA

Are you the parent of a child who didn’t have enough oxygen or blood flow at birth?

Duquesne University, Pittsburgh, Pennsylvania
Cooper University Hospital, Camden, New Jersey

Email address: Parentstudy@hotmail.com
Phone: XXX-XXX-XXXX

Your help is needed to help us learn how to provide better care to families like your own.
If you are the parent of a child less than 18 years old who didn’t have enough oxygen or blood flow around birth and are willing to volunteer 1-2 hours of your time for an interview and/or to fill out a questionnaire, please contact me. We can arrange a convenient time to meet. You will receive a $20 WAWA gift card for helping with the interview or a $30 gift card if you also fill out questionnaires. Contact information is below. Thank you for your time and help. Please feel free to pass this along to a friend, colleague, or relative.

Who Am I?
I am a nurse researcher looking to understand your experiences and feelings, both around the time of your child’s birth and now. The goal of this study is to understand these feelings and experiences so we can help families like yours.

Natalene Kramer, RN, MSN, CRNP-BC, PhD(c) parentstudy@hotmail.com (555)555-5555
You may also leave your contact information in the box at the front desk and I will contact you within five (5) business days.

It is important for us to understand the experiences and feelings of parents of children who have no disability, just a little disability, a moderate amount of problems, and many problems. If you think that you and your child went through this experience, we would be grateful for your help.

Your Expectations
Nobody is ever prepared for their child to have problems at birth. Some children who didn’t have enough oxygen or blood flow at birth seem to be just fine. Some have just a little bit of a problem and some children have many problems. At this time we know very little about the experiences of parents like you. Your feelings are very important! We want more information to understand your feelings and needs so that we can give families just like yours the best care that we can.
Appendix D

**Parent Demographic Questionnaire**

Name _______________    Subject Number _________

1. What is your age?
   - Less than 18 ____
   - 18 to 25 ____
   - 26 to 35 ____
   - 36 to 45 ____
   - 46 to 55 ____
   - More than 55 ____

2. What is your marital status?
   - Single ____
   - Married ____
   - Divorced ____
   - Widowed ____
   - Unmarried, in committed relationship in same household ____
   - Unmarried, in committed relationship in different households ____
   - Unmarried, not in committed relationship ____

3. Where do you live?
   - Apartment ____
   - Hotel ____
   - Group Home ____
   - Single Family Home ____
   - Other ____ Please describe ______________

4. Who do you live with? (please check all that apply)
   - Parents(s)____
   - Spouse____
   - Friend(s)____
   - Significant other____
   - Grandparent(s)____
   - Other____

5. How many total children do you have?
   - One (1) ____
   - Two (2) ____
   - Three (3) ____
   - Four (4) or more ____
   - how many ____

6. How many of your children live with you? ____

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7. What is your yearly household income?
   - Less than $25,000
   - $25,000 to $50,000
   - $50,000 to $75,000
   - $75,000 to $100,000
   - More than $100,000
   - Prefer not to answer

8. What is your ethnic background?
   - White or Caucasian
   - Hispanic
   - East Indian
   - Asian or Pacific Islander
   - African American or Black
   - Native American
   - Middle Eastern
   - Other
   - Prefer not to answer

9. Are you comfortable writing and speaking in English? Yes ____ No ____

If no, with what language are you most comfortable? __________________________
Appendix E

Parent Intake Form

Subject Number: _______________________

1. What is your child’s first name? ____________, age? _________

2. What kind of delivery did your child have?
   Home birth ______
   Hospital, vaginal birth ______
   Forceps or Vacuum ______
   Planned cesarean birth ______
   Emergency cesarean birth ______

3. What was done for pain during labor and/or delivery? (Check all that apply)
   General anesthesia (put to sleep) ______
   Spinal or epidural anesthesia (needle in back) ______
   Pain medicine in IV ______
   Nothing ______

4. Did it work? Yes _____ No _____

5. Who was present at the delivery? ______________________

6. How long did your child stay in the hospital after delivery? ______________

7. What problems did your child have when he/she was born?
   ______________________________________________________________________
   ______________________________________________________________________
   ______________________________________________________________________

8. Which of the following most applies to your child? (Please choose one)
   No disability ______  Mild Disability ______
   Moderate disability ______ Severe Disability ______

9. Did you or your partner have any problems after delivery? Yes _____ No _____

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10. If so, please describe.

__________________________________________________________________________
__________________________________________________________________________

11. Is there anything else you would like me to know about you or your child at this time?

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
Appendix F

Impact of Childhood Neurologic Disability Scale


Subject #: _______________  Child’s Age: _____  Today’s Date ( / / )

We would like to know how you feel your child’s condition affects either your child’s or your family’s everyday life at the present time and during the past 3 months. For each condition or health problem listed, indicate by a checkmark, how much impact has your child’s condition had on various aspects or you/your child’s life.

The conditions include:
1. Inattentiveness, impulsivity, or mood
2. Ability to think and remember
3. Neurologic or physical limitations
4. Epilepsy (overall problem of having epilepsy – its social consequences, degree of control and type of seizures, treatment and side effects)

We would like you to answer all of the questions, but you do not have to complete any question(s) you are uncomfortable answering.

CONDITION: Does inattentiveness, impulsivity, or mood affect the following areas of your child’s or your family’s everyday life?

<table>
<thead>
<tr>
<th>Condition</th>
<th>A lot</th>
<th>Some</th>
<th>A little</th>
<th>Not at All</th>
<th>Does Not Apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td>Social life – acceptability by others</td>
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*aFeelings about himself/herself or self confidence
CONDITION: Does your child’s *ability to think and remember* affect the following areas of your child’s or your family’s everyday life?

<table>
<thead>
<tr>
<th></th>
<th>A lot</th>
<th>Some</th>
<th>A little</th>
<th>Not at All</th>
<th>Does Not Apply</th>
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<td>Overall health</td>
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<sup>a</sup>Feelings about himself/herself or self confidence

CONDITION: Do other *neurological or physical limitations* (movement or coordination, vision, or other sensory problems [ADL]) affect the following areas of your child’s or your family’s everyday life?

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<th></th>
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<th>A little</th>
<th>Not at All</th>
<th>Does Not Apply</th>
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<sup>a</sup>Feelings about himself/herself or self confidence
CONDITION: Does *epilepsy* affect the following areas of your child’s or your family’s everyday life (Social consequences, seizures and treatment)?

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<tr>
<th></th>
<th>A lot</th>
<th>Some</th>
<th>A little</th>
<th>Not at All</th>
<th>Does Not Apply</th>
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</tbody>
</table>

*Feelings about himself/herself or self confidence

Please rate your child’s overall ‘Quality of Life’ on the scale below. Choose the number which you feel is best and circle it.

1 | 2 | 3 | 4 | 5 | 6

POOR | EXCELLENT
Appendix G
Example Questions From the Parenting Stress Index- Short Form

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This questionnaire includes 36 statements. Read each statement carefully. For each statement, please focus on the child you are most concerned about and circle the response that best represents your opinion. Answer all questions about the same child.

Circle SA if you strongly agree with the statement.
Circle A if you agree with the statement.
Circle NS if you are not sure.
Circle D if you disagree with the statement.
Circle SD if you strongly disagree with the statement.

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<table>
<thead>
<tr>
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<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>1. I often have the feeling that I cannot handle things very well</td>
<td>SA</td>
<td>A</td>
<td>NS</td>
<td>D</td>
</tr>
<tr>
<td>2. I find myself giving up more of my life to meet my children’s needs than I ever expected</td>
<td>SA</td>
<td>A</td>
<td>NS</td>
<td>D</td>
</tr>
<tr>
<td>3. I feel trapped by responsibilities as a parent</td>
<td>SA</td>
<td>A</td>
<td>NS</td>
<td>D</td>
</tr>
</tbody>
</table>
Appendix H
Examples of Questions from Ways of Coping Questionnaire


Key: 0= Does not apply or not used 1= Used somewhat 2= Used quite a bit 3= Used a great deal

Please try to respond to every question

<table>
<thead>
<tr>
<th></th>
<th>Does not apply or not used</th>
<th>Used somewhat</th>
<th>Used quite a bit</th>
<th>Used a great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I just concentrated on what I had to do next – the next step</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
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<tr>
<td>2</td>
<td>I tried to analyze the problem in order to understand it better</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>I turned to work or another activity to take my mind off things</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
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<tr>
<td>4</td>
<td>I felt that only time would have made a difference – the only thing was to wait.</td>
<td>0 1 2 3</td>
<td></td>
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<td>5</td>
<td>I bargained or compromised to get something positive from the situation</td>
<td>0 1 2 3</td>
<td></td>
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Appendix I
Patient Health Questionnaire (PHQ-2)


Over the last 2 weeks, how often have you been bothered by any of the following problems?

<table>
<thead>
<tr>
<th>Over the last 2 weeks, how often have you been bothered by any of the following problems?</th>
<th>Not at all days</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Little interest or pleasure in doing things</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>(b) Feeling down, depressed, or hopeless</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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</table>
Appendix J

Invitation to participate in on-line survey

Dear Parent,

Are you the parent of a child who did not have enough oxygen or blood flow at birth?

If you are the parent of a child less than 18 years old who had a lack of oxygen or blood flow around the time of birth and are willing to volunteer less than one hour of your time to share your experiences and feelings by filling out several surveys, your help is welcome. You are invited to participate in this study entitled, “Parents of Children Who Had Hypoxic-Ischemic Encephalopathy: A Mixed Methods, Exploratory Study.”

I am a nurse researcher looking to understand your experiences and feelings from both then and now. The focus of this study is to understand these experiences and feelings in order to develop ways to provide better care and help families like yours.

Your answers to this survey will be completely anonymous and will only be presented along with many others in such a way that you cannot be identified. The researcher is not able to trace you through the computer.

I thank you in advance, for your support and generous contribution of time.

If after you complete the survey, you would be interested in participating in an interview to further understand your experiences and feelings please check the “I am interested” box at the completion of the survey. If you complete an interview, you will receive twenty dollars ($20) as a Thank You.

Sincerely,

Natalene Kramer

Natalene Kramer, PhD(c), MSN, CRNP-BC