

Maternal Perceptions About Parenting a Child Affected by Catastrophic Epilepsy: A  
Phenomenological Study

by

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Abstract

This qualitative study explored the maternal perceptions of life with a child affected by catastrophic epilepsy, which is a severe form of childhood epilepsy that includes difficult-to-control seizure activity, intellectual disability, other developmental disabilities, and a poor prognosis. Limited qualitative research exists regarding the lived experience and meaning of maternal caregiving for children with this stigmatized, severely debilitating condition. This hermeneutic phenomenological study informed by van Manen (1990) involved two audio-recorded, in-depth interviews with each of five participants who were the biological mothers of children with a catastrophic form of epilepsy.

The essence of the study's findings was one of maternal commitment to a beloved child in a seizure-centered life. The themes that emerged from the data shared by study participants were: "A Child with Catastrophic Epilepsy: 'Waiting for the Other Shoe to Drop,'" as a response to their child's daily, unpredictable, and potentially life threatening seizure activity; "Mobilizing resources: A Constant Preoccupation and Effort," to meet their child's complex needs; "Providing Care: An Often Overwhelming Responsibility," due to the intensive organization and provision of intensive, on-going physical and psychosocial care; "Effects of

Care on Caregiving Parents: ‘Confined to a Helpless Situation,’” from which neither they nor their children could escape and over which they had little control; and “Caregiver Coping: Celebrating the Child While Mourning the Losses.” Mothers who participated in this study deeply loved and admired their children and found joy, meaning, and purpose in their experience as their child’s primary caregiver despite the many challenges that such caregiving presented,

The theory of ambiguous loss (Boss, 2006, 2010) provides insight into a unique kind of loss that reflects a response to someone who is physically present but psychologically absent as exemplified by children with catastrophic epilepsy who were described by their parents in this study. The parental experience that may have reflected ambiguous loss in this study complicates both grief and relationships and prevents closure in response to the loss. Participants in this study, however, engaged in behaviors that were consistent to varying degrees with guidelines proposed by Boss that contributed to their ability to cope with the ambiguous loss they may experience.

Children with catastrophic epilepsy present with complex health issues that are challenging and sometimes life-threatening. Caregivers are challenged by an overloaded healthcare system where busy health care providers care for typically developing children as well as those with special needs. Parents of children with catastrophic epilepsy face particular challenges in addressing their children’s health-related needs due, in part, to the frequency with which they require provider assistance, including informed responses to their questions and concerns about their child. Research is warranted to investigate health care provision alternatives such as palliative care that would involve parents as respected partners in health care planning and decision-making.

Maternal Perceptions About Parenting a Child Affected by Catastrophic Epilepsy: A  
Phenomenological Study

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by

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## **DEDICATION**

This study is dedicated to the parents striving daily to provide every opportunity for their child with catastrophic epilepsy. The purpose of the study was to bring awareness and education about the constant state of responsiveness to seizures and the extensive care and commitment necessary for children with debilitating epilepsy. It is my hope that sharing the stories of the mothers who so graciously participated in this study serves as a source of support and the message that, 'you are not alone,' for other families enduring similar circumstances. I also hope the participants' experiences and voices provide insight for healthcare professionals that could lead to more empathetic and compassionate care for affected children and their families.

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## **Chapter 1: Introduction**

Catastrophic epilepsy is one of the most severe and debilitating forms of childhood onset epilepsy. Children who are affected by catastrophic epilepsy typically experience difficult-to-control seizures, intellectual disability, (Shields, 2000) and other disabilities, thus requiring intensive parental involvement and caregiving. At the time of this study, few qualitative research studies had been conducted for the purpose of gaining insight into the perspectives of parents who cared for a child with catastrophic epilepsy. This qualitative hermeneutic phenomenological study aimed to explore the experiences and perspectives of mothers who cared for their child with this severe disorder and the meaning that mothers ascribed to their experience.

### **Statement of the Problem**

The seizure disorder of epilepsy is the most common neurological disorder in children (Ekinici, Titus, Rodopman, Berkem & Trevathan, 2009). It is a heterogeneous condition in that the epilepsy affects each child in a different way. Almost half of children affected by epilepsy, also experience intellectual disability. The severity of epilepsy is associated with age of onset, with more detrimental effects occurring when the onset is at a younger age. Catastrophic epilepsy, a general term used to describe a form of epilepsy characterized by uncontrolled seizures and intellectual disability, always begins before the age of five years and has a poor prognosis. There are many different causes for catastrophic epilepsy; the seizures, however, are often the primary cause of the intellectual disability (Rantanen, Eriksson, & Nieminen, 2011).

Each child with catastrophic epilepsy presents in a different way depending on the underlying cause of the epilepsy, seizure type, severity, and frequency, and response to treatment (Rantanen, et al., 2011). Children with catastrophic epilepsy are usually completely dependent

on their caregiver for all primary care; however, the range of individual medical and physical issues affects each child and family somewhat differently (Vendrame, et al., 2009). On one end of the spectrum, children are unable to move, talk, or communicate, and require medical care around the clock. These children may require a ventilator in order to breathe, a gastrostomy tube for feedings, and catheterization to urinate. They require continual monitoring in order to administer emergency medications for a status epilepticus seizure, which will not stop without intervention.

At the other end of the spectrum, catastrophic epilepsy can appear more medically stable but still cause severe impairments in the child due to issues related to intellectual disability and limitations of movement and communication. For example, children with catastrophic epilepsy may be able to eat but lack the fine motor skills to feed themselves, or they may be able to urinate but require diapers because they are unable to toilet train. Monitoring remains crucial even for children with less medical involvement because they are also at risk for a potentially fatal status epilepticus seizure (Beleza, 2009). Due to the many different presentations of catastrophic epilepsy, the day-to-day responsibilities and the parent's overall responsibilities differ somewhat for each family. There are, however, commonalities among children with this severe form of epilepsy.

Every parent caring for a child living with catastrophic epilepsy experiences the troubling issue of how to effectively treat the often daily, uncontrollable, and sometimes-prolonged seizures (Granata, 2011). The plasticity of a developing brain allows abnormal, damaging neurological connections that repeat and become ingrained when a child has frequent seizures (Smith, 2010). This results in most antiepileptic medications becoming ineffective because the brain becomes resistant to the seizure medications (Sahin, et al., 2011).

In addition to antiepileptic medications, other treatment options for seizures experienced by children with catastrophic epilepsy are available but have been shown to have little efficacy. Of these other options, surgical intervention has proven the most promising for children with the condition; however, not all children with this form of epilepsy are surgical candidates. Surgical outcomes vary with each patient and are dependent on the underlying cause of the epilepsy (Beleza, 2009).

Little research exists in developing epilepsy treatments specific to the immature brain. Therefore, options are limited for parents trying to find help for their child with catastrophic epilepsy. Treating and finding a cure for epilepsy is just beginning to be focused on by the medical community and government (de Boer, Mula, & Sander, 2008).

In addition to an inability to control their child's seizures, other challenges that parents of children with catastrophic epilepsy collectively face include financial issues and the fear, stigma, and ignorance of the general public surrounding epilepsy (Kurth, Lewis, & Walker, 2010; Ngugi, Bottomley, Kleinschmidt, Sander & Newton, 2010). Children with catastrophic epilepsy must confront a dual issue: they are stigmatized for having an intellectual disability and are also stigmatized for having epilepsy (Lee, 2011).

In addition to attending to significant health care needs, parents of children with catastrophic epilepsy face a significant financial burden associated with care. In the past, parents have had to place their child in an institution because they could not care for them at home. Today, family financial issues may force a child to go into a group home. For example, the high cost of medications to treat children's seizures and other health issues typically is not fully covered by health insurance. The cost of medications alone can bankrupt families (Jennum, Gyllenberg, & Kjellberg, 2011). In addition, families cannot always afford to have a nurse or

experienced caregiver come into the home to watch their child, which leaves the full responsibility of care to one of the parents who often must leave employment in order to meet the intensive caregiving needs of their child. The resulting one-income household adds to the family's financial stress as does medical costs for adaptive equipment, monitoring devices, home modifications, and various therapies (Granata, 2011).

In order to find the best treatment options and to manage the complex medical issues associated with catastrophic epilepsy, affected children must be seen by many different specialists (Jennum, et al., 2011). Sometimes the family's insurance will not cover the expense of these specialists. Accessing government assistance involves waiting lists with triaged openings. The triaging process can occur in a manner that sometimes results in children never receiving services.

It can be surmised that parents of children with catastrophic epilepsy face many challenges related to caring for a child with a medical condition of this severity and the related issues of social stigma and financial difficulties. Parents may find themselves with little hope for an adequate level of assistance. Little research, however, has provided insight into the lived experience of parenting a child affected by catastrophic epilepsy.

## **Purpose**

The purpose of this qualitative research study was to gain insight and understanding about what it was like to parent a child with catastrophic epilepsy. The research question that was addressed in this study was, "What are the maternal experiences and perceptions about and meaning associated with caring for their child affected by catastrophic epilepsy?"



## **Significance of the Study**

Based on the researcher's review of the research literature, this study is one of the first phenomenological qualitative research efforts to provide insight into the maternal perspectives about life with a child affected by catastrophic epilepsy. The literature reviewed addressed childhood epilepsy, but was limited regarding maternal experiences with childhood epilepsy in general or catastrophic epilepsy in particular. Much of the research literature focused on chronic conditions that included epilepsy and addressed stigma that was associated with epilepsy in general.

The findings from this study may be useful to parents with a child who has been diagnosed with catastrophic epilepsy, in part, because it may provide them an opportunity to reflect on their own experiences with their child and gain insight into the experiences of other parents facing similar challenges. The research findings may also be useful to health educators and other health professionals due to the revelation of insights that may help such professionals better understand parenting children with this severe disorder, the decisions parents must face and ultimately make, and the impact of catastrophic epilepsy on both children and parents. The research findings may thus potentially inform the care and support that health education professionals and health providers offer to children with this condition and those who parent them. The knowledge and understanding gleaned from this study may ultimately provide an impetus for ongoing efforts to fund and conduct research on treatment and ultimately a cure for epilepsy, a relatively common and sometimes debilitating condition. It may also lead to a general increased understanding of the effects of epilepsy, especially regarding how this particularly severe form of childhood onset epilepsy affects the daily experience of parenting a child with the disorder.

## Research Design

The researcher used a qualitative approach informed by a hermeneutic phenomenological theoretical orientation to explore and describe maternal perceptions about life with their child affected by catastrophic epilepsy. She selected a qualitative approach for this study because qualitative inquiry leads to an in-depth understanding of human experiences (Patton, 2002). Moreover, the information-rich data collected as a result of using a qualitative approach was anticipated to provide an emic or insider's perspective on parenting a child with this severe condition. Qualitative inquiry is particularly indicated in circumstances where little research about a phenomenon exists and a "complex, detailed understanding of the issue" is needed (Creswell, 2007, p. 40).

A phenomenological orientation is appropriately used when the intent is to discover meaning and lived experience (Creswell, 2007), as was the case in this study. The researcher sought to discover maternal perceptions and experiences related to caring for a child with catastrophic epilepsy and the meaning that the parents ascribed to their experience. A hermeneutic approach is appropriate because the study reflected an interpretive approach to understanding (Creswell, 2007) parenting a child with catastrophic epilepsy. In addition, qualitative research is indicated when the researcher seeks to empower study participants such as in the case of this study. The research process enabled parents of children with catastrophic epilepsy to share their voices and their stories during open-ended interviews. During the interviews the researcher sought to create a non-judgmental and supportive atmosphere that minimized power issues that could have potentially arisen between her and her study participants (Creswell, 2007).

The hermeneutic phenomenological research design for this study involved two audio-recorded, in-depth, open-ended interviews with each of five purposively selected parents. During the first interview, the researcher and study participants addressed the research question; in the second interview, the researcher continued to address the research question but incorporated a photoelicitation process. During the second photoelicitation interview, the researcher used photographic images taken by the study participants as a catalyst for discussion with them. The participants' narrative about the images aided in capturing and gaining insight into maternal perspectives and experiences regarding caring for their child with catastrophic epilepsy.

All study participants had direct experience with parenting a child with catastrophic epilepsy and were willing to voluntarily share those experiences with the researcher. This study enabled the researcher to gather data that will ultimately increase the awareness of health educators and providers regarding the perceptions, challenges, and rewards of parenting a child with this chronic and severely debilitating disorder.

### **Researcher's Capabilities and Assumptions**

The researcher was qualified to conduct this study based, in part, on her role as a parent and personal caregiver for a child with catastrophic epilepsy for five years. Her direct experience with caregiving served to facilitate the rapport and trust building process with study participants that led to information-rich interviews (Patton, 2002). The researcher's qualitative research, knowledge, and skills were a consequence of successfully completing a graduate-level academic course in qualitative research and evaluation methods.

At the onset of this study the researcher held the following assumptions:

- Parents of children with catastrophic epilepsy were willing to voluntarily participate in this study.
- Study participants would have a stake in sharing their maternal perceptions about life with their child affected with catastrophic epilepsy because they believed such sharing could increase awareness among people in general about the devastating effects of epilepsy on children.
- Children with catastrophic epilepsy were stigmatized by society in general due to both intellectual disability and because epilepsy is a generally stigmatizing health problem.
- Caring for a child with catastrophic epilepsy would be stressful to the parents she interviewed due to the seizures themselves as well as the emotional, physical, and financial burdens associated with the care of affected children.

### **Definition of Terms**

Intellectual Disability: Rosa's Law, signed on October 5, 2010 by President Barak Obama replaced the term "mental retardation" in federal statutes with "intellectual disability." Intellectual disability will be used throughout this study, replacing terms such as mental retardation, cognitive delay, or cognitive deficit.

Intractable Epilepsy: Seizures that cannot be controlled with the use of medication.

### **Limitations**

The researcher identified the following limitations associated with this study.

- The focus of this qualitative study was on catastrophic epilepsy in childhood.

Findings were not intended to be generalizable to the general population of those who

are parenting children with catastrophic epilepsy or to those who are parenting children with other forms of epilepsy. Consistent with qualitative research process, however, the researcher employed thick description in an effect to facilitate readers' assessment of the transferability of findings associated with this study to other settings and situations (Patton, 2002).

- The sample for this study was anticipated to be heterogeneous. There are several characteristics of seizures and overall child development experienced by the children whose parents participated in this study that influenced the maternal experience of caregiving. Seizure-related characteristics that could impact the parenting experience included the child's age of onset for seizures, frequency and severity of seizures, level of seizure control, and number and kind of anti-epileptic drugs (AEDs) prescribed for the child. In addition, the children's developmental characteristics varied, including physical, intellectual, oral, and gross motor development. The varying range of effects associated with catastrophic epilepsy led to different caregiving experiences for parents.
- The study participants' personal characteristics in terms of gender and race/ethnicity limited the voices and perspectives documented in this study to those of Caucasian women who were the biological mothers of children with catastrophic epilepsy.

### **Study Delimitations**

This study was delimited to:

- Individuals who were actively engaged in parenting a child with catastrophic epilepsy.
- Residents of the State of North Carolina.

- Individuals who were 18 years of age or older.
- Individuals who were English speaking and able to read English.

## **Summary**

This qualitative hermeneutic phenomenological study focused on the childhood condition of catastrophic epilepsy and maternal perceptions in caring for children with the condition. Consistent with a hermeneutic phenomenological approach, data were collected by means of two in-depth, open-ended interviews with each of five study participants. The second of the interviews involved a process of photoelicitation using participants' photographic images as a catalyst for discussion. The lived maternal experience of catastrophic epilepsy is a phenomenon that can affect caregivers in important ways.

The researcher who conducted the study, including facilitating all interviews associated with the study, personally cares for a child with catastrophic epilepsy. She found that her direct experience with the phenomenon led to rapport building with study participants and contributed to her ability to elicit rich information about the phenomenon. At the time of this study, there was limited literature focused the maternal perceptions about life with a child affected with catastrophic epilepsy. A complete review of the literature that the researcher provided in the following chapter provides an overview of epilepsy and addresses what is known about catastrophic epilepsy, including parenting a child with this health issue.

## **Chapter 2: Review of Literature**

### **Introduction**

An estimated three million Americans have epilepsy, with the majority of cases occurring in children and youth. The incidence of epilepsy in childhood is 50-100 per 100,000 children (Milroy, 2011). Those with an onset of epilepsy during childhood tend to experience the most devastating results from the condition because their brain was still developing at the time their seizures had begun (Vendrame, et al, 2009). Catastrophic epilepsy begins in childhood, involves seizures that are difficult to control, and typically involves intellectual disability (Shields, 2000). The incidence of catastrophic epilepsy is more difficult to determine due to its many etiologies. For example, infantile spasms are the most common form of catastrophic epilepsy, occurring in 9% of all children diagnosed with epilepsy (Shields, 2000).

The purpose of this study was to gain insight and understanding about the lived experience of parenting a child with catastrophic epilepsy from the perspective of mothers who had direct experience caring for their children with the condition. In this review of the literature, the researcher will provide data drawn from the published scientific literature regarding epilepsy with a focus on childhood epilepsy and what is currently known about the impact of seizures on children. The literature review will also describe the current state of knowledge about catastrophic epilepsy and explore current methods used to assess and treat this severe form of epilepsy. The researcher will also present information about parental perceptions and stigma surrounding the condition.

### **Epilepsy**

Epilepsy is diagnosed in people who have had two or more seizures that were not provoked by substance use, fever, infection, hormones, or other specific causes (Fisher &

Leppik, 2008). The health problem of epilepsy tends to be most severe when the seizures begin in infancy and early childhood (Rantanen, et al., 2011). The brain, an electrochemical organ consisting of millions of neurons, is the source of seizures and is directly affected by them. Neurons in the brain communicate by using an electrical signaling pattern performed by neurotransmitters (Smith, 2010). A seizure occurs in response to a surge of electrical activity anywhere in the brain and sometimes in multiple areas of the brain.

Researchers and clinicians have identified over 40 different types of seizures (Shorvon, 2011a). Children with catastrophic epilepsy commonly experience one or more of several types of seizures. They may have a convulsive grand mal seizure that involves both stiffening of all or part of their body (called tonic seizure) and rhythmic jerking movements of their body or any body part, including the eyes. They may also experience myoclonic seizures resulting in quick, shock-like jerking movements; periods of staring associated with petit mal seizures; uncontrolled laughing associated with gelastic seizures; or spasms that involve jerking movements of the torso, giving the child a jackknife appearance. Like all children between two and five years of age, those with catastrophic epilepsy can also experience febrile seizures involving both tonic and clonic seizures in response to high fever (Shorvon, 2011b).

The terms, “generalized” and “focal” are used to describe the origin of the seizures. Focal seizures originate from and occur in one hemisphere of the brain (Beleza, 2009). Such seizures may involve the whole hemisphere or a localized area in the hemisphere. Generalized seizures, on the other hand, involve both hemispheres of the brain. In some cases, the seizure may originate in a specific area in one hemisphere but ultimately involves both hemispheres (Beleza, 2009). Children with catastrophic epilepsy generally have more generalized seizure types (Shields, 2000).



## **Impact of Epilepsy on Children**

Three million Americans have epilepsy, with the majority of cases occurring in children and youth. About 40 to 70 people per 100,000 population are diagnosed with epilepsy every year; however, in countries with fewer resources, the incidence is 120 per 100,000 per year (de Boer, et al., 2008). The incidence of epilepsy in young children is higher than that of other age groups. Those with an onset of epilepsy during childhood tend to experience the most devastating results from the condition because their brain is still developing (Vendrame, et al, 2009).

Up to 40 percent of all children with epilepsy between four and fifteen years of age have one or more additional neurological conditions, most commonly intellectual disability (de Boer, et al., 2008). Intellectual disability can result in physical disability, such as an inability to walk or difficulty swallowing. Seizures in this group often recur because of a cascade of events that begins with difficulty swallowing, leading to difficulty in taking antiepileptic medication, and poor nutrition. According to one study, children with physical and intellectual disabilities were more prone to constipation and infections that, in turn, exacerbated the seizures they experienced (de Boer, et al., 2008).

Children with epilepsy have a mortality rate that is 8.8 times higher than the general pediatric population (Meyer, Shamdeen, Gottschling, Strittmatter & Gortner, 2011). Uncontrolled epilepsy can reduce a child's average life expectancy by up to 18 years (de Boer, et al., 2008).

## **Childhood Epilepsy**

Epilepsy is the most common neurological condition in children worldwide. The condition develops during childhood in 70% of people with epilepsy (Berg, 2011). In children,

epilepsy can be manifested as uncomplicated and benign or as complicated and catastrophic. Few seizure types exist between these two ends of the spectrum. However, forty (de Boer, et al., 2008) to fifty-seven percent of all children with epilepsy will have intellectual disabilities (Rantanen, et al., 2011). The intellectual disabilities experienced by children with epilepsy can range from mild to severe.

### **Benign epilepsy.**

People with epilepsy in childhood typically have a diminished quality of life (Sahin, Miller, Holmes & Sheth, 2011). Even children with benign, uncomplicated epilepsy frequently have serious life and medical issues compared to their peers. The occurrence of poor social outcome as adults is higher among those with epilepsy than any other chronic illness (Camfield & Camfield, 2011). People living with epilepsy are more prone to depression and suicide. The risk of suicide in people with epilepsy is five times that of people without epilepsy (Berg, 2011). People who developed epilepsy during childhood are less likely to graduate from high school, marry, or become gainfully employed, and are more likely to live alone, commit a crime, binge drink, and have an unplanned pregnancy (Berg, 2011). These individuals are also more likely to have learning disabilities, attention-deficit hyperactivity disorder, autism, and anxiety (Sahin, et al., 2011).

The conclusions from these studies suggest that benign, uncomplicated epilepsy still has side effects, even with short durations of epilepsy during childhood (Rantanen, et al., 2011). Intellectual disabilities occur early in the course of epilepsy. The early insult to the brain is an explanation for the continuing issues of people who experienced epilepsy only during childhood (Rantanen, et al., 2011). Epilepsy-associated intellectual disabilities may affect the individual throughout their lives, even when their epilepsy is in complete remission.

### **Catastrophic epilepsy.**

Catastrophic epilepsy in childhood is a severe disorder, due in part to the uncontrolled seizures and intellectual disability that characterizes this form of epilepsy (Shields, 2000). Unfortunately, this form of epilepsy encompasses a significant number of children with epilepsy (Rantanen, et al., 2011). Often, the seizures and intellectual disability are the result of an underlying cause; however, the seizures may also be the cause of the intellectual disability.

The seizures in children with catastrophic epilepsy are difficult and sometimes impossible to control (Shields, 2000). Several factors influence the degree of severity of the seizures. The underlying cause is an important factor that influences the intellectual prognosis. The younger the child is when the seizures start, the more severe the intellectual disabilities. Underlying cause and age of onset are the two most important factors that influence the severity of the condition (Rantanen, et al., 2011). Many authors argue that the most important indicator of intellectual outcome is age of seizure onset (Vandrame et al., 2009; Beleza, 2009; Rantanen, et al., 2011) as well as seizure frequency and duration (Vandrame et al., 2009).

Families of children with catastrophic epilepsy often find intellectual disabilities as much of a concern, or even more of a concern, than the seizures (Ferro, Avison, Campbell & Speechley, 2011). Catastrophic epilepsy often presents with comorbidities such as the inability to walk, communicate, eat, swallow, and other physical complications. In addition to the physical side effects, severe behavioral issues may occur in children with catastrophic epilepsy.

Children with catastrophic epilepsy have higher death rates, with the primary cause of death in people with epilepsy being sudden unexplained death of epilepsy (SUDEP) (Berg, 2011). Other causes of death include infection and status epilepticus, which is a prolonged seizure event that does not stop on its own and requires emergency intervention.

### **Etiology of catastrophic epilepsy.**

There are a number of underlying causes of catastrophic epilepsy, including structural, genetic, and encephalopathy-related origins. This following discussion addresses each of these possible causes of the disorder.

***Structural problems.*** Abnormal brain structure and genetic conditions can lead to catastrophic epilepsy. The cause for the majority of cases of complicated, catastrophic epilepsy, however, is unknown (Avanzini, 2011). Structural causes of catastrophic epilepsy include hippocampal sclerosis, hemorrhage, hypoxic-ischemic areas, and cortical dysplasia. Hippocampal sclerosis is the most common cause for temporal lobe epilepsy, which occurs in seventy percent of people that are surgical candidates for the treatment of epilepsy (Johns & Thorn, 2008).

Hypoxia-related infantile spasms, also known as West Syndrome, are the most common and one of the most severe forms of catastrophic epilepsy (Vandrame et al., 2009). Infantile spasms account for nine percent of all diagnoses of children with epilepsy (Shields, 2000) and, like other underlying causes of catastrophic epilepsy; it has a distinctive diagnostic EEG pattern. The most common cause of infantile spasms is hypoxia during the prenatal or postnatal period (Shields, 2006). A hypoxic-ischemic area of the brain also can result in cerebral palsy. Cortical dysplasia or abnormal migration of neurons during embryology results in clusters of normal neurons in abnormal locations (Brooks-Kayal, 2011). Surgical removal of the cortical dysplasia often improves seizure control and development.

***Genetics.*** Mutated genes cause several forms of catastrophic forms of epilepsy. Genetic disorders include Angelman Syndrome (Clayton-Smith, 2010) and Dravet Syndrome (Granata, 2011); Rhetts Syndrome, which is a genetic disorder that most commonly affects female children;

Fragile X Syndrome, the most frequently inherited intellectual disorder; tumors associated with tuberous sclerosis; and other genetic problems (Brooks-Kayal, 2011).

***Encephalopathy.*** Some syndromes that cause catastrophic epilepsy have specific clinical findings, and EEG features which form the basis for diagnosis (Beleza, 2009; Rantanen, et al., 2011; Sahin, et al., 2011). Epileptic encephalopathy is the diagnosis sometimes given to children with catastrophic epilepsy if there are no other clinical features suggesting a specific underlying condition. The lack of development seen in children with epileptic encephalopathy is a direct result of seizures. If the seizures are controlled, these children can regain normal intellectual function, although this seldom occurs (Sahin, et al., 2011).

#### **Brain development and catastrophic epilepsy.**

All catastrophic forms of epilepsy occur before five years of age, which is a critical period of developmental plasticity in the brain (Shields, 2000). Brain plasticity refers to the molding of the brain that occurs during learning, particularly during periods of children's brain growth and development. Adults have little to no plasticity of the brain; their brains are in a more permanent state. Adults who have seizures can experience the loss of certain functions without affecting their development, whereas children with seizures who lose certain functions can experience failed development (Berg, 2011).

The plasticity of a child's brain has positive and negative implications. It allows for new neuronal paths in the brain to form, but it also allows abnormal, detrimental connections to occur that can be difficult or impossible to correct (Shields, 2000). Abnormal connections lead to developmental issues and seizures, since plasticity allows an abnormal path to form, resulting in epileptic activity. Epileptic activity, in turn, contributes to severe behavioral impairment and intellectual disabilities. Surgical removal of the brain defect sometimes improves development

in children with epilepsy. The plasticity of the immature brain allows for alternative connections to form in post-surgical children with epilepsy (Smith, 2010). Once a connection develops whether, positive or negative, it is repeated and strengthened (Brooks-Kayal, 2011). Seizures disrupt the opportunity to make functional connections (Berg, 2011).

Children with catastrophic epilepsy may experience resistance to the medications used to treat their seizures. The underlying physiology suggests that the increased number of gaps in neuronal transfer that are present in affected children is due to a failure to remove nonfunctioning neurons (Beleza, 2009). Researchers have also observed that children with early onset epilepsy have reduced white matter and overall brain matter (Smith, 2010). The progression of epilepsy in childhood is due to the abnormal networking that occurs in a developing brain. Once an abnormal connection occurs, it becomes more ingrained. It is difficult to interrupt and correct this connection (Brooks-Kayal, 2011) with medication or other measures.

### **Cortical vision impairment.**

In addition to other physical and intellectual challenges they face, children with catastrophic epilepsy are frequently affected by a form of blindness called cortical vision impairment (CVI). This type of blindness occurs when the cortex of the brain does not process visual information. CVI can be the result of hypoxia, which also frequently results in debilitating seizures (Good, 2009). Although children with catastrophic epilepsy may have CVI, some recovery of vision may be possible.

Epilepsy is the most common neurological condition in children and can be debilitating. Stigma surrounding epilepsy continues to be an issue for children with epilepsy and their families. The earlier the onset and the higher the frequency of seizures, the poorer will be these

children's prognosis. Catastrophic epilepsy involves difficult to control seizures and intellectual disability. There are many possible causes of catastrophic epilepsy, but the cause of seizures is usually unknown (Avanzini, 2011).

## **Diagnosis**

In addition to the child's history and clinical assessment, a diagnosis of epilepsy is enhanced by the use of an electroencephalogram (EEG), now available with video monitoring, that involves capturing and recording of the electrical activity of the brain (Andermann, 2011; Williams, Jarrar, & Buchhalter, 2011). Magnetic resonance imaging (MRI), functional magnetic resonance imaging (fMRI), single photon-emission computed tomography (SPECT), positron emission tomography (PET), and magnetoencephalography (MEG) scan are additional diagnostic imaging tools used to assess the brain and its function.

## **Treatment**

The treatment of catastrophic epilepsy typically involves medication or surgery, neither of which has been consistently shown to be effective. Several of the treatment options for epilepsy have side effects. Other treatment options used to gain control of epileptic seizures include the implementation of a ketogenic diet and administration of intravenous immunoglobulin. The researcher will briefly discuss medication, therapy, and monitoring and other equipment in treating epilepsy in the following section.

### **Medication.**

Medication such as antiepileptic drugs (AEDs) and steroids are used in the treatment of catastrophic epilepsy. Children with this form of epilepsy are often treated with several AEDs (Beleza, 2009). The efficacy of AEDs and their side effects tends to increase with increasing dosage because it is generally difficult for any drug to cross the blood-brain barrier. Children

receiving AED treatment often experience adverse systemic effects with drug doses high enough to cross the barrier (Beleza, 2009).

Intellectual disabilities occur in response to many AEDs. This can increase the already present intellectual disabilities seen in many children suffering from epilepsy (Rantanen, et al., 2011). Oral aversion can develop in response to taking multiple AEDs for extended periods of time. Children with intellectual disabilities and oral aversion brought on by AEDs often will stop eating or drinking. This leads to the need for a gastrostomy tube in order to ensure adequate nutrition (Camfield & Camfield, 2011).

Another side effect of AEDs is a reduction in bone mineral density, thus increasing the risk of bone fractures (Sheth, Binkley, & Hermann, 2008). The bone mineral deficits seen in childhood due to AEDs also increase the likelihood for osteoporotic fractures later in life. The sleep disorders that frequently occur in children with epilepsy are often related to AEDs (Ganata, 2011). The maximum dose of AEDs may be required to gain seizure control, but often at the expense of sleep.

The use of steroids has been effective in controlling some children's seizures (Pellock, et al., 2010). Adrenocorticotrophic hormone (ATCH), for example, is a steroid that is a first choice medication in treating infantile spasms. Intravenous immunoglobulin (IVIG) is a blood product that has also been tried in the treatment of childhood epilepsy. A ketogenic diet that is a low carbohydrate and high in fat is sometimes used to treat drug resistant epilepsy (Beleza, 2009).

### **Therapy.**

In addition to surgery and medication, various intensive therapies are used in treating catastrophic epilepsy. Such therapies are beneficial in improving development in affected children (Beckung, 2000). The goal of therapy is to try to make new, positive connections



within the brain in an effort to promote the child's development. Children with epilepsy often have global disabilities and motor and sensory dysfunctions (Beckung, 2000).

Physical Therapy (PT) is used to facilitate children's independence, mobility, and strength. The goal of pediatric PT is to facilitate the formation of normal motor patterns in order to help the child achieve developmental milestones (Peranich, Reynolds, O'Brien, Bosch, & Cranfill, 2010). Children with catastrophic epilepsy often have physical issues that require orthopedic devices in order to bear weight or walk (Granata, 2011). Occupational therapy (OT) addresses sensory issues that often impede children's ability to explore their environment (Peranich, et al., 2010). Occupational therapists work to develop fine and gross motor skills in order for a child to participate in everyday living. OT and speech therapy often are used together to address feeding issues. Speech therapy involves working with oral motor and language skills to promote communication and swallowing (Peranich, et al., 2010). Many other therapies are beneficial for children with epilepsy, such as music therapy, hippotherapy, and vision therapy.

### **Monitoring and equipment.**

Children with catastrophic epilepsy may require various types of physical monitoring. Continually monitoring AED blood levels ensures a safe, therapeutic medication level (Beleza, 2009). Some children, particularly those with frequent seizures, require monitoring of their oxygen levels, because a lack of oxygen can be experienced during a seizure. Monitoring the child for seizure activity is frequently necessary in catastrophic epilepsy in order to administer emergency medications for seizures (Granata, 2011).

Due to constant or frequently recurrent seizure activity, neuronal connections often are absent within the developing brain. For these children, completing basic tasks in life such as holding a toy, crawling, or walking are impossible because the paths within the brain were never

formed. As a consequence, children with catastrophic epilepsy often experience abnormal muscle tone that can require orthotics. Orthotics aid the child by properly positioning the feet, ankles, and knees in order to enable the child to bear weight without damaging tendons and joints. Ankle-foot orthotics (AFO) or knee-ankle-foot orthotics (KAFO) provide support and allow for increased mobility (Nemeth, 2011). Splinting, serial casting, bracing, electrical stimulation, and proper static positioning are interventions used to combat abnormal muscle tone. These interventions are required to maintain range of motion and prevent limitation of movement, pain, and contractures (Riddick-Grisham & Deming, 2011).

In effort to foster children's exploration of the environment, additional support for children with catastrophic epilepsy may involve gait training. Gait training is a progressive skill that can require years to develop but modified walkers called gait trainers can provide lower extremity strengthening and mobility during the training process. Other ambulatory equipment includes canes, crutches, and anterior and posterior walkers. Stenders are a type of adaptive equipment that places the child in supported, standing positions to promote bone strength. Non-ambulatory equipment includes manual and powered wheelchairs (Riddick-Grisham & Deming, 2011).

Children with catastrophic epilepsy often exhibit sensory issues. Equipment that allows for sensory integration may include weighted or pressure vests, vibrating toys, and modified swings. They may experience improvement in their gross motor skills by using therapy balls, mobility devices, modified tricycles, and positioning chairs. Perceptual development and fine motor skills are often lacking in children with catastrophic epilepsy. Seating devices may be required for children with catastrophic epilepsy for classroom sitting, bathing, and feeding. Children with catastrophic epilepsy often wear helmets to protect their heads if they fall during a

seizure or when they experience increased mobility without the awareness they need to walk safely (Granata, 2011).

Children with catastrophic epilepsy may use communication devices and oral motor tools to promote development. Oral motor tools combat oral sensory issues and promote feeding. Children with catastrophic epilepsy may or may not take food by mouth. These children may not chew and require their foods to be pureed. Oral skills are necessary to promote feeding, chewing, and oral exploration (Riddick-Grisham & Deming, 2011).

Catastrophic epilepsy begins in childhood and can have a devastating effect on the developing brain. The cause is often unknown, but can be structural or genetic. This form of childhood epilepsy involves difficult to control seizures along with intellectual disabilities. Other issues experienced by the child are physical disabilities, sensory issues and cortical vision impairment. Stigma associated with both epilepsy and intellectual disabilities can be experienced by the family. The maternal experience in caring for children with catastrophic epilepsy may include processing associated stigma and learning how to care for their child.

Overall, epilepsy is common but can be extremely devastating physically and intellectually when the onset occurs in childhood. Catastrophic epilepsy, the cause of which is frequently unknown, occurs in and severely affects children under five years of age due to two primary issues: difficult-to-control seizures and intellectual disabilities. These children are typically dependent on their parents for complete care. Their experience and that of their parents can be negatively affected by the stigma associated with epilepsy.

## **Stigma**

Stigma has surrounded epilepsy since it was first described 4000 years ago and continues to be associated with epilepsy today (de Boer, et al., 2008). Stigma means negatively labeling

people considered contagious, impure, violent, mad, or who have an abnormal behavior, and disqualifying them from full social acceptance for whatever reason (Acevedo, 2011; de Boer, 2010). Society may view people with epilepsy as having lower social worth due to the assumption that they cannot participate in social interactions. Goffman, a sociologist who studied stigma, described epilepsy as a feature that was profoundly disgraceful and inhuman (Fernandes, Snape, Beran, & Jacoby, 2011).

Three different types of stigma relate to epilepsy. The term, “felt stigma,” refers to the shame of the condition experienced by the person with epilepsy. Felt stigma reflects a fear of “enacted stigma” that refers to the actual act of discriminating against a person with epilepsy (Fernandes et al., 2011). Stigma by association is “courtesy stigma” (Acevedo, 2011), as illustrated by what the parent of a child who has seizures may experience. People with epilepsy often see stigma as a larger issue than the seizures themselves (Fernandes, et al., 2011). Felt, enacted, and courtesy types of stigma may directly affect the quality of life for children with catastrophic epilepsy and their parents.

Throughout history epilepsy has been associated with beliefs about its origins that have been demonic, supernatural, superstitious, or magical (Magiorkinis, Sidiropoulous & Diamantis, 2010). In the 20<sup>th</sup> century, professionals in the field described people with epilepsy as irritable, stubborn, egocentric, uncooperative, and aggressive (de Boer, 2010). They published materials that stated that people with epilepsy were quick to point out the mistakes of other people and were unable to admit their own mistakes (de Boer, 2010). Today, people with epilepsy are seen as introverted and overanxious (Fernandes, et al., 2011). A survey conducted in 2002 by 20 Epilepsy Foundation affiliates across the country involved high-school-aged adolescents. Survey findings indicated that youth in general were still unsure if epilepsy was contagious and

considered the condition a form of insanity (Austin, Shafer, & Deering, 2002). A survey conducted with a random sample of 560 companies revealed that employers considered hiring a person with epilepsy to be a major problem (Jacoby, Gorry, & Baker, 2005).

Epilepsy provokes stigma because the disorder represents a symbolic or tangible danger to people (Fernandes, et al., 2011). Seizures are an involuntary, uncontrolled event that some individuals are uncomfortable witnessing. Some people view those who live with epilepsy as primitive individuals whose behavior is inconsistent with normal social interactions (Fernandes, et al., 2011). Intellectual disabilities are present in an estimated forty percent of people with epilepsy (de Boer, et al., 2008). Often, the stigma that is associated with epilepsy is exacerbated due to the additional stigma associated with intellectual disabilities.

Science and medicine are working to repair the perception of epilepsy; however, legislation is still lagging in improving the lives of people with epilepsy and their families (de Boer, et al., 2008). Legislators are key players in shifting and shaping public awareness and attitudes in regards to epilepsy. The Global Campaign against Epilepsy expresses the moral obligation of legislators to support anti-stigma actions through statute and legal processes (Fernandes, et al., 2011). At the time of this study, “Out of the Shadows” was an initiative to alter the negative perception of people with epilepsy (Fernandes, et al., 2011). The goals of the “Out of the Shadows” and other initiatives are to reduce stigma and contribute to overcoming the economic and quality of life barriers for people with epilepsy and their families.

### **Maternal Experience**

This study explored the meaning and lived experiences of parenting a child with a debilitating form of epilepsy from a maternal perspective. Children with catastrophic epilepsy are a heterogeneous group who may be at various developmental stages and experience progress

at differing rates. This phenomenological research study that explored the experiences and perceptions of biological mothers with a child who was diagnosed with catastrophic epilepsy and the meaning they as mothers associated with caring for a child with this severe disability is among the first studies of its kind.

### **Quality of life.**

Debilitating epilepsy requires lifelong care, with the parents continually processing the diagnosis and its implications for their child. There are changes in family dynamics in response to having a child diagnosed with catastrophic epilepsy. The parents have concerns for the affected child and their other children. A study conducted in 2006 interviewed primary caregivers of children with epilepsy and intellectual disabilities. The study found that parents played a pivotal role in communicating with healthcare providers, the health care system in general, and the school system. This study also found that the caregivers educated each other about the care of similarly affected children and managed the consequences of the condition for their own child (Buelow, McNelis, Shore & Austin, 2006). Another study using a survey questionnaire found that parents of chronically ill children, some of whom had epilepsy, struggled with such issues as caregiving, financial resources, family life, social life, and maintaining a professional career (Hatzmann, Heymans, Ferrer-i-Carbonell, van Praag, & Grootenhuis, 2008).

A survey conducted with mothers of children with intractable epilepsy found that they mothers were at a high risk for clinical depression, anxiety, and stress (Wirrell, Wood, Hamiwka, & Sherman, 2008). Parents of children with catastrophic epilepsy often have feelings of isolation and perceive a lack of freedom in their lives. They seek support from each other but may not receive the emotional support they need from the other spouse (Wirrell, et al., 2008). A

questionnaire was used to examine the relationship between intractable childhood epilepsy and maternal fatigue and found that mothers of children with catastrophic epilepsy can experience health issues as the result of stress (Mohammed, 2006). Parents of children with catastrophic epilepsy, for example, may experience physical pain or disability as the result of carrying their child who cannot walk, and may feel helpless and inadequate to care for their child (Mohammed, 2006). Their original hope for the child's future may present a major issue for them, as might them facing the implications of debilitating epilepsy. Fear about the future and their child dying from injury or a seizure is common among these parents (Buelow, et al., 2006).

There are several reasons parents may feel stressed or overwhelmed when caring for a child with catastrophic epilepsy. A child's intellectual disabilities and behavior problems are the strongest risk factors for maternal depression (Ferro, et al., 2011; Mohammed, 2006); both of these issues are commonly cited concerns with catastrophic epilepsy.

Dean's exploration of parental concerns for a child with catastrophic epilepsy found that parents were at a high risk for increased parental stress due to the continual disruptions in their lives that resulted from the unpredictable nature of epilepsy (Dean, 2011). The constant monitoring of the child in order to observe seizure occurrences and frequency could be taxing. Childhood epilepsy often resulted not only in intellectual disability, but also in behavioral problems and sleep disturbances (Granata, 2011). Often these children could not communicate, which may lead to maternal frustration or aggression. Children with epilepsy often seemed unhappy, cried, and screamed (Wirrell, et al., 2007). Due to the child's inability to communicate, parents found it difficult to comfort their child. Children with catastrophic epilepsy were noted to be unable to adapt to changes in their physical and social environments.

This lack of adaptability was found to isolate the child and his or her caretaker (Wirrell, et al., 2007).

Parenting a child with epilepsy in general could negatively influence the marital relationship as affirmed by findings from a four-part questionnaire completed by parents of children with epilepsy (Ferro, et al., 2011). Communication between parents could be poor because they were consumed with managing the child. Maternal alone time and resources were often limited. Parents of children with epilepsy reflected dissatisfaction with their social situation. A child might experience seizures resulting from birthdays, Christmas parties, or unfamiliar situations, with the outcome of restricting maternal social opportunities (Hatzmann, et al., 2008).

Maternal depression, anxiety and stress had implications for caring for their child with epilepsy. Some parents of children with epilepsy were found to develop effective coping strategies and balance their lives well, but other parents become overprotective and emotionally over-involved with their disabled child, as indicated by responses to a survey conducted in 2008 (Cushner-Weinstein, S., Dassoulas, K., Salpekar, J., Henderson, S., Pearl, P., Gaillard, W. & Weinstein, S., 2008). The increased stress experienced by parents could have a negative impact on the child, leading to the development of a poor relationship between a parent and a child who manifested behavioral issues (Buelow, et al., 2006).

Parents suffering from caregiver burnout might develop negative attitudes toward their child. Responses to a questionnaire revealed that parents of children with epilepsy could exhibit hostile and intrusive behaviors toward their child or simply be less involved (Rodenburg, Meijer, Dekovic & Aldenkamp, 2007). Distorted maternal care could cause the child to exhibit more behavior issues (Buelow, et al., 2006). Overprotective parenting could potentially result in



abnormal social development of the child. In general, the reactions of the parent to the child with catastrophic epilepsy were noted to affect the functioning of the child (Hatzmann, et al, 2008).

### **Financial issues.**

Children with epilepsy have higher rates of contact with all sectors of health care and have a higher rate of medication use (Jennum et al., 2011). Medication costs and frequent copayments could be a source of financial stress (Dean, 2011). Family finances often deteriorate in the face of debilitating epilepsy (Westphal-Guitti et al., 2007). The financial situation becomes even worse with higher socioeconomic costs and lower employment rates and income. Families that have a child with debilitating epilepsy must often survive on a single income (Ganata, 2011). The child's ongoing care needs as well as their therapy, health care provider, and testing appointments, coupled with a lack of special needs childcare assistance usually required one parent to become a fulltime caretaker.

The estimated financial burden for a lifetime of epilepsy was estimated to be \$6.8 million in 2010 (Ngugi, et al., 2010). Substantial costs can be incurred for the healthcare of individuals with debilitating epilepsy that are unrelated to epilepsy. An estimated annual expense of \$15.5 billion in direct and indirect costs was required in 2010 to care for the three million Americans living with epilepsy (Kurth et al., 2010). The financial situation associated with childhood epilepsy can be significant, particularly for low-income families who spend a disproportionately large share of their income on their child's care.

### **Support.**

Supportive assistance can come from immediate and extended families, friends and the community. A marital relationship can be a strong source of support. Family supports allow the

parent to have a break and can be beneficial to relieve or alleviate the stresses experienced by other children in the family, particularly stress experienced in response to maternal depression. (Ferro, et al., 2011).

Often, friends and family members are not comfortable caring for a child with catastrophic epilepsy (Buelow, et al., 2006). The availability of community assistance for a child with catastrophic epilepsy and their families varies with different states. At the time of this study, the federal government offered supplemental security income (SSI) for children with catastrophic epilepsy who qualified financially and physically for such support. Qualifications included the nature of the disability and income status. There were different programs that assisted children with developmental disabilities and those who were medically fragile (DHHS, 2010). The allocation of openings in these programs, however, occurred in a way that children could be on the waiting list for years. Emergency situations received priority, including children who were homeless, those at risk for physical harm, and children who had inadequate caregivers. These programs ranked routine cases in priority according to disability to determine eligibility for program openings.

## **Summary**

Catastrophic epilepsy occurs in children with devastating results. The children have difficult-to-control seizures, intellectual disabilities (Shields, 2000), and often experience other developmental issues. Children with catastrophic epilepsy require close monitoring for seizure occurrence, frequency and duration. Monitoring may also be required for such issues as safety during seizures, unsteady gait, or a mobile child with limited intellectual function. Often, children with catastrophic epilepsy are completely dependent on their caregiver. The caregiver may have to provide medical care to their child such as administering medications or oxygen or

feeding their child through a gastrostomy tube. The expense of caring for a child with catastrophic epilepsy can be enormous due to the cost of medication, specialists, therapists, equipment, and home modifications.

The researcher identified few qualitative studies that explored the maternal experiences of parenting a child with catastrophic epilepsy. This study aimed to gain insight into the maternal perceptions of parenting a child with catastrophic epilepsy. This phenomenon was valuable to investigate for several reasons. Such an investigation was anticipated to heighten awareness and provide information about the lived experience of catastrophic epilepsy and its care from a maternal perspective. The researcher sought to highlight maternal perceptions in caring for a child with catastrophic epilepsy in an effort to provide an emic or insiders' perspective to this severely debilitating form of epilepsy. Literature exists about maternal experiences with chronic conditions affecting children, including epilepsy as a chronic condition. This study, however, focused on the maternal perceptions of one of the most devastating forms of childhood epilepsy. Gaining knowledge and an understanding of the daily lives of parents who provided care for their children who were affected by catastrophic epilepsy could, in turn, assist the medical community to effectively address the needs of such children and their families. In the following chapter, the researcher will address the methods that she used to conduct this study.

### **Chapter 3: Methodology**

The purpose of this hermeneutic phenomenological qualitative study was to explore and describe the experiences and perceptions of individuals who were parenting a child with a severely disabling type of epilepsy called catastrophic epilepsy. Qualitative research offered the researcher a powerful means of gaining insight into a previously underexplored area (Creswell, 2007; Patton, 2002) such as the area of parenting a child with catastrophic epilepsy. In this chapter, the researcher will describe the elements that comprised the study design, including the research question, qualitative approach, phenomenological theoretical orientation, sampling strategy, data collection methods, and data analysis strategies. The audit trail that the researcher maintained throughout the research study as well as other strategies to ensure study credibility will also be addressed in this chapter.

#### **Study Design**

The use of a qualitative research design using a hermeneutic phenomenological theoretical orientation provided the researcher with an opportunity to conduct an in-depth study of the lived experience of parenting a child with catastrophic epilepsy. The researcher chose a qualitative approach for this study because it provided a means to explore everyday life and describe human experiences (Magilvy & Thomas, 2009). The study focused upon the real life circumstances of participants, the understanding of which evolved through the research process. Qualitative research is particularly appropriate for previously underexplored topics (Creswell, 2007; Dowling, 2004; Patton, 2002) such as parenting a child with catastrophic epilepsy.

In this study, a phenomenological orientation focused on the researcher gaining a deeper understanding of maternal perceptions about life with their child affected by catastrophic

epilepsy. The researcher used van Manen's theoretical orientation of hermeneutic phenomenology to reach an understanding of the deeper meaning of the experience by enabling individuals' to reflect on their experiences (van Manen, 1990). Phenomenological research of this nature seeks to ask, How is this (parenting a child with catastrophic epilepsy) experienced? Is this what it means to (parent a child with catastrophic epilepsy)? Is this what the (parenting a child with catastrophic epilepsy) experience is like? (van Manen, 1990).

In the phenomenological description, the researcher is mindful of the research question and draws the reader in such a way that the reader questions the maternal perceptions about life with their child affected by catastrophic epilepsy (van Manen, 1990). The emergently designed phenomenological theoretical orientation was used to provide the reader with insight into the significance of the maternal experiences and perceptions they had with their child on a daily basis. The hermeneutic approach allowed for the researcher's interpretation of data related by participants, including the identification of the essence of the maternal perceptions about life with their child affected by a catastrophic form of epilepsy.

The researcher used six research activities consistent with hermeneutic phenomenological research to guide the study. First, the research focused on a phenomenon that was of great interest to the researcher. van Manen emphasized that a phenomenon that seriously interested the researcher was essential to phenomenologically based human science research (van Manen, 1990). Second, the researcher investigated the participants' perceptions about their lived experience by absorbing all aspects of study participants' experience as she spent time with them and sought to gain insight into maternal perceptions about life with their child (van Manen, 1990). Third, the researcher reflected on the major themes that emerged in the data collection process, which captured the phenomenon of parenting a child with catastrophic epilepsy. Two

methods of data collection in this study included audio recorded in-depth, open-ended interviews and a photoelicitation process that served as a catalyst for obtaining information rich data.

Fourth, the researcher described the phenomenon by writing and rewriting in an effort to capture multiple aspects of parenting a child with catastrophic epilepsy. Fifth, the method helped the researcher remain focused on the research question and on the pursuit of answers. Finally, the researcher structured the research by investigating, analyzing, and viewing the data in both parts and the whole (van Manen, 1990).

The aim of this study was to transform the participant's experiences and perspectives shared with the researcher into a textual understanding. Data for this phenomenological inquiry was contributed by five study participants in response to open-ended questions posed by the researcher during two audio-recorded in-depth interviews, one of which was a photo-elicitation interview. Data from the interviewing process were analyzed to produce an in-depth understanding of parenting a child with catastrophic epilepsy (Magilvy & Thomas, 2009) and to identify the essence of the experience (van Manen, 1990).

### **Sample and Setting**

The researcher used purposive sampling (Patton, 2002) to identify and select a sample of five individuals who had direct life experience with the phenomenon studied: parenting a child with catastrophic epilepsy (Creswell, 2007; Jackson, Drummond & Camara, 2007). Catastrophic epilepsy is not a common condition; therefore, the inclusion of five parents within a particular geographical region may have reflected all who are available to provide their perspectives on the phenomenon.

The criteria for study participation included parents who were: a) primarily involved in and responsible for caring for a child diagnosed with catastrophic epilepsy, b) English speaking and able to read English; c) 18 years of age or older; and d) willing to voluntarily participate in at least two interviews and take photographs for use during one of the interviews. Exclusion criteria included parents of a child with a benign form of epilepsy, parents who were not the primary care takers of a child with catastrophic epilepsy, or individuals who served as hired or episodic caretakers for children with this disorder. The researcher spoke with potential study participants who contacted her by phone in an effort to determine if they met study criteria and to schedule the interviews.

### **Sample recruitment.**

The researcher enlisted the aid of family support specialists associated with a family support network that was located in a regional children's hospital to identify participants who met criteria for this study. Family support specialists associated with the network gave the researcher's contact information to potential participants who were known to them (Appendix A). The researcher also used a type of purposive sampling called snowball sampling, whereby participants involved in the study suggested other parents in similar circumstances who they thought might contribute to the study (Patton, 2002). In either case, the researcher requested that the family support specialist or study participant initiate contact with the potential parent known to them to ascertain the referred parent's interest in study participation. The family support specialist or study participant then requested that the referred interested parent contact the researcher within one week and provided the individual with the researcher's contact information.

### **Sample selection.**

The researcher explained the study during a telephone call received from parents who met the criteria for study participation and who contacted her with an expressed interest in and willingness to participate in the study. Though catastrophic epilepsy is a relatively rare condition, the researcher recruited five individuals who met the criteria for study participation. The first five participants who contacted the researcher had met study criteria and thus were included in the study. These individuals were women who were the biological mothers of their child with catastrophic epilepsy. No fathers contacted the researcher with interest in participating in the study.

The researcher scheduled the first interview once the parent agreed to participate in the study. The age of the child with catastrophic epilepsy was not an exclusion criterion as long as the children were under the age of 18 years. In order to increase the potential for a wider range of maternal experiences, the researcher hoped to recruit participants with differently aged affected children.

### **Research setting.**

The researcher conducted the interviews in a secure, private room at a regional children's hospital. The location was familiar to the parents and centrally located in the region. The Family Support Network housed in the children's hospital had several dedicated rooms to conduct support meetings and specialists affiliated with the Network agreed to provide private space for the interviews. The familiarity of the space enabled the parents to be more at ease locating the interview site and engaging in the interview.



## **Data Collection Methods**

The data collection method for this study involved two interviews with each of five participants, with a photo-elicitation process included in the second interview. A brief third follow up interview was posed to participants as a possibility in order to follow-up on questions or a need for clarity regarding the data but the researcher did not need the third interview. The in-depth interviews were audio recorded with permission of participants. The researcher took handwritten notes during the interviews and transcribed the audio recordings verbatim.

## **Ethical Considerations**

The researcher carefully considered ethical issues in planning and conducting this hermeneutic phenomenological study. The researcher was initially concerned that the methods of data collection might be potentially intrusive but found that intrusiveness was not an issue as she gained knowledge about the personal feelings and thoughts of parents who participated in the study. The researcher conducted the study guided by beneficence or the view of doing no harm and non-maleficence in terms of limiting any adverse effects on participants posed by their participation in the study (Walker, 2007).

She obtained written informed consent (Appendix B) from the participants before each of the interviews began, with the understanding that participants could stop participating in the study at any time. She assured that participants' identities would be anonymous and remain confidential. She ensured anonymity by using pseudonyms in the transcription of data and written reports of the study. The researcher received approved from the East Carolina University and Medical Center Institutional Review Board for conducting this study (Appendix C).

The researcher presented the informed consent documents to each participant prior to initiating the first interview. The informed consent document explained the study to each parent, including risks and benefits of participation, and offered them the choice to participate or decline participation (Walker, 2007). The document addressed the potential benefits of participation in the study, including the opportunity they had to explain their day-to-day life with their child who had debilitating epilepsy. They were informed that the information they shared could increase health professionals' insights into catastrophic epilepsy and the experience of parenting a child with the condition. Other possible benefits included their contribution to understanding catastrophic epilepsy since maternal perceptions about caring for a child with this condition had not been previously reported in the research literature. An additional benefit to participants in this study was that the in-depth, open-ended interview process might afford them a chance to reflect upon their experiences of parenting their child, thus providing an opportunity for them to gain additional insight into themselves and their role as parent and caregiver.

The risks to parents participating in this study included the possibility that talking about their experiences could be emotionally distressing. It was a sensitive topic for parents to explore; their responses during the interview were unknown at the time they provided consent. Offering them the free choice to decline participation at any time during the interview process was crucial.

### **The Interview Process**

Two open-ended interviews provided the in-depth data that addressed the purpose of the study. Hermeneutic type interviews aim to keep the questions open-ended and keep the participant oriented to the phenomenon of parenting a child with catastrophic epilepsy (van Manen, 1990). The researcher conducted each interview using a hermeneutic, conversational

style that allowed for participants' reflection and enabled the participant to feel empowered and comfortable in sharing information related to the focus of the study. Again, the researcher recognized that the topic of study might be sensitive to participants (Walker, 2007) but shared that she, too, was caring for a child with catastrophic epilepsy, which helped in establishing trust and rapport.

In addition to the conversational style of the interviews, the researcher established a rapport with study participants by engaging in non-judgmental empathetic neutrality (Patton, 2002). Her empathetic neutrality and non-reactivity during the interview helped to provide security for the participant to reveal sensitive information (Patton, 2002). The researcher also engaged in re-consenting the participants prior to the second interview and during the course of all interviews.

When a participant became emotionally upset during the interviews, the researcher used the following strategies advocated by Mitchell and Irvine (2008) to enable participants to manage their emotions and gain a sense of personal control. She enabled participants to control the pace of the interview and the depth of information they provided. The researcher was comfortable with extended periods of silence. She sometimes changed the topic to something more neutral or asked the participant if she or he would like to take a break from or stop the interview. If the participant expressed a desire to take a break, the researcher stopped the audio-recorder as a sign of suspending the interview. In all cases, the well being of the participant took precedence over the pursuit of the research. The director of the Family Support Network was qualified to provide professional support in the event a parent needed such support or consultation. This individual was present in a nearby office during each interview and had

agreed to respond to a participant who needed support or assistance. In the end, participants did not indicate a need to avail themselves of such support.

The researcher used an interview guide (Appendix D) so that each participant responded to similar questions, though the researcher used the interview guide flexibly, without needing to use the same wording or the same order of questioning with each participant. The interview guide provided a starting point for study participants to reveal and expand upon their life experiences, thus providing direction during the conversation (Patton, 2002). When the interview provoked participants' feelings of sadness or grief, the researcher provided support as previously described. Feelings tap into human life and aided the researcher in exploring the perceptions and lived experiences participants (Patton, 2002) associated with parenting their affected child.

During each interview, the researcher used follow-up questions to gain depth and further explore participants' perceptions about parenting their child. The duration of the interviews ranged from 83 to 110 minutes. None of the participants had to leave the interview prematurely, which the researcher anticipated might occur due to a need or issue that they or their child with catastrophic epilepsy might have.

### **Interview one.**

The researcher explained the study and obtained informed consent from participants in the study prior to commencing the first interview. At the beginning of the interview she engaged in small talk with participants in an effort to establish rapport. Once she saw that the participant was comfortable, she began to facilitate the interview using the interview guide (Appendix D). At the conclusion of the first interview, the researcher explained the photography activity and the

photo-elicitation process, provided the participant with written directions (Appendix E) for the experience, and scheduled the second interview during which photoelicitation process was used.

As part of the photoelicitation process, the researcher requested that each parent take four photographs that reflected their perceptions about what it was like to parent a child with catastrophic epilepsy. Study participants took their photographic images using a digital camera. The researcher requested that participants email their photographs to her at least two days before the second interview. She then printed two copies of each of the participant's photographs and brought the printed images to the second interview.

### **Interview two.**

During the second interview, the researcher engaged in a re-consenting process with participants. They voiced no questions or concerns about the study at the initiation of the interview. The researcher initiated the second interview by asking study participants to explain each of the photographs they had taken, beginning with any photograph they wished. The photographic images then served as a catalyst for discussing what it was like for them to parent their child with catastrophic epilepsy.

The photoelicitation interview afforded an additional opportunity for participants to convey their perspectives, thus providing a different lens through which the researcher had an opportunity to view the maternal experience of care giving. The researcher requested that the study participants take only four pictures so that they did not feel overwhelmed by the activity and were able to prioritize the key points they wanted to make in communicating what it was like to parent their child. The photographic images presented the participants' reality and served as a method that the researcher used to explore that reality (Close, 2007). The goal of the photo

elicitation process in this study was to encourage participants' reflection at a personal level. Photography is a visual language that has meaning and an interpretation (Close, 2007). This method provided an effective approach to generate an internal evaluation of the parents' thoughts and feelings.

### **Interview three.**

The researcher had initially negotiated a third, elective interview with participants. She did not need the additional interview, however, to follow-up on or explore additional or unexpected information shared by study participants during the first two interviews.

### **Data Analysis**

The researcher conducted interviews during the months of February 2012 and March of 2012 and transcribed the interviews verbatim. She then coded and analyzed the data in order to present findings associated with the data collected from each of the five study participants. In this section she will describe the analytical process.

She initiated data analysis at the beginning of data collection by writing analysis and interpretation memos in response to the data that study participants shared (Sample format, Appendix F). After transcribing each interview verbatim, she repeatedly read the interview transcripts, listened to audio recordings, reviewed her notes, and clarified unclear concepts with participants during the second interview (Magilvy & Thomas, 2009). In preparation for coding the transcripts, she prepared a codebook. The first draft of a codebook was comprised of initial codes that emerged from the data, their definitions, and inclusion and exclusion criteria.

After initially coding the data, the researcher reviewed the codes and, when necessary, re-categorized and recoded the data and revised the codebook (Appendix G). After coding all data, the researcher then sorted and reviewed similarly coded data, eventually identifying categories, patterns, and themes that emerged from the data. These common categories, patterns, and themes were aggregated, organized, and presented as findings (Magilvy & Thomas, 2009), with the inclusion of particularly illustrative quotations providing evidence of the researcher's analysis and interpretation of data. The findings revealed the essence of the mothers' experiences and perceptions as well as themes related to understanding their experiences and perceptions about life with a child affected by catastrophic epilepsy.

### **Study Credibility**

The researcher's study design reflected credibility by means of objectivity, ethical diligence, and rigor (Jackson et al., 2007). She stayed in touch with her subjectivity by regularly identifying her personal assumptions and biases and writing about them in a researcher's journal throughout the course of the study. The researcher made every effort to be ethically diligent, including having participants review and sign informed consent documents, ensuring re-consent during the course of the study, and ensuring the confidentiality of information and anonymity of participants. The researcher received approval for the study by the University and Medical Center Institutional Review Board (UMCIRB) (Appendix C). The use of rigorous methods created high-quality data to be analyzed (Patton, 2002).

For this study, the researcher used several strategies in designing and implementing a credible study. In addition to purposive sampling, the use of thick description, writing as part of the analytical process, and active engagement in reflexivity, the researcher addressed study

credibility by employing the triangulation of data, maintenance of an audit trail, ensuring methodological congruence, and conducting member checks. Each of these strategies will be addressed below.

### **Triangulation.**

Triangulation of data is an important credibility strategy. The researcher accomplished triangulation in this study by using more than one type of data and more than one source of data. Triangulation afforded her a process to consider the consistency of findings by using more than one method of data collection (Patton, 2002). In this study, the researcher incorporated data triangulation by obtaining the perspectives of five different participants and methodological triangulation by conducting two interviews with each participant and employing photoelicitation as an additional data collection method.

### **Audit trail.**

The researcher used an audit trail to provide documentation of all elements of the study. The audit trail would enable an outside auditor to review the study, including all actions taken by and decisions made by the researcher (Wolf, 2003). In addition to all documents related to this study, the audit trail in this study included a research log, researcher's journal, analysis and interpretation notes, and a codebook, each of which will be described below.

**Research log.** The researcher maintained a research log in which the researcher included the dates and times of all actions, participant contacts, and decisions pertaining to the study (Sample format, Appendix H). The researcher initiated the log at the inception of the study and maintained it until the study was completed.



***Researcher's reflexivity journal.*** The researcher's reflexivity journal (Sample format, Appendix I) enabled the researcher to write continuously about her engagement in the study from her own perspective. The purpose of the journal was to enable her to identify and document her initial and evolving personal self-awareness of her biases, assumptions, values, and beliefs associated with the focus of the study. Documenting these personal issues helped to insure her objectivity when conducting and writing the study (Bishop & Shepard, 2011). It also contributed to her ability to be more fully present to whatever study participants wished to share with her. In addition, the journal enabled her to assess her own impact on participants and the research environment and the impact of the research environment and participants on her (Bishop & Shepard, 2011; Patton, 2002).

***Analysis and interpretation memos.*** The researcher wrote dated analysis and interpretation memos in the form of written notes that captured her analytical thought processes. She used these dated memos to document her thoughts while immersed in the data, particularly during data collection and analysis. The memos provided a way to document how she was thinking about the data during the course of the study. Her analysis and interpretation memos served as a means of helping her conceptualize the data (Birks, Chapman, & Francis, 2008).

***Codebook.*** The researcher developed and used a codebook to ensure that, while coding, it was clear how the codes were defined so she could then accurately and consistently apply the codes to segments of the data that ranged from words or phrases to sentences. The coding itself helped in the process of analyzing the textual material (Wolf, 2003).

#### **Methodological congruence.**

Methodological congruence refers to the careful planning of coherence and purpose among parts of the study (Thurston, Cove, & Meadows, 2008). The components of the study

must be cohesive in order to achieve congruence. The research question, qualitative approach, sampling, data methods and analysis must fit together and be consistent with one another.

Consistent with hermeneutic phenomenology, for example, the research questions in this study reflected an exploration of meaning and lived experience. Also consistent with hermeneutic phenomenology, the researcher conducted in-depth, open-ended individual interviews rather than using other data collection methods such as observation or focus group interviews (Creswell, 2007; Patton, 2002).

### **Member checks.**

The researcher invited participants to provide feedback on the findings associated with the study. The checks served as means of validating the research findings in that participants assessed the representation of their experiences and perspectives in the findings. Such member checks enhanced rigor by allowing participants to confirm the accuracy of such representation in the data (Bradbury-Jones, Irvine, & Sambrook, 2010). The member checks provided an opportunity for the researcher to make necessary corrections and to document challenges related to the findings. In the end, the participants were given an opportunity to read and react to the themes discovered by the researcher in an effort to ensure the correct interpretation of findings (van Manen, 1990).

The researcher was able to contact three participants for the purpose of conducting member checks. Two of the study participants could not be reached within the timeframe allotted for the member checks. In this study, the researcher conducted the member check by emailing a preliminary copy of the final thesis to the three participants after contacting them by both telephone and email to request that they read the study with careful attention to the findings

presented in chapter four. She then made a follow-up phone call to each of them five days later to elicit their feedback, comments, and suggestions.

## **Summary**

Since little is known about parental perceptions of life with a child affected by catastrophic epilepsy, the researcher conducted a hermeneutic phenomenological qualitative study that involved five mothers who had a child with this severe and debilitating form of epilepsy. The researcher collected data for this study from each of five study participants by means of two in-depth, open-ended interviews, the second of which involved a photoelicitation process.

In addition to purposive sampling, the researcher's engagement in reflexivity, her use of thick description, and writing as an analytical activity, she used several strategies to address study credibility. These strategies included methodological congruence; triangulation of data; maintenance of an audit trail that included a research log, researcher's reflexivity journal, analysis and interpretation memos, and codebook; and member checks. Ethical considerations she addressed included ensuring consent at each interview, assuring participants that the researcher would maintain confidentiality of information and use of pseudonyms and changing or removing any personally identifying information in order to ensure participants' anonymity.

In terms of data analysis, the researcher transcribed the recorded interviews verbatim, repeatedly read, coded and analyzed the data, and identified the essence of participants experience as well as themes that emerged from the data. In the following chapter she presents the findings associated with the study according to the patterns and themes that emerged from

the data. Findings are accompanied by selected participant quotations that provide supportive evidence of the researcher's analysis and interpretation.

## **Chapter 4: Findings**

The researcher used a hermeneutic phenomenological approach in this qualitative study that explored study participants' perceptions of parenting a child with catastrophic epilepsy. Guided by van Manen (1990) and aided by an interview guide, the researcher conducted two audio-recorded, in-depth open-ended interviews with each of five study participants, with both interviews occurring within a fourteen-day period of time. A photo elicitation process employed during the second interview involved four to five photographs taken by each participant. During the second interview, these photographic images served as a catalyst for study participants' discussing their lived experience of parenting their affected child.

### **Study Participants' Characteristics**

Five married, Caucasian women who were the birth mothers of and primary caregivers for their child with catastrophic epilepsy voluntarily participated in the study. Despite efforts to recruit male parents for this study, no males contacted the researcher with interest in study participation. All of the participants and their families lived in the southeastern United States. All participants remained at home to care for their children. Their spouses were employed full-time outside of the home primarily in the areas of construction and manufacturing. One spouse worked for a supply distributor.

The study participants were the biological mothers of the affected children and their siblings; two of the participants, however, had additional children with a different father. With the exception of one family, the biological fathers of the children with catastrophic epilepsy resided in the home. The exception was the presence of one child's stepfather in the home; the stepfather had been a part of this ten-year-old child's life since the time this child was four-years-old.

The study participants' family composition at the time of the interviews included the mother of the child who was the study participant, the father of the child (or stepfather in one case), and the child or children living in the home. No extended family members or live-in care assistants resided with the families. The total number of children in the home varied among the study participants. For two participants, the family was comprised of the child with catastrophic epilepsy and one additional child. The family of another participant was comprised of two children in addition to the affected child and another participant's family constellation included three children in addition to the affected child. For one participant, the child with catastrophic epilepsy was an only child.

One participant's family of six, including two adults and four children, lived in a two-bedroom apartment after foreclosing on their home. The other participants' families rented or owned a home or mobile home. Four out of five participants received a Supplemental Security Income (SSI) that reflected their socioeconomic status. In order for a child to receive SSI there is an income limit requirement for caregivers and disability requirements for the child.

### **Characteristics of Study Participants' Children with Catastrophic Epilepsy**

The study participants' children with catastrophic epilepsy ranged from two to ten years of age; four children were female and one was male. The participants reported various etiologies for their child's catastrophic form of epilepsy. The children's etiology, seizure history, and physical and cognitive status at the time of the study are summarized in Table 1.

Table 1: Description of Participant's Children with Catastrophic Epilepsy

	Diagnosis	Age at the time of study	Age of seizure Onset	Mobility	Estimated cognitive age
Elaine	Dravet Syndrome	10 years	2 months	Limited	18 months
Mary	Infantile spasms (unknown etiology)	5 years	4 months	Mobile	6 to 9 months
Alice	Infantile spasms (asphyxiation at birth)	2 years	2 months	Immobile	Newborn
Kay	Angelman Syndrome	8 years	< age one	Limited	9 to 12 months
Ben	Encephalitis	7 years	3 years	Mobile	18 months

Table 1 presents a summary of the participants' children and the epileptic, mobility, and level of cognitive age they experienced. The catastrophic epilepsy the children experienced was due to genetic, acquired, or idiopathic causes. The age at which the children's seizures began raised a key concern for participants because they became aware that the younger the child was at the onset of epilepsy, the more severe the child's disability. Four of the five participants' children experienced seizures before they were one year of age.

The participants' children ranged in chronological age from two to ten years. Their mobility varied from being completely immobile to being mobile with some support such as leg braces, a walker, or other supportive device. Some study participants talked about their child's lack of mobility as presenting additional physical challenges for them as caregivers. Others perceived that their child's intellectual disabilities presented serious concerns because their child was mobile and a lack of awareness on the part of the child posed safety risks for her or him.

The estimated cognitive ages for each child ranged from newborn to 18 months of age, reflecting the profound effect of catastrophic epilepsy on the children's intellectual and developmental levels.

Two of the participant's children had been diagnosed with infantile spasms, which was the most common etiology for catastrophic epilepsy (Vandrame et al., 2009). The infantile spasms experienced by one child were due to cord asphyxiation at birth, leading to an onset of infantile spasms at two months of age. At the time of the study, this child was two years old, immobile, and had an estimated cognitive level similar to that of a newborn. The second child who had infantile spasms of unknown etiology experienced her first seizure at four months of age, six hours after receiving routine childhood vaccinations. At five years of age at the time of the study, this child was mobile and had the estimated intellectual ability of a six- to nine-month-old. She received palliative care in the home that was provided in effort to support the family with the child's health and behavioral issues.

Two of the participant's children experienced catastrophic epilepsy as a consequence of the genetic etiologies of Angelman Syndrome and Dravet Syndrome respectively. The child with Angelman Syndrome was eight years old at the time of the study and had initially experienced seizures before the age of one year. This child experienced limited mobility and an estimated cognitive level of nine to twelve months of age. The child with Dravet Syndrome experienced a grand mal seizure at two months of age. At the time of the study, this ten-year-old child had limited mobility and an estimated intellectual level of eighteen months of age.

One participant's child experienced encephalitis at the age of three years that resulted in a catastrophic form of epilepsy. This child was seven-years-old at the time of the study, physically mobile, and had an estimated intellectual level of an eighteen-month-old.



All of the participants' children continued to experience seizures despite concerted efforts to control them with medication, diet, surgery, and other interventions. The children experienced multiple seizure types and daily seizure activity. Four of the participant's children experienced the onset of seizures within their first year of life and one child developed seizures at three years of age.

The following section of this study report is organized according to themes that emerged from the data. The essence of the findings for the participants in this study was one of maternal commitment to a beloved child in a seizure-centered life. The themes that emerged from the data included, "A Child with Catastrophic Epilepsy: "Waiting for the Other Shoe to Drop," "Mobilizing Resources: A Constant Preoccupation and Effort," "Providing Daily Care: An Often Overwhelming Responsibility," "Effects of Care on Caregiving Parents: "Confined to a Helpless Situation," and "Caregiver Coping: "Celebrating the Child While Mourning the Losses."

**Theme: A Child with Catastrophic Epilepsy: "Waiting for the Other Shoe to Drop"**

Participants maintained a constant state of readiness and responsiveness regarding their child's seizures, with their vigilance underscoring the significance of epilepsy in the participants' lives and the lives of their children. Participants' constant concern about seizure activity and their ability to respond appropriately echoed throughout the interviews with all five of the study participants. Such vigilance was required because, at the time of the interviews, all of the participants' children experienced daily, uncontrolled seizure activity. Moreover, the participants' children had not been seizure-free since the onset of epilepsy.

Catastrophic forms of epilepsy are characterized by difficult-to-control seizures (Shields, 2000) and the participants spoke at great length about the constant anguish, anxiety, and need for vigilance associated with a sense of, as one participant stated, "waiting for the other shoe to

drop,” (Sharon). The fears they spoke about were primarily related to at least one of the following: the potential life-threatening consequence of every seizure, their ability or inability to stop the seizure if it did not subside within an expected duration of time, and the potentially negative impact of the seizure on the child’s physical and intellectual development.

The frequency of seizure activity posed concerns for participants but it was difficult for them to determine the rate of seizure recurrences because, while some seizures were obvious, a short seizure could be missed completely by the caregiver and other kinds of seizure activity might not be physically manifested. Donna described the physical movement of her child during an obvious seizure:

*Her eyes go wide with a fixed stare, and then they roll back into her head. Her body goes very stiff and it appears that volts of electricity are running through her body.*

Not all seizures the children experienced were detectable. Donna, Jayme, Lindsay and Sharon shared the results of past electroencephalograms (EEGs) with the researcher and discussed the frequency of seizures recorded for their child within a given period of time. Sharon, for example, described the frequency of her child’s seizures that was visualized as brain wave activity on an EEG:

*She had over a hundred seizures on her last twenty-four hour EEG.*

All of the participant’s children experienced daily seizures at the time of the interviews but the frequency of seizures varied with each child. Participant vigilance was needed because different factors caused increased seizure activity such as the child having a cold or lacking sleep (Donna & Jayme), though unexplained increased seizure activity also occurred. The study participants described many seizure types experienced by the children including tonic-clonic (grand mal), absence (petit mal), myoclonic, cluster, and atonic (drop) seizures (Donna, Jayme,

Kim & Sharon). One participant's child who experienced infantile spasms had several clusters of seizure activity daily, each of which lasted up to ten minutes in duration (Lindsay).

The frequency of seizures was one epilepsy-associated issue describing by study participants as disturbing, but the duration of the seizure activity was another difficult and sometimes frightening issue for them. They described their children's seizures lasting anywhere from seconds to hours. Donna, Jayme and Sharon spoke about their children experiencing status epilepticus that occurred to such a severe degree that the children required a drug-induced coma to bring them out of a prolonged, life-threatening seizure. Jayme described her experience with her child's status epilepticus seizure when her child was three years of age.

*It was like he was born that day. He lost every skill. We are still trying to regain skills, but with every grand mal it's a setback.*

As Jayme described, prolonged seizures could result in a loss of skills the children had gained and developmental setbacks. Donna's daughter, for example, often had grand mal seizures that would result in a loss of skills. As Donna explained,

*When she has a grand mal [seizure] that lasts several minutes, they wipe her out and she will sleep for an hour or so. I wonder to myself, "What is it going to be this time?"*

*Because it never fails that she loses development after each big grand mal. Sometimes she regains the skill pretty quickly and other times not at all.*

Several study participant's explained that regression in a child's development could occur abruptly following a prolonged seizure or gradually during a time when their child was experiencing an increase in the frequency of seizure activity for some reason (Jayme, Kim, & Lindsay).

The participants affirmed that the nature of their child's epilepsy required that they be continually on alert. It also kept them on constant edge, leaving them unable to relax. As one participant stated,

*I am always waiting for the other shoe to drop, I can never really relax.* (Sharon)

Participants revealed many concerns about which they had to be alert during the time their children were having seizures. Seizure-associated physical challenges such as poor oxygenation, especially during a prolonged seizure, presented such great concern that Donna, Jayme and Sharon used monitoring units to check their child's oxygen level and heart rate during a seizure. With the onset of each seizure, participants were left wondering how long the seizure was going to last, what effect it would have on their child, and how many more seizures would their child experience on that particular day. For the study participants, being at the mercy of the inevitable next seizure left them emotionally drained and in a heightened state of vigilance.

Once a seizure started, participants were vigilant in monitoring it and providing any care that might be needed such as getting things out of the child's way and ensuring a patent airway. Such care also included timing the seizure and, at a certain point, administering emergency medication to try to bring the seizure to an end. Sometimes the emergency medication failed to work and the participants had to call 911 for emergency assistance (Donna, Jayme, & Sharon).

After the child came out of the seizure, she or he often slept, particularly if emergency medication had been administered. Several participants described an alteration in their child's mood after receiving emergency medication to stop a prolonged seizure. One participant revealed the following consequence of the medication on her child:

*A seizure can make her grouchy, but she is a bear after she wakes up from having Diastat [medication].* (Donna)

In addition to the immediate concerns associated with daily seizures, the participants expressed disappointment and sometimes anger about the lack of epilepsy education and awareness evidenced in health care and other professionals. Their frustration was triggered by the responses they received from some providers to the frequent calls they made in an effort to obtain assistance or advice regarding their child's seizure activity or other issues. Their frustration was evident as they described their encounters with some healthcare providers, social workers, and school system personnel. Participants believed that neither health nor school professionals understood that, in the case of their children, epilepsy was impossible to control, devastating to both child and parent, and potentially deadly. In addition, participants explained that people lacked an understanding that all seizures were harmful to the child, regardless of whether the seizures were convulsive and observable or non-convulsive and unobserved. Kim offered an example of that lack of understanding:

*She [child with catastrophic epilepsy] was having a minor surgical procedure, and the nurse asked, 'Does she have the bad seizures'?*

In summary, the theme of participants' constant feeling of being on alert and "waiting for the other shoe to drop," particularly regarding their child's seizures, emerged from the interview data. Although the children of the study participants had significant intellectual and global disabilities and the participants faced multiple challenges in caring for their child with special needs, it was the child's epilepsy that kept the participants on constant guard. Their child's seizures were unpredictable, uncontrollable, and occurred daily. The characteristics of their child's seizure activity caused study participants to be particularly vigilant because they could not predict how often seizures would occur during a particular day, what kinds of seizures the child would experience, how long each seizure would last, if emergency medication would be

needed to stop a seizure, if emergency medication would be effective in stopping a seizure, and how each seizure and the medication used to treat it would ultimately affect the child. Several of the participants described the outward appearance of a seizure or, in contrast, seizures with a lack of obvious symptoms. The appearance of the seizures depended on the seizure type the child experienced. The participants recognized lost skills and developmental progress that occurred in their children after a prolonged seizure. All of the study participants expressed discontent with and described scenarios related to the grossly apparent lack of knowledge about and awareness of epilepsy among healthcare and other professionals.

In view of the nature of their children's seizures and their many special needs, the participants continually and actively sought resources to meet those needs. A discussion of various sources of support identified and coordinated by study participants for the care of their children with catastrophic epilepsy is presented in the following section.

### **Theme: Mobilizing Resources: A Constant Preoccupation and Effort**

Participants worked continually to mobilize resources for their children. All of the children received support from a state funded program for the purpose of keeping the child in the home and out of an institution. The children received support from either the State-supported Early Intervention Program or the public school system. Two of the five participants had private insurance coverage. At the time of the study, one child was enrolled in an early intervention program and received palliative care at home and three participant's children attended public school where they received various therapies. One child received homebound schooling that entailed home visits by teachers and therapists. The major resources that participants mobilized were: palliative care, two state-supported programs, and private insurance, each of which will be discussed in the section that follows.

**Palliative care.**

One participant's child received home-based palliative care which entailed home visits by a palliative care pediatrician who assessed the child's status, prescribed emergency medication, and facilitated care. The palliative care referral came after this child screamed for the majority of her four years of life and only slept between two to four hours per day. This extreme situation warranted intervention that came in the form of palliative care for the purpose of implementing comfort and support measures for both child and family.

**State-supported programs.**

The study participants explained three age-specific state-supported programs that provided helpful resources for their children. These programs were the Community Alternative Program for Children and the School-Based Program for children aged three and older as well as the Early Intervention Program for children less than three years of age. Participants' explanations of each of these programs are presented below.

***Community Alternatives Program for Children.*** All of the participants' affected children received what was called, "Community Alternatives Program for Children" (CAP/C), through the state of North Carolina. Eligibility for CAP/C required a medically fragile diagnosis for children three years of age and older who would otherwise require long-term hospital or nursing facility care. The program provided Medicaid coverage that financed the majority of each child's healthcare costs and provided a limited amount of money each year for home modifications. This program also included nursing care in the home while the parent worked or, in the case of the participants in this study who were all stay-at-home parents, it provided limited hours of care that typically amounted to about twenty hours per week.

In addition to CAP/C, two additional major sources of state support for the care of children with catastrophic epilepsy were the state Early Intervention program that served children from birth to age three and school-based support which began after the child's third birthday.

***State Early Intervention program.*** The initiation of services before the child turned three years of age involved them in a state-supported program called the "Early Intervention Program." At the time of this study, Early Intervention evaluated and coordinated services for infants and toddlers under three years of age who faced a variety of life-long illnesses and disorders, including epilepsy. Early Intervention program personnel became involved in the families' lives at a crucial time when participants were still processing the life-altering event of having their child diagnosed with catastrophic epilepsy and while they were learning to consistently and accurately detect seizures and administer medication to control them.

The Early Intervention program involved participants in working with a case manager to arrange therapies prescribed by both the child's pediatrician and the pediatrician working for the program. Participants then had to interview and select the therapists who would come into their homes to work with their child. The program conducted routine evaluations of the child's progress and participants attended monthly meetings with an Early Intervention case manager to assess the child's needs. Early Intervention program professionals guided participants to equipment, tools and services potentially useful in caring for their child.

***State public school-based program.*** Once children reached the age of three years, they became ineligible for the Early Intervention program and were transferred to the public school system. Participants then communicated with the school system to assess and determine therapy goals. School-related therapy goals were associated with restrictions that frequently led



participants to choose additional private therapies either at home or a therapy facility. The goals of school-based therapists were geared toward the child being in a classroom in a school setting and were therefore inconsistent with participants' therapy goals for their children. For example, according to one participant, a school therapy goal was for the child to sit at a desk, while the participant's therapy goal for her child was mobility (Sharon).

Participants viewed scheduling therapy in a school-based delivery system of services as potentially problematic. It was difficult to schedule in-home therapy since school systems often could not afford to schedule such therapies and pay for therapists' travel time. Thus, in order for the child to receive all the therapy services for which they were eligible, participants transported their children to the school in their district multiple times per week. Moreover, scheduling different therapies posed challenges since participants had to avoid overlapping or conflicting therapy hours, inaccurate estimations of transport time, and the scheduling of similar therapies on the same day which, in the latter case, was usually prohibited by insurance coverage. For example, a participant could not schedule a private occupational therapy session on the same day that their child received school-based occupational therapy.

In addition to challenges posed by the logistical and scheduling issues associated with therapy, actual sessions with a therapist were only a part of the child's therapy. Participants had to learn what to do from each therapist at each session so they (participants) would be able to continue to implement the therapy at home. All participants generally believed that continual involvement in learning and providing various therapies at home would enable their children to derive the best benefit of the therapy and perhaps eventually attain the goals of the therapy (Donna, Jayme, Kim, Lindsay, & Sharon).

Participants also identified various federal and state assistance programs that could provide services for people with disabilities, with such programs varying among counties within the State where they resided. The assistance offered typically depended on the needs of the child and the family income. After all factors were evaluated at county and state levels, the child could receive Medicaid in addition to home modification assistance, respite care, in-home nursing care, and assistance in covering the cost of some portion of the therapies and medication needed by the child. Because of the child's condition and typical family income, it was possible for some participants to qualify their child for supplemental security income, Women, Infants and Children (WIC) nutritional assistance, and other assistance programs.

#### **Health insurance.**

Participants viewed health insurance as essential in the provision of care for a child with catastrophic epilepsy and worked closely with insurance companies to meet their child's needs (Jayme & Kim). Participants had to gain a clear understanding of insurance policy coverage and the amount of money they needed to budget for deductible and out-of-pocket expenses. Many of their insurance plans covered a limited amount of therapy visits each year but required a co-payment with each visit. Participants then had to discover other ways of financing the remaining therapy sessions. Some medication costs were covered by insurance companies but usually required a co-payment. Participants worked closely with insurance companies when trying to purchase equipment or modify their home in order to meet their child's needs. They worked with physicians, therapists, and office staff personnel to obtain required documentation for insurance companies in support of meeting their child's special needs.

Supporting the health care of children with catastrophic epilepsy involved the participants in the challenge of identifying and linking together a wide variety of resources and individuals to

address their children's needs. Study participants had what they experienced as the daunting task of researching and understanding federal and state assistance and other programs, completing applications, providing evidence of eligibility, requesting evidence from physicians to support eligibility, understanding and adhering to program requirements, regularly undergoing program-required evaluations, working closely with case managers associated with each program, understanding the budgetary constraints and allowances associated with each program, and meeting the requirements of each program. In the end, they were concerned about and worked constantly on mobilizing the resources needed to care for their child.

**Theme: Providing Daily Care: An Often Overwhelming Responsibility**

Although interview data indicated that providing care for a child with catastrophic epilepsy varied with each child, all parents revealed feeling “*overwhelmed*” in their efforts to meet the daily needs of their child. The study participants were immersed not only in constant hands-on care provision, but also in constant travel to appointments, daily decision-making regarding care, and the provision of on-going therapy for their child.

Study participants were all mothers who expressed being overwhelmed by the magnitude of the responsibility they shouldered in caring for their child. The child's father or stepfather was present in home with all of the participants, but the men in these particular families assumed the role of moral supporter and family provider. The mothers in these families engaged in most of the decision-making and care for the child. Four of the five participants were not raised in the geographical area where they resided at the time of the study and had minimal or no extended family directly involved in their child's daily care (Donna, Kim, Lindsay, & Sharon). Four of the five participants had other children who were engaged to a limited degree in caring for their sibling with catastrophic epilepsy (Donna, Kim, Lindsay, & Sharon).

It must be noted that participants held no expectations for significant improvement in their child's condition. They perceived that their child's need for complete care would continue unabated for the remainder of the child's life. A participant stated:

*You take for granted a normal child that can get themselves dressed and brush their own teeth. You can just follow up with those children. You physically have to do all this for this child forever. (Kim)*

During the interviews study participants discussed the dimensions of care for their child in terms of: a) physical care, b) psychosocial/emotional care and c) the planning and management of care. Each of the dimensions of care will be addressed in the following section of this chapter.

### **Physical care.**

The study participants described the physical dimension of care for their child with catastrophic epilepsy as “*relentless*” (Donna, Kim & Lindsay). Elements of care included monitoring and administering treatment for seizure; monitoring treatment side effects; providing bowel, bladder and skin care; planning and ensuring adequate dietary intake; and assuring physical safety. Donna described the relentless nature of the care in the following way:

*I feel like I'm in that movie, Groundhog Day, where I am doing the same thing over and over all day long.*

***Seizure monitoring and treatment.*** All study participants affirmed that children with catastrophic epilepsy required constant monitoring. They reported the necessity of continuous monitoring due in large part to the unpredictability of their child's daily seizure activity. Seizures that their children experienced ranged from being easily apparent to undetectable and short in duration to prolonged. Each detectable seizure had an unpredictable outcome, with some

seizures resolving spontaneously, while others required emergency intervention. Of greatest concern was that each seizure, particularly a prolonged seizure, was potentially lethal. Jayme described the scenario of her child's first seizure:

*I heard this weird noise and I ran into the bedroom and he was convulsing. I called 911, and [while] talking to the guy on the phone he was turning blue and wasn't breathing. By that time he [911 dispatcher] was talking me through CPR.*

For some participants, the continual monitoring of seizures involved the use of multiple baby monitors in the house so that they or other caregivers could hear and see the child at all times. In the case of a prolonged seizure or extreme behavior such as screaming or sitting still and staring for prolonged periods of time (which could indicate a seizure), they or other caregivers needed to provide the child with emergency anticonvulsant medication rectally, and then monitor the child after the administration of medication for resolution of the seizure and side effects such as respiratory distress or other signs of medication-related problems.

According to all study participants, a change in daily routine or environment sometimes triggered seizure activity or extreme behavior (Donna, Jayme, Kim, Lindsay & Sharon). In the event that the child had to spend the night away from home, for example, emergency medication could be needed to help the child cope with the new environment or routine. Sharon described the following recent event that required the administration of emergency medication to her child, though she was uncertain about the precipitating event for the behavior:

*Yesterday, she did require oxycontin at 8:30 in the morning, which is her prescribed PRN [as needed] medicine, and she took her nap and slept until 1:20. When she woke up it was downhill [The child was inconsolable, screamed, and hyperventilated for an extended period of time], so our nurse had to give her more PRN medicine, some more*

*chloral hydrate [sedative], more clonidine [sedative], more oxy [contin] to get her calm, finally had to put her to sleep [the child was in a sedated sleep].*

Participants reported that, in addition to administering the emergency treatment of seizures, they also provided their child with daily medication intended to control or at least reduce the frequency of seizures. They gave prescribed anticonvulsant medication to their child two to three times daily by administering the medication in liquid, dissolvable wafer, injection, suppository, patch, or pill forms. Some children, however, could not use certain anticonvulsants that might otherwise have been helpful to them in controlling their seizures. Two participant's children had gastrostomy tubes (g-tube) through which they received nutrients and medications. In explaining the limited options for seizure medication available for her child due to the presence of a gastrostomy tube (g-tube), Sharon said,

*Topamax only comes in pill form, so she can't try that medication, because we can't administer it through her g-tube.*

Participants had to constantly monitor their affected child for adverse side effects or reduced effects associated with regularly administered medications used to control seizures. They reported that their children had experienced drug-related side effects such as increased seizure activity, extreme drowsiness, respiratory depression, skin rashes, and other problems (Sharon & Donna). In addition, when daily medication was started or emergency medication used, participants had to ensure that they maintained an adequate supply of medication. They maintained regular contact with their pharmacy and had to remember to call the pharmacy in sufficient time to reorder the medication.

In addition to medication, study participants used other methods of seizure control for their child. Donna's child, for example, used a vagal nerve stimulator that was surgically placed

under the child's skin and attached to the vagal nerve in her neck. Moving a magnetic device over the implanted stimulator sometimes helped to stop a seizure. The participant kept the magnetic device within reach at all times so she could use the magnet to try to stop the seizure as soon as possible after it began. She then monitored her child for continuing or subsequent seizures. Lindsay, Kim and Sharon reported that they had received surgical consultations for their children and were planning similar implant surgery for them in the future.

***Dietary intervention.*** Donna, Jayme, Lindsay, and Sharon had instituted a ketogenic diet for their children as a means of decreasing or preventing their children's seizures; one of these participants was in the process of implementing the diet at the time of the interviews. For some affected children, a constant state of ketosis could serve to decrease seizure activity (Beleza, 2009). Participants who prepared a so-called ketogenic diet had to measure the intake of food, liquids, the special formula used in the diet, and the child's urinary output. Such a diet involved participants in daily measurements of urinary ketones in order to assure that the child maintained a state of ketosis. One participant described what it was like to administer the diet.

*Everything has to be measured in grams, so I had to get a special grams scale. The ketocal is nasty tasting, so she doesn't like it. She is only allowed so much to eat and drink each day. By six o'clock she usually has reached her maximum amount and is only allowed water, but she is starving. It is a diet from hell, and her stomach is torn up from this high fat, nothing but fat diet. I don't know how much longer I can do this. It seems to help her seizures some, but is it worth her being upset with her stomach issues and starving? I've got to think about her quality of life. (Lindsay)*

***Bowel, bladder, and skin care.*** Bowel, bladder, and skin care posed potentially significant and interrelated issues for the participants' children, particularly since the children

were not and probably never would be bowel or bladder trained. The children's daily care involved frequently changing diapers, wet clothing and bed sheets, and skin care. One of the challenges that study participants spoke about was finding diapers large enough to fit their children and the continuous need to monitor their child for urinary and fecal incontinence. As one participant reported:

*She always wakes up wet; I have to wash her sheets over and over again. (Kim)*

Participants voiced concerns about their children's skin that was presented by the dual problem of incontinence and reduced mobility or immobility. Since some children were unable to independently change their body position, participants and other caregivers had to frequently turn them, at minimum every two hours, to avoid the breakdown of skin over pressure points, especially in the sacral area. Every participant checked her child often for evidence of incontinence since the presence of urine and feces against the skin contributed to skin breakdown. The children sometimes expelled a large amount of feces after the absence of a bowel movement for several days, which was a problem exacerbated by immobility and some medications. Fecal incontinence presented serious challenges in terms of skin cleanliness and care. Immediate treatment and even more frequent position changes had to be instituted when the child showed any initial signs of skin rash or breakdown in order to prevent consequent, difficult-to-treat ulcerations and infection.

Additional skin integrity problems arose from the possibility of self-injury and wet fingers. The children's fingernails needed to be cut often to help them avoid inadvertently scratching themselves during uncontrolled hand and arm movements. In addition, some children habitually kept their fingers in their mouths, which could cause a breakdown of the skin around their fingers. Sharon recounted several issues related to her child's constantly wet fingers:



*We have to keep children's garden gloves on her hands because they are always in her mouth, and [she] needed something waterproof. The skin between her fingers will crack and bleed. Her therapist was concerned about a fungus infection that can result. She was telling me that another one of her patients ended up in the hospital because of an infection coming from this same problem.*

The children's use of leg braces presented another skin issue. Participants' children typically wore leg braces for support and the promotion of mobility. They checked their children's feet and ankles each time they put on and removed the braces for evidence of "pressure points" on the skin. They carefully monitored any red marks on the skin to ensure the discoloration resolved before re-applying the braces. If the red mark remained, they knew it signaled a need to institute skin care and have the braces adjusted.

Maintaining skin integrity in the presence of fecal and urinary incontinence was an ongoing challenge and focus of attention for participants as they provided physical care for their child. In addition to implementing specific strategies to prevent problems related to skin breakdown and pressure sores, participants had to constantly attend to ensuring other aspects of their child's care such as dressing and feeding.

***Dressing and feeding.*** Participants explained that the daily physical care of their children included changing their clothing and bedding several times during the day as a consequence of their child soiling or wetting her or his clothes. For Donna and Lindsay's children, a side effect of several medications coupled with a lack of overall muscle tone led to excessive drooling. These children wore bibs in a sometimes-futile attempt to keep their clothes dry.

Four of the five participants' children lacked the fine motor skills and intellectual ability to feed themselves, so participants or other caregivers fed them each meal. Some of the children ate by chewing their food, while others lacked the ability to chew and required that their foods be pureed or provided by mouth in a liquid form. Two children had a gastrostomy tube (g-tube) through which they were provided liquid feedings.

All of the participants' children had undergone a "*swallow study*" to assess their ability to swallow without aspirating food or fluids into their lungs. Participants continually evaluated their child's ability to swallow prior to administering food and liquids and adjusted their feeding strategies accordingly. Lindsay, for example, had to add a thickening substance to all fluids in order to allow her child to have more control over swallowing and to avoid aspiration. Sharon's child experienced oral aversion, in which the child would not take anything by mouth and thus required g-tube feedings. Participants sometimes purchased various feeding devices to aid in the feeding process.

***Bathing.*** Donna, Jayme, Lindsay and Sharon indicated that bathing their child posed concerns since a change in temperature or the stimulus of water itself could trigger a seizure. Even if the child could sit up independently, a bath presented a safety concern due to frequent seizure activity. A seizure could cause a child to hit her or his head, especially if the child was confined within a small, hard space such as a bathtub during a convulsion. Aspiration of bath water was also possible if the children were not closely monitored.

Some participants elected to purchase a bath chair so their child could be fully supported during bathing. Their bath chairs were typically made of a mesh material and had straps to support and securely hold the child in the chair. Parents physically lifted the bath chair in which their child was sitting into and out of the bathtub.

**Physical safety.** Participants continually observed their child in the interest of ensuring safety, since the intellectual and physical disabilities of children coupled with relatively frequent, and unpredictable seizure activity continually presented a potential safety risk. A participant explained:

*She scoots around. The kitchen freaks me out. I'm afraid she might pull a pot on top of her, or she'll she might pull at something and it will fall over on her.* (Kim)

Participants indicated that physical safety during a seizure was something for which they felt great responsibility. During a seizure, participants needed to remove any objects that could injure their child and, during a violent convulsion, do everything possible to protect the child's head from injury.

The use of protective equipment such as helmets and adaptive beds could be helpful in preventing self-injury. Participants' children who were mobile often used helmets that, in the case of two children, were custom-fitted. The helmets helped to prevent head injury from a violent convulsion or a fall that resulted from unpredictable seizure activity or an unstable gait. Three of the participants had obtained adaptive beds with netting that zipped up to enclose the bed in order to prevent their children from falling out of the bed and becoming injured, particularly during a seizure (Sharon, Donna, & Kim).

For those children who were mobile, capabilities for movement presented physical safety issues. Sharon shared that her child walked with an abnormal gait, which increased the one-on-one care needed to prevent injury due to the child's gait, intellectual disabilities, and unpredictable seizure activity. Sharon explained that she was extra attentive and took additional injury prevention measures to keep her child mobile. One injury prevention example she shared was the installation of gates to restrict her child's mobility to the child's bedroom and to keep the

child out of the kitchen. The restriction was helpful not only for injury prevention, but also because the child experienced emotional distress when walking outside of the bedroom. As Sharon explained,

*We can only let her walk in her room. If we let her walk around the house it over-stimulates her and she has a meltdown after about thirty minutes. So, outside of her room we keep her in her chair.*

**Transporting.** Integral to physical care of the child was the role of participants in transporting the child to health care providers. Transporting the child with catastrophic epilepsy presented physical challenges that the participants of this study faced at minimum daily and, more typically, multiple times a day. Repeated acts of lifting and carrying the child while transitioning from wheelchair to car seat and back again, and pushing a wheelchair with an older age child could exact a physical toll on participants. In their efforts to transport the child, it was often necessary for participants to prepare a bag of items that contained emergency medication as well as such items as a change of clothes, diapers, wipes, food, drinks, toys, and other items the child might need. Car seats large enough to accommodate and support older-age children were challenging to locate to purchase and often expensive. Moreover, the children needed their heavy and unwieldy wheelchairs to accompany them to every destination, thus necessitating that participants lift the wheelchairs into and out of cars

Participants viewed driving their automobiles as potentially hazardous because, while engaged in driving, they also continually monitored their children for seizure activity. In the event of a seizure, they pulled off of the road to care for their child and possibly administer emergency medication (Lindsay). Upon arriving at their destination, participants unloaded the wheelchair and lifted the child from the car seat to the wheelchair, retrieving the bag before

leaving the car. After the appointment, the participant lifted the child, wheelchair, and bag back into the vehicle. Upon arrival at home, the participant repeated the process again, and yet again for each destination such as school, therapy, grocery store, laboratory, health care provider's appointment, or other destination, during the course of a day. All the while, participants constantly monitored their children for problems in general and seizure activity in particular.

***Assistive equipment.*** Participants indicated that they typically used a variety of equipment to physically care for their child affected by catastrophic epilepsy. All of the study participants' reported that their children wore leg braces to support the position of their feet. Such braces were helpful in promoting walking, but in the case of children who could not walk, the braces stretched muscles and ligaments and supported the alignment of the children's feet. Participants put the braces on their children's legs daily.

Participants of children who were mobile said their children used a "*gait trainer*" (a medical walker with a chest harness and seat) or other supportive equipment in their efforts to assist their children in walking or learning to walk (Sharon, Donna, Kim, & Jayme). As noted earlier, increased mobility and unpredictable seizures necessitated that a helmet be used, particularly since sudden falls typically accompanied seizures and protecting the child's head was a priority.

Study participants reported that communication with their children posed significant frustration and challenges. The participants' children in this study were nonverbal and their intellectual disabilities led to limited or completely impeded communication capabilities. Participants reported that their children's impaired ability to communicate posed significant challenges when trying to determine their child's wants, needs, or sources of discomfort.

The inability or reduced ability of affected children to communicate was a source of frustration and a significant challenge for both study participants and their affected children. Some children and study participants used various assistive devices to facilitate communication. One participant described a simple push button device her child used that had a picture, sound, and a platform on which to set the object matching the picture and sound (Kim). Communication devices used by the participants' children had as few as one or two response choices to however many choices the child could master. Some I-Pad applications for communication offered them a visual coupled with a sound. Regardless of specific communication device, all offered pictures and voice for the children to use in their attempts to communicate and make simple choices.

### **Psychosocial care.**

The participants expressed that helping their child to be content was their aim in the process of providing care. In fact, all participants described exerting much energy toward continuously striving for their child's contentment. Such efforts involved soothing their child, physically moving their child, or playing music or a toy with sound for them. The psychosocial care of the child highlighted the interactions and one-on-one attention necessary to meet the needs of children with catastrophic epilepsy. One participant explained:

*I use the same protocol every day, I don't change. I don't allow for her to get overly upset. We try to cut it [state of discontent] off before it gets to that point. We try to make her happy and content, just maintain [a state of contentment]. (Sharon)*

Participants explained that they frequently and carefully observed alterations in their child's mood, which could be ever changing. In reference to her child's frequent mood changes, Donna commented that,

*It goes from hour to hour, minute to minute, day to day on how she is going to be.*

Participants indicated that such mood changes could be due to seizure activity, a side effect of medication, frustration from an inability to communicate, not feeling well, a reaction to an environmental change, or other factors.

In summary, the responsibilities in providing daily physical care for a child living with catastrophic epilepsy were extensive and multifaceted and the need for care unrelenting with no expectation of change. Study findings revealed that parenting a child with catastrophic epilepsy demanded a deep commitment to care. Participants in this study were committed to supporting and assisting their child in innumerable ways. The unpredictable nature of epilepsy had participants' continuously on guard and deeply committed to the close monitoring of their child for seizure activity and the administration of emergency medicine when warranted. They expressed a commitment to keeping their child safe and secure. Above all, they wanted to do everything possible to ensure that their children were content.

Participants expected that their commitment to meeting the sometimes-formidable daily care needs of a child with catastrophic epilepsy would never end. Instead, the commitment would go on for an unknown number of years until the child's death. Although some participants recognized the remote possibility that their child would learn and be able to respond by beginning to engage in some level of independent care, they also recognized that, in the case of catastrophic epilepsy, the possibility of even a minimal level of independent care would rarely be an outcome.

### **Planning and organizing care.**

Participants indicated that, like the actual provision of care, the process of planning and organizing care for a child with catastrophic epilepsy was time consuming, continuous, and

taxing. When the child was first diagnosed, participants often experienced difficulty coming to terms with the life-altering event of having a child with catastrophic epilepsy. During this time, study participants said that they invested a great deal of time and energy learning about their child's condition and seeking assistance from a variety of professionals. They found, however, that researching and understanding a complicated neurological condition such as that experienced by their child could be difficult and time-consuming. They found themselves actively and sometimes desperately seeking medical advice at the time of diagnosis since successful seizure control could significantly impact the outcome of the condition, particularly in terms of the seizure-related intellectual disabilities that could occur. After the diagnosis they continued their ongoing search for information about catastrophic epilepsy.

***Organizing resources for care.*** Study participants found themselves interacting with a variety of health-related professionals while seeking the care needed by their child. A participant explained:

*Once this [catastrophic epilepsy diagnosis] happens it's not just you and your family anymore, it's a whole freaking forest of people [healthcare providers, social workers, school and others] to deal with. (Donna)*

The participants discussed the innumerable appointments and phone calls they made on behalf of their children, especially since a countless number and variety of professionals worked with or needed to be consulted about their child. These individuals included physicians, nurses, therapists, and other health-related professionals such as nutritionists; speech, occupational, and physical therapists; medical laboratory personnel; radiology and imaging personnel. In addition, social workers, school personnel, and other professionals played a role in their child's life.



All of the participants indicated being taxed by the process of making and receiving phone calls and keeping and following up on the multitude of appointments that contributed to the physical care of their child. Three parents described the unrelenting process of organizing and managing care:

*It's exhausting because you are always on the phone with somebody. (Lindsay)*

*There is always a therapist in the house. (Kim)*

*You always got a doctor's appointment, or somebody to call. (Jayme)*

Participants revealed that communication related to therapy alone was time consuming. All therapy sessions, regardless of site, required that the participant be in close contact with each therapist, often by telephone, in order to routinely to schedule, cancel, and reschedule appointments, and to discuss equipment, the child's progress, concerns about or changes in the child's status or needs, their own provision of the therapy as taught by the therapist, and insurance issues.

Participants in the study reported that their children often had multiple therapy sessions each day of the workweek. In addition to working with the child, therapists provided participants with demonstrations and instructions for continuing the therapy on days the particular therapist was not scheduled. Participants were thus charged with the daily implementation of various therapies at home in order to provide the care that would potentially enable their children to attain the goals set for them.

An additional issue that continuously confronted participants was the sense of intrusion that came from the constant "parade" of professionals who were continuously in their homes. They indicated that such unending interactions could be wearing on them. According to Kim,

*I didn't realize how much I like my privacy until I had people coming into my home all the time. I was so aggravated at times, and didn't want them in my home. I have these strangers in my house telling me how to parent and care for my child. I'm glad I had them, but it's frustrating too, it's just a whole different ballgame. (Kim)*

**Documentation.** All of the participants raised the issue of organizing and maintaining documentation when caring for their children. Such documentation included, for example, copies of results from laboratories, genetic testing, imaging and EEG reports; documents from physicians; equipment manuals; and other materials. Participants received assessments and progress reports from therapists and teachers. School systems required that an Individual Education Plan (IEP) be developed for each child. The document constituted a legal agreement between the school and parents regarding childcare while the child attended school. Participants often chose to document information about their children's current medication and maintained a list of the medications the child had taken in the past and reasons for stopping or changing medications. All participants involved in this study kept a daily log of their children's seizure activity, medications administered, bowel movements, appointments, developmental milestones, and other daily issues they viewed as important.

**Physicians' care.** From the time of diagnosis onward, the child's pediatrician typically played a pivotal role in the oversight of care, particularly in detecting a disability or problem and setting in motion the necessary medical and other services to help the child. The variety of physician specialists alone who assessed and treated the child could be daunting: pediatricians, neurologists, radiologists, gastroenterologists, orthopedists, endocrinologists, geneticists, ophthalmologists, cardiologists and others contributed to the child's care. Participants engaged in an ongoing cycle of organizing care in which they identified specialists, arranged for their

pediatrician's to refer their children to specialists, made appointments, transported their children to appointments, made decisions about issues presented during appointments, implemented and followed up on recommendations, and engaged in further appointments.

Although their pediatricians were helpful in selecting needed specialists for their children, study participants also discovered physician specialists by using the social networking groups that they accessed via Facebook, Yahoo, or others sources. A participant discussed utilizing social networking media to learn of and sometimes interact with specialists across the country:

*We raised money to go to Detroit to see [...a particular specialist]. So many infantile spasms [IS] kids on the yahoo IS group go to him. He even gets on there [the on-line Yahoo Infantile Spasm group] and responds to questions or asks the parents questions.*

(Sharon)

Study participants explained the importance of finding physicians with whom they were comfortable and who they trusted with their child's care. All participants said they wanted the best for their children and sought to be respected, heard, and understood by those who provided care. They described a wide range of experiences in working with physicians and other healthcare providers. A participant described the range of her experiences in the following way:

*I have met people that are compassionate. They are in this field because they care about people and they want to see, they have hope for cures, they are dedicated, they honor our opinion, and are very respectful to you as a parent, and respectful to your child. I have encountered people who talk over my kid like she doesn't hear what they are saying, and say she would never walk or sit up and she was going to die soon, and say just terrible*

*things. I ran into people with terrible bedside manners. They are very textbook and talk down to me like I was ignorant. (Donna)*

In addition to appointments with physician specialists, participants' children were also involved in being evaluated and treated at a variety of outpatient clinics such as feeding and seating clinics. They were also subjected to various in-patient or outpatient diagnostic testing procedures and participated in a wide variety of in-home and out-of-home therapies.

***Testing procedures.*** All participants reported the need to schedule and prepare their children for a variety of tests to determine, assess, and monitor their child's condition. Their brain structure was assessed by means of imaging tests such as a magnetic resonance imaging (MRI) or computed tomographic scans (CT scan); their brain function was evaluated using imaging tests such as positron emission tomography (PET scan) or magnetoencephalography (MEG Scan). Seizure activity was routinely evaluated by electroencephalography (EEG), which could require sedation and child restraints during the application of leads. The site for the EEG could be the doctor's office, hospital, or home where, in some cases, the child would be monitored over a period of several days. The EEG was often conducted in the hospital in order to enable the use of video-recording so visual images could be matched with the child's seizure activity. Additional challenges specifically associated with EEG preparation included the necessity for the child to be fasting, taken off certain medications, and sometimes sleep deprived before an EEG. Participants had to carefully schedule, plan, and prepare their children for these various tests that would continue to be performed periodically throughout the children's lives.

***Outpatient specialty services and clinics.*** Participants frequently used outpatient specialty services and clinics to address their child's special needs. They mentioned three outpatient services or clinics in particular: leg brace services, seating clinics, and feeding clinics.

*Leg brace services.* Leg braces posed commonly experienced issues for developmentally disabled children such as those with catastrophic epilepsy. Participants indicated that leg braces, typically used to support the lower limbs and hips in proper alignment, stretch the leg muscles, and aid in walking. The braces needed to be frequently adjusted as children gained weight and grew taller. The initial casting required for leg braces was time consuming and physically constraining, but was a process that was required to mold children's legs, and possibly hips, for the eventual use of braces. Thereafter, selecting, fitting, and using leg braces required many visits, particularly since children tended to grow out of their leg braces every six months to a year and thus had to be periodically refitted for new braces.

Participants were responsible for monitoring their child's legs daily for evidence of pressure from the braces and possible skin breakdown. Any evidence of pressure required a visit for refitting. Leg braces required that participants expend time and effort in order to assure well-fitted braces, but braces that fit well were not all that participants had to consider. Kim explained, once braces were fitted, shoes to fit over the feet and braces were difficult to find.

*I gave up and ordered a pair of hatchback shoes that are made to fit over the brace. But, they are so expensive. (Kim)*

*Seating clinics.* Participants described their children's wheelchair or modified stroller as a type of equipment that also required multiple fittings and maintenance sessions, usually at a "seating clinic." They recounted the initial visit to the clinic as one that involved placing the child in multiple chairs to see which chair had the best fit for the child as well as the features the participant desired. Of particular importance was the amount of support afforded the child by specific chairs. Participants said that the chair must keep the child safe and well supported but

also promote development by allowing the child some control over an area of deficiency such as head or trunk control.

Multiple seating clinic visits were required once the clinic received the special order wheelchair so that the child could be evaluated for support while seated in the chair and then again after using the chair. In the end, participants indicated that choosing and using a wheelchair required considerable research and planning as well time and effort to select the chair, place the order, ensure an appropriate fit for the child, and maintain the chair.

*Feeding clinics.* Feeding clinic visits were a frequent necessity for children with catastrophic epilepsy. All of the study participants indicated that their children had experienced feeding, swallowing, or chewing issues. Participants expressed great concern, for example, about aspiration when their children had swallowing issues since aspiration into the lungs could lead to potentially fatal pneumonia. Feeding clinics enabled the children to be assessed and treated for such issues.

Using the feeding clinic required a pediatrician's visit and referral. A study that involved an imaging test to evaluate the ability of the child to swallow was typically conducted in a hospital prior to the feeding clinic appointment. The evaluation of the child at a feeding clinic involved a team of specialists that usually included a speech and occupational therapist in assessing the child. After observing the child eat, the team offered participants ideas regarding techniques to improve feeding, and set feeding goals. This process required considerable planning by participants to schedule appointments, transport the child to appointments, and ensure the child was hungry upon arrival at the clinic. Once techniques were explained or strategies tried, participants did their best to follow through with the daily implementation of the strategies to improve the child's feeding and swallowing ability. The participants' children

needed additional visits to and supervision by nutritionists when they used special diets to reduce seizure activity such as the ketogenic or modified Atkins diets.

**Therapy.** Participant's children were continually involved in various therapies. Participants mentioned commonly used therapies such as physical therapy, occupational therapy, speech therapy, developmental therapy, and vision therapy. During the first three years of life, different therapists visited the home once or twice a week for each area of therapeutic need. After age three, therapy was typically provided through the child's district school system. Each therapist assessed and set therapy goals for the child, determined the frequency of therapy, and worked directly with the affected child and the participant on a regularly scheduled basis.

Donna, Kim and Sharon opted to use several alternative therapies with their children such as hippotherapy, which used a horse as part of the therapeutic process; music therapy to help soothe the child; and crainosacral therapy that involved a hands-on alternative treatment for the central nervous system. Sometimes participants chose out-of-home therapy to enable the child to have access to specialized equipment that was not available in the home, could not be transported to the home, was impractical to obtain, or was too expensive to purchase. A participant, for example, described making weekly visits to a children's hospital for her child's therapy because the hospital had a "*lite gait*," which is a harness support system that could be used in conjunction with a treadmill to aid in walking (Jayme).

Regardless of the purpose or site of the therapy (whether offered as a home-based or out-of-home service), the participants were responsible for interviewing, selecting, and working closely with each therapist. Participants scheduled their child's daily care needs around these multiple daily therapist visits in order for their child to derive maximum benefit from each therapy session (Lindsay & Sharon). In addition, for therapy sessions that took place outside of

the home, participants committed significant time and effort in transporting the child to the sessions. They had to transfer their child from chair to car, drive to the therapy site, transfer the child from car to chair upon arrival at the facility, observe the therapy session, learn various techniques demonstrated by the therapist, and engage in the reverse process to home. For some children, seizure activity due to environmental change posed an additional concern and consideration during all out-of-home trips.

In summary, participants not only provided direct care for their children with catastrophic epilepsy, but also had the sometimes-daunting task of planning and organizing their children's care with a multitude of professionals. They discussed everything that was involved in treating their child's condition and providing for their child's comfort. It seemed to them that the planning and organizing was never ending.

All participants discussed planning for current care while keeping in mind anticipated future needs and the efforts that had to be made to plan and prepare for those future needs. Such future planning might include possible surgical treatments, a converted van as the next vehicle purchase, adding a ramp for achieving wheelchair access to the home, modifying a bathroom to accommodate a wheelchair, and countless other future plans related to caring for a child with catastrophic epilepsy.

The daily care required by the child and efforts to mobilize resources on behalf of their child often left the participant with minimal time to personally process the life-altering child-centered events that had occurred in their lives. The participants were at different stages in processing the effects of the child's condition on themselves, due in part to the time, effort, and focused attention required to care for their child's extensive needs. During the interviews, the



participants shared a great deal about how they were affected by caring for their child. Their perspectives will be presented in the following section.

**Theme: Effects of Care on Caregiving Parents: “Confined to a Helpless Situation”**

Study participants revealed that providing care for their children was rewarding and provided a sense of purpose in their lives. They clearly affirmed that they loved their child despite the demands made on them physically and emotionally in providing the complete care and attention that their child needed and in terms of the many personal losses that the child’s condition precipitated.

**Rewards of providing care.**

Participants reported a wide range of emotions associated with their efforts to parent a child with catastrophic epilepsy. Above all, they all expressed a deep love and concern for their children. They felt a sense of reward and purpose in the caregiving process and believed that their child was a blessing to them and their family. They expressed joy in parenting their children. As a study participant explained:

*Love and blessings just far outweigh the pain. (Donna)*

They described parenting their child as a life altering experience that touched them in the most profound way. They believed their parenting experience resulted in them becoming a better person who was better able to relate to people and to do so with greater empathy. As a participant reflected,

*I think she has made us better people. Having her makes you be a better person. I’m very sentimental to the parents of special needs children and to the children. As compared to before [having a child with catastrophic epilepsy], I probably didn’t pay attention so much. (Kim)*

Their child's condition encouraged them to enjoy every moment as it comes and to try to focus on the simple joys of life. It was a continual struggle for their child to learn and develop so when their child mastered a task, regardless of how small, participants said it gave them reason to celebrate. Overall, the perception expressed by the participants was that parenting a child with catastrophic epilepsy provided a sense of personal accomplishment and reward. Donna's comment captured this perspective.

*At the same time, [despite] all the trials and challenges, it is one of the greatest blessings I've ever had in my life. Seeing her happy or make even the tiniest developmental milestone is just such a joy. She is such a blessing. As hard as it is, it is so rewarding.*

There were many people directly involved in the care of the child over the years. Sometimes the experience of caring for a child with catastrophic epilepsy deeply and positively affected others as well. A participant explained:

*I always think that is another way she has affected people in a positive way. One of our babysitters is now in occupational therapy school, because in high school she was a babysitter. (Kim)*

Participants observed that their children could bring them much personal joy. They felt a sense of purpose in having a child to care for, nurture, and protect. It could be rewarding to see the accomplishments that their child struggled to achieve. They sensed a positive bond with their child and, for at least one participant, no words were required to communicate their feelings for each other. As this participant revealed,

*She may never be able to communicate with me in a way that I communicate. I've just been very in tuned with her and feel like we understand each other. (Sharon)*

The positive emotions and aspects of caring for their child provided all of the participants with comfort and strength. Each participant described her child as a blessing and mentioned the great extent to which their child had shaped the person who they (the participants) had become.

### **Challenges of providing care.**

For the participants in this study, the provision of care for their children could be physically demanding and, for some, associated with chronic physical conditions. In addition, participants reported that caring for a child with catastrophic epilepsy was emotionally taxing. Several participants used a roller coaster as a metaphor for their daily emotional state, and began to cry when talking about their child and caring for her or him. In addition to feelings of joy, love, and pride, the study participants expressed personal feelings of helplessness, devastation, apprehension, guilt, fear, and sorrow.

***Physical demands.*** The physical demands made on the parent of a child with catastrophic epilepsy took a toll on some participants. For some participants, their child's immobility or requirement for physical support resulted in chronic physical issues for them as caregivers. Participants expressed concern about their lack of physical stamina or capability, particularly as their children grew larger and heavier, or experienced muscle spasms or lack of muscular control. The physical demands of caregiving sometimes aggravated one participant's prior injury. This participant presented a photographic image of a back brace during the second interview photoelicitation process, signifying the physical strain that the physical care of her child could exact. Lindsay, Donna, and Kim described the physical outcomes of handling their child:

*The biggest challenge is that she is such dead weight. She doesn't help to sit herself up or roll over or do anything. I don't know if it is her, or my weight, or past work but I*

*have got the worst shoulder problems here lately. It will make my whole hand go to sleep and that makes it hard because I can't feel what I am doing with her. It's challenging to just hold her sometimes and she is super extending and she throws herself back and you have to push the other direction to sit. (Lindsay)*

*The physical needs are a lot more obvious and a lot more challenging. Carrying around a toddler is a heck of a lot easier than carrying around a ten-year-old. (Donna)*

*The toughest part is physically. I have a terrible back from high school. I cheered which I wish I never did. I have two discs that don't have a lot of fluid in them, so it's amazing to me that I am not in traction. It will catch sometimes, that is what is hard. (Kim)*

**Exhaustion.** The participants shared a common feeling of exhaustion that they related to such issues as the physical demands of providing care, sleep deprivation, and the overwhelming emotional commitment to their child and their child's care. They related their exhaustion to being constantly “*overwhelmed*” (Lindsay) with caring for their child and emotionally on edge, particularly since their children's seizures were unpredictable, life threatening, and unable to be controlled. Their lives involved the continuous and ongoing orchestration of physical care and therapy for their child: monitoring, providing constant care for, and transporting their child to innumerable appointments. All the while, participants searched for answers, resources, doctors, therapists, treatments, and ultimately a cure.

The child's condition was one of complete dependence on the participant as caregiver with no expectation for marked improvement in the condition. Participants said they felt overwhelmed and continually exhausted from the level of care needed by their child, including being constantly “*on the go*” (Jayme) with their child in an effort to negotiate the stream of

seemingly never-ended appointments required as a part of care. Lindsay described her child's care as:

*Very overwhelming, there is such a high need.*

Participants frequently saw no end in sight for the intensive care required by their child. It could be a struggle for them to continue to cope with performing daily tasks, while also trying to prepare for next steps in addressing their child's condition. Their relentless search for answers, treatment, and a cure added to their exhaustion as did the insomnia that their child periodically or constantly experienced.

Some participants related that their child's insomnia or interrupted sleep necessarily resulted in sleep deprivation for them and thus contributed to the general exhaustion they felt. One participant, for example, submitted a picture of a bed during her second interview as part of the photo-elicitation process. She said that the photographic image illustrated the lack of sleep experienced by her and her family because her child only slept two to four hours each night. She stated:

*I feel so sleep deprived. I don't get a lot of sleep. She [daughter with catastrophic epilepsy] doesn't sleep. No one sleeps a lot. My other daughter sleeps in my bed. My husband sleeps with her [in a separate bed, but in the same room as the child]. Our sleeping arrangement is so messed up. We don't have a traditional sleep schedule. She [daughter with catastrophic epilepsy] sleeps in a seizure bed that is all covered. [The photographic image of] a bed represents how chaotic our lives are even at night. Night time is supposed to be a calming time and seems to be our most chaotic. (Sharon)*

**Sorrow.** Participants expressed a shared sense of loss and sorrow. The losses they experienced were evident in many areas of their lives. They grieved for the loss of typical

development for their child despite the deeply positive feelings they had for their child. They grieved for the loss of dreams and aspirations they had for their child that could have included playing sports in the backyard, graduating from a prestigious college, and others. A participant stated:

*We were looking forward to the talking and walking, getting her in dance, playing sports, going and doing things in the woods and water that is a big part of who I was. It wasn't practical to do those things. (Donna)*

As parents, participants grieved the loss of their child walking, talking, and becoming an independent person. Some mothers who participated in the study found it sometimes hurtful to watch typically developing children of similar age as their child. Kim explained:

*I see little girls walking into the elementary school and it breaks my heart all over again, because I want her to be doing that [going to school].*

In addition to the emotional losses associated with their child's condition and what might have been, participants experienced confinement and a loss of spontaneity in their lives such as not being able to pack up and go on a trip at the last minute. Simple every day events such as going out to a restaurant to eat could become more of a chore than a pleasure due to the preparation required and child's temperament or mood at the time. A participant stated:

*Before [having a child with catastrophic epilepsy] it was so much easier to pick up and go. And, now you have to plan around refill of medicines, and do you have enough to take on the trip and her mood. There is a lot to take into consideration now. (Lindsay)*

Participants were saddened by the helplessness they felt regarding their inability to improve their children's quality of life. They reported feeling sorrow associated with having to witness their child struggle with repeated, uncontrolled seizures, the developmental setbacks

associated with some seizures, other developmental challenges, and various illnesses. It could be difficult to watch their child continually fail to reach developmental milestones regardless of effort or to lose the progress they had made following one prolonged seizure.

An inability to control their child's seizures could be devastating for parents. Despite their best efforts at trying multiple medications, diets, and various interventions to achieve control, their child's seizures continued every day. In addition, the impact of relentless medical testing on their children was difficult for participants to witness. As Sharon explained,

*I feel confined to a helpless situation.*

**Personal sacrifice.** The losses participants experienced involved many areas of their personal lives. For these participants, parenting a child with catastrophic epilepsy meant the loss of employment or career, personal ambitions, and independence. All of the study participants were stay-at-home mothers primarily because of the grueling demands associated with caring for their affected child. The loss of a job or career had cascading effects in that unemployment meant a loss of financial resources, which resulted in a more constrained lifestyle.

The participant's daily schedule was crowded with their children's therapies, doctor's appointments, medication pick up, phone calls to make, caring for the child, including continuing and often several therapy recommendations. The daily personal desires of the parent were lost in meeting the daily needs of their child. Their lives became increasingly isolated.

**Isolation.** Participants found that their children were more at ease in familiar environments such as their home and became stressed when they were removed from their familiar home environment. For the child, an increase in stress could lead to increased seizure activity and alterations of mood. While helpful in some respects for the child, having to remain

in a familiar environment could result in the participant's physical and social isolation. As a participant explained:

*It's so limiting. It's just easier to sit at home than it is to get everything rounded up and to go and then she's fussing cause she is in her element at home.* (Donna)

Parents said that the isolation they experienced extended into the social and spiritual aspects of their lives. Participants and their spouses found it difficult to maintain social interactions with family and friends due to their busy schedule of parenting and caring for their child. Confinement to the child's familiar environment such as the home could be socially isolating for the family. For social events that did occur, the time of year and location of a social activity may not accommodate the needs of a child with catastrophic epilepsy. Issues such as summer heat or exposure to strobe lights, for example, could increase seizure activity.

Participants recognized other factors that could exclude the family from social events such as a lack of wheelchair accessibility or the necessity for their child to be quiet. Two participants noted the inability of the family to attend church services together (Jayme & Kim) due to the audible sounds the child made. According to Kim,

*Going to things like parades or church as a family is not possible. It's just too hard.*

According to Jayme, Sharon, and Kim, parenting a child with catastrophic epilepsy could lead to a sense of emotional as well as physical isolation. Some parents felt alone and trapped in a situation over which they had little control (Sharon). A participant explained:

*I'm not gonna lie. I had a major break right after she was diagnosed. It's like you are in this tunnel. You are talking with genetic doctors and early intervention starts. I think it was a few months into that, I felt like nobody has a clue of what I am going through and having this child you would give your life for.* (Kim)



The child's impossible-to-control seizures could be frightening to observe. Although participants observed their child's seizures day in and day out, the situation typically was not one with which other people were comfortable, could relate to, or comprehend. Extended family and friends may have wanted to help the participant, child, and family but it was difficult for them to cope with the potentially life-threatening seizures that these children experienced.

The participants were the primary, direct caregivers, which involved making complex and sometimes difficult decisions. This could leave participants feeling emotionally isolated. Jayme and Sharon described the emotional isolation that they experienced:

*I feel like there is nobody in the world that knows what I am going through. (Jayme)*

*[In her photoelicitation process] I took a picture of a woman in a corner crying because I feel very alone, very isolated, and the corner represents the isolation. I feel very trapped in a helpless situation. It's challenging in the fact that I want to help her and I can't. I feel very helpless. (Sharon)*

In summary, participants in this study experienced various forms of isolation occurred that included physical, social, spiritual, and emotional isolation. There were many factors surrounding catastrophic epilepsy that left participants with such feelings. Confinement to the child's familiar surroundings posed physical isolation issues for participants. Circumstances that were unaccommodating for their child resulted in social isolation. The child's behavior and potential for seizures could result in spiritual isolation. Perceiving oneself as alone and in a helpless situation led to participants' feelings of emotional isolation.

***Fear, anxiety and helplessness.*** Participants perceived that catastrophic epilepsy was a devastating condition that altered the family as a whole and the lives of family members as individuals. It could be a daily struggle for many families to process the events of their lives and

the effects that their child had on the family. Their child had a condition that was not likely to drastically improve, particularly to the point where the child would become fully independent. It was likely that the child would instead always depend on the participant for complete and constant care. Participants believed that their children's complete dependence on them could be overwhelming and a source of personal helplessness, anxiety and fear.

Study participants spoke about the love and devotion they felt for their child, while also recognizing the helplessness, fear and anxiety they experienced in caring for their child. Their anxiety often increased when parenting a child who was unable to communicate and thus convey such things as the source of their discomfort. The participants were thus left guessing about the child's problem while trying, at times unsuccessfully, to help their child. The unpredictable nature of epilepsy left participants feeling continually on edge and apprehensive. A participant explained:

*You might be having a good day and the next minute your stomach just drops, cause you hear something or you found something or she does something. It [child's condition] worries you. (Lindsay)*

The child's health status in general could be anxiety provoking for participants. A child might stop eating and require the placement of a gastrostomy tube. He or she might experience a status epilepticus (prolonged) seizure, leaving the parent fearful about whether the child would survive and apprehensive about the consequences of the seizure for their child's development. Starting or stopping a treatment was often a time of great concern for parents since the consequences could not be anticipated. Donna described her reaction to the deterioration in her child's condition:

*The fact that she has become pretty much wheelchair bound over the last year has been very heartbreaking for me. There are days when I absolutely accept that and I am ok with that, and there are other days I am devastated.*

In terms of their child's condition and the consequent intensive care situation with which they dealt all day, every day, all of the participants expressed feeling "helpless." They all revealed that they had been devastated by the loss of a typically developing child. At the same time, they felt apprehensive about providing quality care for their child, yet also felt guilty about neglecting other family members including their spouse and other children while they provided such care.

When thinking about their child's future, participants said they were fearful (Donna, Kim, Lindsay & Sharon). Their fears included the sudden death of their child due to a seizure and a seizure-related regression in skills or quality of life for their child. Participants expressed fear for the decline of their own health. Participants said that the possibility of their own death left them fearful about who would care for their child.

All of the participants were concerned about the future. The possibility of their child's sudden death weighed heavily on their minds. In discussing her thoughts about the death of her child, one participant said she would find some comfort in the death of her child because she knew that her child would no longer suffer. Participants also worried about the life expectancy of their child and who would care for their children later in life, particularly after the participants had died. Two participants explained:

*A part of me almost wishes that my child will pass at an early age so I don't have those worries. Worry about me dying and not having anybody to take care of her. I would not*

*have thought that before about any of my children that are normal, typically developing.*

*So it's very conflicting to have those types of feelings.* (Sharon)

*I don't want her in a [nursing] home. That scares me so I will wake up in the middle of the night and think, 'Oh my gosh, what if something happened to us.' It's frightening.*

(Kim)

In summary, participants said they experienced helplessness, anxiety and fear about the day-to-day responsibilities associated with parenting a child for whom potentially life-threatening seizures were a daily reality. Caring for the child with thoughts about the future was also a source of fear.

***Reactions of others.*** Extended family and friends sometimes offered support in the process of caring for the child with catastrophic epilepsy or became a source of anxiety or frustration for participants. Participants recognized that it could be difficult for family and friends to witness the parents and child experiencing the struggles resulting from catastrophic epilepsy. Some family members and friends found it too painful to be present to the affected child and family or did not comprehend or accept the severe nature of the condition. The study participants also commented on the reactions of strangers that could be both positive and negative.

***Family and friends.*** Discussion related to how extended family perceived the child's condition was an emotional topic for participants. They all described family and friends as supportive and also contributors to the anxiety they experienced in parenting a child with catastrophic epilepsy. The siblings of the child with catastrophic epilepsy were part of the experience. All but one participant had other children in addition to the child with catastrophic epilepsy. The participants expressed concern about the well being of their other children.

The four participants who had other children expressed feelings of guilt when speaking about them. They felt guilty, for example, when family outings had to be limited or curtailed due to the child with catastrophic epilepsy. The child with catastrophic epilepsy consumed participants' time and energy to such a degree that other children in the family received limited attention. Some participants felt guilty about asking siblings for help in the daily care of the child with catastrophic epilepsy. A participant commented,

*I'll ask her sister for help and it does make me feel guilty. (Kim)*

Some participants believed that the child with catastrophic epilepsy could have a positive impact on siblings. They suggested that experience with the child could have a similar impact on the siblings as it had on the parents by shaping their compassion and understanding for others. A participant stated:

*Hopefully in the end I think overall both of my children will benefit greatly in having her as their sister. (Kim)*

Family and friends could be a source of support and also contributed to participants' feelings of devastation and anxiety. Several of the participants recalled the loss of friends and family and those from whom they had grown distant. Donna expressed her belief that immediate family members found it too difficult to witness her pain and struggles so they distanced themselves:

*When they [family] see that you are in pain and struggling, it hurts them too, cause they love you and they can't image what life would be like if they were in that situation [parenting a child with catastrophic epilepsy]. And so for them [family] it's easier for them to just stay distant.*

All participants believed that some family members were in denial about their child's condition. The condition impacted parents, siblings, grandparents, and immediate and distant family differently. Study participants perceived that family members sometimes did not know how to help them or their child. Participants explained that they sometimes chose not to divulge the child's daily seizures or other occurrences to family members because it was difficult for family members to process that information (Sharon). Three of the participants explained:

*I leave it [explaining child's condition] very simple and direct, because if I go into this whole dialogue [about the child's condition] they [family and friends] are not going to understand anyway [....] My three-year-old probably understands more than my family understands. My husband's family is in denial. They think, I don't really know what they think, because they don't really talk to me about it. But, I imagine they probably feel that what is happening is not as bad as what we sometimes think it is. They are very much in denial about the situation. They are the type that thinks you can just pray it out.*

(Sharon)

*It's [child's condition] just too painful for my mother-in-law.* (Kim)

Participants also contended that some family members and friends could be supportive and helpful in caring for their child. Lindsay and Kim explained:

*Friends are great; sometimes they are just a little more supportive just because family is a little more in denial of what the true outcome could be.* (Lindsay)

*I thought, 'Oh my goodness, this [catastrophic epilepsy] is going to put my Mom in the grave.' But, she was the strongest one out of all of us. I thought, 'Wow, look at my Mom.' I just thought this [grandchild with catastrophic epilepsy] was going to crush her, but she stepped right up to the plate.* (Kim)

*Public reaction.* Participants described a variety of responses by the general public to their children. Children with catastrophic epilepsy tend to have the appearance of a typical child; there might not be any visual abnormalities to indicate a child with medical issues. However, medical issues and intellectual disability became apparent when someone witnessed the child in a wheelchair or was present to the child's unusual sounds, behaviors, or seizure activity. The children often attracted attention and people tended to stare. Participants found that negative public reactions could result in added stress for them. As Kim explained,

*She is such a cute little girl. She doesn't physically look different. But, she is in a wheelchair and not talking. But, seeing her in a wheelchair they all look. Ever since she was a young thing I can remember putting her in a grocery cart and she would just slump over, and it was awkward. I would have to pad it and put pillows and strap her in. I know that people would always look and wonder what was going on. It is stressful to have to do that and your child is all slumped over.*

Participants noted that reactions from strangers also could be positive and restore their confidence that people were still caring and compassionate. It might have been a simple smile from those individuals to the parents. The positive reaction might have been a statement about a beautiful child. The acknowledgement of the child could be comforting to the parents of children with catastrophic epilepsy. A participant stated:

*A lot of people stare or ask questions. Just wonder why she is behaving a certain way. And people will come up being very supportive and encouraging. Random people will come up and say how beautiful she is and she touched their heart and they are a total stranger. Its moments like that, that reinforce there are still good people out there.*

(Donna)

Participants also recounted situations where the public had negative reactions to their child. They indicated that the public might not understand that a child who appeared to be over four years of age was still drinking from a bottle. A stranger might not understand why a parent was carrying a child who appeared to be old enough to walk independently. A participant described an experience that occurred in a restaurant.

*One time I was carrying her in a restaurant and a man said, “Why don’t you put that child down and let her walk on her own?” And my mom said, “She would if she could, but she doesn’t walk.” He felt bad; he thought I was just carrying her. (Kim)*

Some people stared at the child and then simply looked away. When the researcher inquired about why participants thought that people stared and looked away, Donna said,

*I think they look away because it [watching the child with catastrophic epilepsy] hurts them; it’s painful for them to see, and imagine that life is so traumatic for us. (Donna)*

Participants’ coping with parenting a child with catastrophic epilepsy was exemplified by a photographic image of the ocean that one study participant presented during the photoelicitation process. She said that the image reflected her perceptions about parenting a child with catastrophic epilepsy. To her, the image represented an ocean of possibility, options, and decisions that she had encountered. She saw the ocean as huge, unknown, unending, and capable of eliciting fear as well as joy. The picture of the ocean was a metaphor for her perceptions about parenting her child.



### **Theme: Caregiver Coping: “Celebrating the Child While Mourning the Losses”**

The participants addressed caring for their child and managing their child’s condition as the reality of their lives. They expressed that often it was not a positive or negative perception, but one that simply reflected their reality. *“It is what it is,”* said Lindsay in describing her perception about caring for her daughter with catastrophic epilepsy. Participants continued their immersion and engagement in the multifaceted care of their children accompanied by emotions that included joy, pride, sorrow, fear, anxiety, helplessness, and acceptance of reality. Where they could exert control, they did. Several participants suggested, for example, that determining what others were privy to know about the status of their child reflected one measure of control that they could exert. They tried to set and help their child achieve realistic goals, with an emphasis on the goal of contentment for their child.

The reality of parenting a child with catastrophic epilepsy was that of moving forward and continuing life despite a lack of control over their child’s condition and the inevitable challenges and set-backs that they faced. Each day could bring new, unanticipated challenges for the child, participant, and family. The reality of living with catastrophic epilepsy was a lack of control over many aspects of the child’s condition, including when and for how long seizures occurred and the kind and duration of their child’s mood swings. As Sharon observed:

*The day changes pretty much all the time. This morning she has been very cranky and cried all day. Our palliative care doctor was at the house this morning brainstorming with me about what is going on with her.*

Participants commonly experienced limitations imposed by their child’s inability to communicate, including an inability to express discomfort or pain. Various medications could cause their child to be irritable or experience other side effects. The participants’ reality was that

of striving to attain and maintain a state of contentment for their child, while recognizing that achieving contentment was an often-elusive goal.

The reality of caring for a child with catastrophic epilepsy was one of relentless, continuous monitoring and care without the expectation of improvement in the child's condition. Travel to a multitude of doctor and therapy appointments would most likely continue. Affected children might learn to do some things on their own, but most likely would need complete care during the entire course of their lives, in part because seizure activity tended to negatively impact developmental progress for these children.

There were strategic and logistical realities for participants who parented children with catastrophic epilepsy. It could be difficult to push a grocery cart and a wheelchair at the same time, for example. Parenting both a toddler and a child who used a wheelchair could be challenging.

*It is very difficult to have a toddler and a child in a wheelchair. I would be not able to take both of them out in public by myself. There is no way, because I cannot chase after him and push a wheelchair at the same time. I feel like I am always leaving one unattended. (Kim)*

The reality was that participants' recognized that their dreams and aspirations for their affected child needed to be simplified. Dreams and aspirations for their children became achieving an ability to sit up or walk, feed themselves, use a communication device, or urinate in a toilet. A study participant described goal setting for her child:

*The dreams and aspirations are still there for her, but they are modified. I still have those as you would [for] any other kid, but they just look different. (Donna)*

The financial reality of caring for a child with catastrophic epilepsy was one of significant financial expense. In this study, the extensive care required by the child resulted in the participant staying home to care for the child. A solo income household could, in turn, lead to financial constraints that were compounded by the child's medical bills.

Parenting a child with catastrophic epilepsy differed in many ways from parenting a typically developing child. Study participants described many different facets to caring for their affected children. Several of the study participants referred to parenting their child as a “*journey*” (Donna). They all experienced love, joy, apprehension, and the realities, particularly of seizure activity, associated with parenting their child. One participant presented a photograph of a butterfly to represent the journey of parenting her child. She explained:

*The butterfly represents the metamorphosis of this journey [parenting a child with catastrophic epilepsy]. It's our family and how it [her family] keeps going through different stages. The initial diagnosis, we work through the maze and climb the mountain so to speak. It is a journey, you grow, evolve and change and it's [butterfly] symbolic of this journey. (Donna)*

### **Coping mechanisms.**

Coping strategies for parents with catastrophic epilepsy evolved in several forms. Study participants expressed several coping mechanisms that supported them in their role as primary caregiver for their severely affected child. These different coping skills included seeking information about the child's condition, talking with other parents of children with the same condition, relying on religious faith, family and friends, and advocating and being the leading force for their child.

***Leading force.*** Each participant expressed a particular coping mechanism reflected in the sub-theme of serving as a leading force in the child's life. The participant strived to control

the content of conversations with others about their child. These others included strangers, family, friends, and healthcare providers. The parent determined the information shared about their child as a coping mechanism, a means of protecting the child, or a matter of maternal control. The participants explained:

*People's reaction to the situation [with the child] depends on how I react to the situation. If I feel like I'm in control and I'm taking the reins and moving forward, I feel like the medical community maybe follows led with me. If I feel like I am kind of wishy-washy I feel like they are more wishy-washy. My pre friends [friends before the diagnosis] don't really ask me about her, but I prefer it that way. But, I prefer it that way. They will ask me how she is doing, and I say fine. I leave it [explaining child's condition] very simple and direct, because if I go into this whole dialogue [about the child's condition] they [family and friends] are not going to understand anyway. (Sharon)*

*My mom and I have a really good relationship, but we really don't converse about her, because I don't take the conversation there. I don't bring the conversations there [about her child], so I am the leading force. If I take the conversations there [about the child] then they follow suit. (Sharon)*

*Over the years my family is coming around more. Part of that is because I am allowing them to. As a mom I have created this safety bubble for us and I feel like I'm now in the part of our journey where I am opening up and allowing my family to come in more [involved with the child]. It's [the child and catastrophic epilepsy] part of their healing process too. (Donna)*

*And it depends on the mood and how much time I have to talk or whatever. Sometimes I'll be really honest and say she has a seizure disorder and others I say she is a sweetie and how old she is or gonna be and keep going. (Lindsay)*

**Faith.** Faith was a means of coping that participants referred to often during the interviews. They said that their faith gave them a sense of hope and comfort. A participant presented a photographic image of a cross during the photoelicitation process indicating that it was a “*symbol of hope*” (Kim). As three participants explained:

*Its' a lot of stress, you just have to put it [the child] in God's hands and have a lot of faith. (Donna)*

*You just have to have faith and look at the bright side of things. (Lindsay)*

*The cross is a symbol of hope, because I always have hope. I am convinced she is going to tell me I really didn't love sweet potatoes so much. (Kim)*

**Family and friends.** Family and friends can be a potentially supportive means to cope with parenting a child with catastrophic epilepsy. Three of the study participants had children after the diagnosis of their affected child. They believed it was a healing experience to have other children. A participant spoke about the how the new addition to the family might possibly help with the care of the child in the future after the parents died. A participant explained:

*I'm so glad I have another one [third child], because when we are dead and gone she [the third child] is gonna have to take care of her [child with catastrophic epilepsy]. But, I feel so blessed that I have another child that can share that responsibility. (Kim)*  
*It was healing to have a child after getting that bombshell [diagnosis of catastrophic epilepsy]. And to know we could have a healthy child again, and I always wanted another child. (Sharon)*

Some family and friends offered support in caring for the child to provide the participant respite and encouragement. One participant said,

*My sister has been so wonderful. She doesn't talk about the doom and gloom. She always talks about the positives. She has been a wonderful support to me. (Kim)*

**Emotional expression.** Participants talked about recognizing and expressing their emotions as a means of coping when parenting their child with catastrophic epilepsy. They indicated that they had to go through an internal process to understand and come to terms with the experience of catastrophic epilepsy in order to achieve a positive outlook. They said that adopting a positive perspective could be manifested as making the very best of each day with one's child. Several participants said that part of their coping was allowing themselves to express rather than suppress their emotions. A participant explained,

*I have to step back. I allow myself to feel and not just stuff it in or feel stupid for feeling like this or this isn't healthy. I let myself cry or get mad, because I do get angry.*

(Donna)

The participants spoke about processing and expressing their emotions with the help of their child with catastrophic epilepsy. One parent referred to her child as the “*calm in the storm*” (Sharon). Another participant stated:

*When I have had a bad day, I just sit next to her, and she makes it all better. (Kim)*

A participant presented a photograph of the American flag to represent how she stands proud, strong, and tall for her child and fights for everything that she can for her child (Jayme).

**Information seeking.** Study participants talked about their constant efforts to seek information about their child's condition or information about anything that would assist their child such as new treatments, equipment, therapies, or other services. They revealed several

personal advantages associated with information seeking such as gaining a sense of empowerment from learning about the child's condition (Sharon), having more productive visits with healthcare providers (Donna), and deriving a sense of well-being from the process. Jayme, for example, found that educating herself about her child's condition was therapeutic.

**Networking.** The participants found that networking with other families going through a similar situation served as a means of coping with the challenges of parenting a child with catastrophic epilepsy. They took advantage of several social networking sites to communicate with one another. Social networking afforded by Yahoo groups and Facebook pages allowed the parents of children with catastrophic epilepsy from around the world to communicate daily.

They were able to use the state-funded Family Support Network as a source of support. The family support network matched parents in similar circumstances and hosted support group meetings and seminars to assist parents through various experiences with their children. Participants indicated that meeting and communicating with other families reminded them that they were not alone and that others shared the experience of having a child with a similar condition.

The participants in this study thus revealed several coping strategies they used as they parented their affected children. Donna, Lindsay, and Sharon spoke about a particular coping mechanism by which they alone determined what family, friends and healthcare providers would know about their child. Jayme and Kim revealed their faith as a source of personal strength while parenting their child. All of the study participants sought information about their child's condition; several of them noted that information seeking was a means of coping with the condition. Networking with parents in similar circumstances had become easier with the availability of internet-based social or support groups specific to catastrophic epilepsy, and

Facebook allowed the study participants to engage in conversations with parents with similarly affected children from all over the world.

*Cycling between emotional highs and lows.* In describing the methods they utilized in coping with parenting their child, participants revealed that they often cycled between positive and negative perceptions about and acceptance of their child's condition and the physical care demands required as a consequence of the condition. During the interviews the researcher observed firsthand their cycling among feelings of joy and sorrow, and acceptance and loss, as participants shared their experiences and perspectives. .

The emotional cycling sometimes presented as times that participants felt they were unable to cope. While participants talked about effectively coping with their child's condition, they also talked about times when they believed they did not cope well at all. One participant described times when she felt at her lowest:

*Sometimes I go into this dark place where I don't leave my house. I don't shower or take care of myself at all. I don't talk to anyone unless it is necessary. I just get in funk where I can't even function.* (Sharon)

In summary, the overarching theme that emerged during the course of the interviews conducted for the study was that of commitment to a beloved child in a seizure-centered life. The five participants were the birthmothers of children with catastrophic epilepsy. The children's ages and abilities varied, however all of the children had significant developmental and intellectual disabilities as a result of catastrophic epilepsy. At the time of the interviews, each of the study participants' children continued to have uncontrolled seizures. The seizure activity was a daily occurrence that left the participants with a feeling of "waiting for the other shoe to drop" in terms of seizure activity. Their children's unpredictable and potentially lethal



seizure activity took priority in and compounded the daily care needed by their special needs children. The participants shared many of the same issues and epilepsy was interwoven through all themes that emerged from the study. All of the participants discussed mobilizing resources as a constant preoccupation and effort in order to support the care their children needed. State-funded programs provided a major resource for the children's care.

The participants shared a common theme of being overwhelmed by the intensive daily care that their children required. Participants constantly monitored their children's seizure activity and administered emergency medication in the event of a prolonged seizure. The participants were not only vigilant in terms of seizure activity, but also avoided external factors that might increase their child's seizure activity when they could. The daily treatment of their child's epilepsy included medications, special diets, and the use of special equipment such as implanted stimulators for seizure control. The participants' children required complete daily care, including skincare, dressing, bathing, and feeding. None of the children were toilet trained so keeping them dry and clean posed challenges in maintaining their skin integrity.

The participants' spoke about the physical demands on them posed by the care they provided due to their children's immobility and the physical stamina that engaging in care and transporting required. The child's physical safety constantly preoccupied the participants. Several of the children experienced drop seizures and wore a helmet to protect their head. All of the children experienced intellectual disabilities that impacted every facet of the child's life, including their ability to communicate and their safety.

The participants explained the various assistive equipment used by their children to walk and communicate. They discussed assisting their children to attain and maintain a state of contentment. The participants explained the one-on-one attention necessary to engage the child

in order for the child to be content. Participants viewed achieving a state of contentment as imperative, because discontent could lead to increased seizure activity.

The study participants spoke at great length about the time, energy, and challenges they faced in planning and organizing care for their children. They maintained documentation pertaining to the child's care that was readily retrievable when there were questions or concerns.

Many specialists were involved in the care of their children. It was often a daunting task to find a specialist, make an appointment, go to the appointment, understand the information provided at the appointment, and then make decisions based on information provided at that appointment. Their children routinely underwent various testing procedures and needed specialty services such as leg braces, and feeding and seating clinics. All of the children of the participants regularly received various therapies that participants were expected to continue providing daily.

The effects of caregiving on participants emerged from the interviews. They described providing care as, "confined to a helpless situation." The participants explained the rewards as well as challenges associated with providing care. They also described the personal impact of caregiving in terms of other effects such as exhaustion, sorrow, isolation, and personal sacrifice. The participants spoke about coping with various reactions to their children's conduct by family, friends, and the public.

A final theme that emerged was caregiver coping that was described as celebrating their child while mourning the losses. There were several coping strategies that participants identified and discussed. These coping strategies included the notion of accepting reality as, "*It is what it is.*" They described a coping strategy associated with being their child's advocate and "*leading force*" on behalf of their child.

Two participants spoke about their religious faith as a source of strength and a coping strategy in parenting their child with catastrophic epilepsy. Other coping mechanisms they mentioned included seeking information about their child's condition and networking with other parents in similar situations. Despite participants' many positive coping strategies, they experienced emotional highs and lows and found themselves cycling among many emotions, including joy and sorrow, and acceptance and loss.

### **Photo Elicitation Findings**

The researcher used a photo elicitation process during this study to attain a deeper understanding of participants' perceptions about parenting a child with catastrophic epilepsy. The photo elicitation process served as a means of triangulating data in the study. As such, the data from the in-depth interviews were confirmed by the data associated with the photoelicitation process with the additional theme of "the journey" that emerged from the narratives about the photographic images taken by the study participants.

As part of the photoelicitation process, the researcher requested that each participant take four photographs and, during the second interview, discuss with the researcher each photographic image they took. Two of the participants took and talked about one additional photograph in addition to the four photographs that the researcher requested they take. The resulting photographic images and the meanings of the images as shared by study participants revealed six main themes: "journey," "providing for the child's needs," "personal commitment to the child's needs," "community care for the child," "coping and endurance," "perceptions of loss," and the "effects of care on the caregiver." The findings specific to the photoelicitation process are presented in this section according to each of the themes.

### **The journey.**

Two participants saw parenting their child as a journey. A photograph of an ocean, oak tree and butterfly captured the essence of the journey for Donna and Kim.

For Donna, the ocean was a metaphor for catastrophic epilepsy. She reflected that, similar to having a child with catastrophic epilepsy, the ocean was a huge, unending, and constantly changing unknown. She explained:

*It [parenting a child with catastrophic epilepsy] is an ocean of possibilities with waves of options and decisions that you encounter every day. You feel like you are on a boat in the middle of the ocean, and it's such a big new world. Lost [unsure how to care for her child] and it's huge and unknown. Each wave could be something new and frightening. There is no end.*

Kim's journey was exemplified by a photograph of a big, strong oak tree with many branches and with the sun streaming through its branches. She had experienced many challenges associated with caring for a child with catastrophic epilepsy. The sun streaming through the tree branches represented her child.

An additional image of a butterfly represented for Donna the metamorphosis she experienced that served as a metaphor for her complete change of life since her child had been diagnosed. She explained:

*The journey [parenting a child with catastrophic epilepsy] is a metamorphosis. It's [butterfly] our family and how it keeps going through different stages. The initial diagnosis, we work through the maze and climb the mountain so to speak. It's a journey; you grow, evolve and change. It's [the butterfly image] symbolic of this journey.*

### **Providing for the child's needs.**

Participants shared photographs of items that they used daily to provide direct care for their child including medicine bottles, food, and bells. They saw the medicine bottles and food as essential components of childcare while, for one participant, the bells provided a source of entertainment to help engage her child as part of her child's emotional care.

Two of the participants presented a photograph of medicine bottles (Sharon & Lindsay) that represented the necessity of administering medication daily or several times per day to treat their children's condition. They expressed concern about maintaining an adequate supply of medication as well as obtaining and administering the medication. The medicine bottles also represented treatment that required participants to monitor their child for efficacy and side effects. Lindsay stated:

*Medicines are a constant. It limits you. You gotta' have it.*

For Lindsay, a picture of various foods represented nutritional challenges in the care of her child. Her efforts to feed her child who had oral aversion issues were often unsuccessful, leading to feelings of frustration and being upset about the outcome of the situation. Another nutritional aspect that upset her was the money she spent on wasted food because her child only accepted a few bites of food at any one feeding.

As a part of childcare, a photographic image of bells reminded Lindsay of her child and the enjoyment her child derived from hearing bells ring. She explained:

*She loves the noise, and anytime I find anything with bells that I could manipulate for her to be able to ring and play with, I get [it]. So I took a picture of bells, she loves the way they sound and I think she sees them. (Lindsay)*

### **Personal commitment to the child.**

The participants talked about several photographs that, for them, represented their commitment to their children. Their narrative about the images revealed that they aimed to prioritize and meet their children's many needs. In addition, in the context of care, the participants' narrative about their photographic images illustrated their recognition that their child needed an interdependent "ecosystem" of care. Such care was provided along a continuum of social interaction that ranged from being physically isolated in the home while health care providers and other professionals came and went, to always being out of the home and "on the go" to and from appointments with health care providers and other professionals.

Lindsay took a photograph of her monthly calendar with each day filled with small hand written notes. The notes documented her child's seizure activity she observed and treated. This particular month her child had started a new medication so she had plotted on the calendar the gradual increase to the desired dosage. The child's appointments filled the calendar. Her child was on a Ketogenic diet so she had also recorded daily food intake, urinary output, urine ketone levels, and bowel movements on the calendar.

A picture of Lindsay's home represented for her the isolation she felt, precipitated in part by her child's needs and inability to adapt to new environments. Lindsay stated:

*I'm always there [home] with therapists or caseworker[s]. It's just easier to sit at home than it is to get everything rounded up and to go and then she's fussing cause she is in her element at home. It also shows the isolation that I feel. I'm isolated to my home and she has taken over our house with toys and equipment. (Lindsay)*

All of the parents discussed being constantly in the car and "on the go" (Jayme) with their child. Two participants shared travel-related images during the photoelicitation process.

One participant shared an image of a car (Jayme) and another offered an image of an odometer in a car that represented the miles she had driven (Lindsay). They stated:

*A photo of my car because we are always on the go to doctors and therapies, this that and the other going on with him. (Jayme)*

*The odometer shows the miles put on the car, cause you are constantly going to the doctor or pharmacy. It's a constant. Somewhere to [go to] do something for her.*

(Lindsay)

### **Community care for the child.**

One participant's narrative about a photograph she had taken of a forest reflected the multitude of individuals, the "*community of people*" who comprised an interdependent "*ecosystem*" of care (Donna) that were involved in providing care for her child with catastrophic epilepsy. Donna explained her image in the following way:

*The forest represents the community of people. The trees represent the other families, doctors, therapists and teacher. Once this happens it's not just you and your family anymore, it's a whole freaking forest of people. As isolated as you feel you are in a dense forest, it's the network of people. The big trees are your scientists and doctors; there are different tiers of plant life. That is what I think of when I think about all the contacts that you have to have. It's an ecosystem. Each one has to have the other to thrive.*

### **Coping and endurance.**

Participants talked about several photographic images that had captured the endurance and self-preservation they acknowledged as necessary to continue moving forward for the sake of their children as well as the family. These photographs reflected strength, courage, and hope.

Donna explained that a photograph of an American Indian warrior illustrated her child's fighting spirit. She thought of her child as brave and someone who had endured a lot as a consequence of her seizures and disabilities. She saw her child as a fighter. For Jayme, on the other hand, a photograph of an American flag indicated that she stood proud and strong for her child and fought for everything the child needed. Kim presented a photographic image of a cross that she said signified her religious faith. Her faith provided her with hope and strength as she cared for her affected child.

Two photographs directly presented the joy and love the participants' felt for their children with catastrophic epilepsy, how their children made them feel, and how their child felt toward them. A photograph of sunshine, for example, was one participant's metaphor for the joy her child brought into her life.

*He is the sunshine in my life. (Jayme)*

A picture of two people hugging was indicative of the affection Kim's child offered her. She said,

*She wants to be loved. You have to put your hair up because she will pull it, cause she wants to be close to you. You can't wear jewelry cause she wants to love and kiss all over you. Slobbering kisses. If you ever had a bad day just sit next to her.*

### **Participants' perceptions of loss.**

There were photographs that captured participants' view of death and its consequences for their child as well as sense of loss and sorrow. These photographic images included a sleeping child, crying woman huddled in a corner, rain, and a bird in flight.



***Death and peace.*** For Sharon, the photograph of a bird flying symbolized the death of her child and consequent peace that death may offer her child. She explained,

*One day she will go and be off this earth and will be in peace. I think I am going to feel very happy for her, in a weird way. Fly and be at peace.*

A picture of a sleeping child held several meanings for Donna. It symbolized that the child might not wake up one day, implied a child's innocence, and also signified silence and peace.

***Isolation and sorrow.*** Sharon's photograph depicted a woman who sat in a corner of a room with her head in her hands. Sharon said the woman was crying, reflecting how upset Sharon was about the situation with her child with catastrophic epilepsy. The corner symbolized the isolation she felt. For Jayme, a photograph of the rain reflected the days when she was feeling "*down and gloomy*" about her child's condition.

#### **Effects of care on the caregiver.**

A picture of a bed and back brace captured the effects of caring for their child on the participants. As mentioned earlier, Sharon's photograph of a woman crying in a corner reflected the emotional effects of care. The photograph of a bed symbolized Sharon's lack of sleep associated with caring for her child with catastrophic epilepsy and that the nighttime routine for her and her family was often chaotic

Kim's picture of a back brace represented the physical pain she experienced in caring for her child. It also captured her genuine concern or fear she felt in caring for her daughter over the long term because of her pre-existing back problems.

In summary, the photoelicitation process yielded information-rich findings that added depth to the study and triangulated data in the study. Two of the participants provided five

photographs, while the remaining three had taken four photographs. The photoelicitation findings were similar to those from the initial interview. The images presented supported the themes discovered during the first interview. An additional theme of a “journey” emerged during the photoelicitation interviews. Study participants described their maternal experience with their child affected by catastrophic epilepsy as a journey that was represented by images of an ocean, oak tree and a butterfly.

The participants expressed that their participation in the photoelicitation process provided a different approach in evaluating their perceptions about parenting their child with catastrophic epilepsy. They indicated that taking the photographs facilitated their deeper reflection about caring for their child.

### **Member Check Findings**

The researcher provided the three participants that she was able to contact with a preliminary version of the final study report. She requested that they provide feedback related to the accuracy with which she represented their perspectives and experiences in the report as a whole and Chapter 4 in particular. She also invited them to offer additional comments in response to any aspect of the study. She obtained participants’ feedback via a telephone call made one week after forwarding the report to them. Participants indicated their agreement with the report, with one participant declaring, “That is my life on paper.” Overall they expressed appreciation for being a part of the study and for the education and awareness about epilepsy that the study offered. As a participant explained, “I’m glad to know others will see this.”

### **Summary**

The findings from this study captured the maternal perceptions of and meanings associated with parenting a child with catastrophic epilepsy. The form of epilepsy experienced

by the participants' children greatly compounded the issues parents typically face in raising a special needs child. These participants led a committed, seizure-centered life. The additional concerns associated with the child's epilepsy kept the participants on constant guard for seizure activity. The unpredictability and potential lethality of their child's epilepsy increased the participants' vigilance and role in interventions such as administering daily medication as well as emergency medication in the event of a prolonged seizure, and monitoring the child constantly for seizures and adverse effects from medication. Some of the participants' children required a special diet or special implanted device to reduce the frequency or duration of their seizures. Epilepsy compounded the issues each participant's child confronted and was interwoven in every aspect of the child's life and life of the child's family. Parents were in a state of constant alert for seizure activity because a seizure could be injurious or life threatening for their child, and have a significant impact on the child's development, including leading to intellectual disabilities and other deficits. Logistically, seizure activity could alter planned daily schedules, including appointments, change the child's mood, require a visit to an emergency room, or other problems.

The participants in this study were unable to work due to the demands of caring for their child with catastrophic epilepsy. Identifying, accessing, and coordinating resources to care for their children entailed time, research, organizing and planning on the part of the caregiver. Parents of a child with catastrophic epilepsy coordinated and accessed numerous physicians, therapists, social workers, and services to address and improve the well being of the child. The participants relayed to the researcher that they were constantly on the telephone searching for a healthcare provider appointment or service. Their time was consumed with making appointments, going to appointments, and making and implementing decisions based on information from appointments.

The study participants spoke at length about being exhausted from managing the care of their child. Parenting a child with catastrophic epilepsy also posed many challenges for the study participants for several reasons. All of the children were nonverbal which made it difficult to understand the child's wants and needs. The participants described the one-on-one attention the child needed in order for the child to be content. Keeping the child calm and content was of importance because emotional upset could trigger seizure activity.

The physical care of a child with catastrophic epilepsy was extensive. The participants described caring for their child's basic needs such as feeding, dressing, bathing, diapering and transporting their child with profound disabilities. The findings also focused on how parenting a child with catastrophic epilepsy affected the study participants. During the two separate interviews with five participants there was much reflection on the joy of parenting their child with catastrophic epilepsy. The participants also spoke at length about sorrow and loss. Many had been employed prior to their child's diagnosis and had therefore experienced a loss of job or career and income. They spoke about the loss of a typically developing child. The study participants expressed feelings of isolation, fear, and anxiety when providing insight into caring for their child. The participants spoke at length about the lack of education and awareness about epilepsy they had experienced with family, friends, and especially with healthcare providers. Family and friends of the participants served as a source of support but they could also cause distress and anger for the study participants in regards to caring for their child with catastrophic epilepsy.

Participants described several coping mechanisms. Several of the mothers spoke about cycling through joy, sorrow, and acceptance. The reality of their situation was expressed as neither a positive or negative, but simply reality. Many of the participants found that educating

themselves or researching about their child's condition was a source of comfort. Several found peace in their faith. They saw themselves as a "leading force" in the lives of their children and getting their children needed care and took a leadership role in determining who they informed about the ongoing status of their child.

The study participants were all eager to participate in the interviews and the photoelicitation process. The findings from this study reflected how catastrophic epilepsy significantly compounded the issues associated with caring for a child affected by a form of epilepsy that resulted in profound intellectual and developmental disabilities. Insight and understanding gleaned from maternal perspectives captured during the interviews can enable health educators and healthcare providers to better understand and thus offer greater and more effective support to parents of children with severe disabilities in general and with catastrophic epilepsy in particular.

## **Chapter 5: Discussion, Conclusions, and Implications**

Epilepsy is the most common neurological condition that affects children worldwide (Ekinci, et al., 2009). This qualitative study focused on maternal perceptions about life with their child who was affected by a catastrophic form of epilepsy. Catastrophic epilepsy is characterized by frequent, difficult-to-control seizures, and intellectual disabilities (Shields, 2000), other developmental deficits, and a poor prognosis. As a neurological condition, epilepsy can have a profound effect on those who experience it, but its impact can be particularly devastating to children who experience a catastrophic form of the condition and the families who care for them. In this phenomenological study, the researcher sought to gain insight into the lived experience of mothers providing care for their child living with catastrophic epilepsy and the meaning they as parents derived from the experience.

Throughout history, epilepsy has been a condition that has provoked stigma and fear. Misconceptions about epilepsy persist (Austin et al., 2002) as does economic and quality of life issues.

This study presents a hermeneutic phenomenological qualitative inquiry into the perceptions of mothers whose child lived with a severe but underexplored type of epilepsy. Hermeneutic phenomenology was appropriate for this study since the researcher sought to gain “a deeper understanding of the nature or meaning of [...] of everyday experience” (van Manen, 1990, p. 9) that was, in the case of this study, parenting children affected by a catastrophic form of epilepsy. In this phenomenological study the researcher aimed to transform the lived experiences expressed by parents during in-depth, open-ended interviews into a textual understanding of the condition and the experience of parenting a child with the condition, ultimately to discover “the essence of the experience” (van Manen, 1990, p.10).

The researcher's involvement in parenting her own child with catastrophic epilepsy provided her with a deep awareness and inclusive view of what it meant to parent a child with this condition and assisted her in relating to, building rapport, and interacting with study participants. It provided a sense of camaraderie that she believed added to the openness and depth of insight divulged by study participants during the interview process. The researcher's personal experience with the phenomenon on which this study was focused also served as a starting point for the study in which she described her own parenting experience with her child with catastrophic epilepsy (van Manen, 1990) and then as an impetus for her to actively engage in reflection and reflexivity throughout the study by maintaining a researcher's journal for that purpose (Patton, 2002).

Purposive sampling, including snowball sampling, yielded five participants with direct life experience with parenting a child with catastrophic epilepsy. Participants voluntarily and willingly consented to be interviewed by the researcher twice within a two-week period for at least one and one-half hours each time. Included in the study were parents who were actively involved in and primarily responsible for caring for a child diagnosed with catastrophic epilepsy. Excluded from the study were parents of children with a benign form of epilepsy or those who served as episodic caretakers of similarly affected children.

The researcher conducted two open-ended, in-depth interviews using a hermeneutic style (van Manen, 1990) with each of five participants after they willingly provided informed consent. The first in-depth interview consisted of open-ended questions focused on eliciting participants' experiences and perceptions about parenting their child with catastrophic epilepsy. The second interview used a photoelicitation process to further elicit participants' perceptions, experiences, and meaning about parenting their child. Both interviews were audio recorded with participants'

permission and the researcher took hand written jotted notes that she later expanded after each interview concluded.

The researcher transcribed the interviews verbatim and repeatedly read the transcripts associated with each interview. She analyzed the transcripts by developing and using a codebook to code the narrative, sorted and retrieved similarly coded narrative segments, read the segments repeatedly, identified categories within and across the segments, and documented themes that eventually emerged from the data. She recorded analysis and interpretation memos throughout the data analysis process that began at the onset of data collection.

In terms of study credibility, the researcher implemented several recognized design strategies (Creswell 2007; Patton, 2002). These strategies included purposive sampling, triangulating data types and sources, maintaining an audit trail, inviting participants to engage in member-checks, and ensuring methodological congruence.

## **Discussion of Findings**

The findings for the study were derived from two separate interviews with each of five participants who were the biological mothers of a child between the ages of two and ten years diagnosed with catastrophic epilepsy of different etiologies. Findings from this study will be discussed in context of the themes that emerged from the study and the current literature regarding catastrophic epilepsy.

### **Parenting as a committed, seizure-centered life.**

Study participants' children experienced profound intellectual disabilities and disabilities that required significant attention, monitoring, and care. It was their children's seizure activity, however, that presented an overriding concern for them and led them to what might be called a seizure-centered life (Granata, 2011). Catastrophic forms of epilepsy are characterized by



frequent, unpredictable, severe, intractable, potentially life-threatening, and certainly life-affecting seizures (Farnalls & Rennick, 2003; Shields, 2000; Shorvon, 2011b). Of necessity, the study participants' centered their lives on their child's seizure activity since such activity affected all aspects of the child's wellbeing. They experienced the anticipation of and actual seizure activity in their children as a source of considerable stress. Consistent with parental perceptions revealed in other studies, the participants in this study spoke at great length about the constant fear, anguish, anxiety, helplessness, and need for vigilance associated with their child's often-daily uncontrolled seizures.

The need for caregiver vigilance has been documented in other studies that explored epilepsy in general and pediatric catastrophic epilepsy in particular. As Beleza (2009) observed, since epilepsy is an unpredictable condition with seizures occurring at unpredictable times, caregivers must stay aware of and react to each situation as it arises. A retrospective analysis of clinical data and neuropsychological testing on 33 infants with epilepsy that assessed the impact of the condition confirmed that monitoring the child is continual and ongoing for a variety of reasons including the child's safety, the effects of new medication, and seizure activity (Vendrame, et al., 2009).

### **A Child with Catastrophic Epilepsy: “Waiting for the Other Shoe to Drop”**

The participant's children required continuous vigilance by the study participant parents for the aforementioned reasons, but particularly for seizure activity. Once a seizure began, the participant monitored it and the child since they recognized that any seizure their child experienced could be life threatening. In the case of prolonged or severe seizure activity when the potential for lethality increased, participants administered emergency medication to try to

stop the seizure or, when the medication was ineffective, called for emergency assistance that sometimes required the institution of a medication-induced coma.

The stress associated with seizures that was voiced by participants in this study was also echoed by Granata (2011) and participants in a study conducted by Dean (2011). Dean's exploration of parental concerns for children with uncontrollable seizures revealed that a high frequency of seizures in children resulted in high parental stress levels and continuous disruptions in daily routines. As Dean suggested, "Parents of children with intractable epilepsy live in a state of continuous anxiety, knowing that another seizure will occur but not knowing when" (2011, p. 210).

Moreover, similar to the caregivers of children with intractable epilepsy in other studies (Cushner-Weinstein, et al., 2008; Dean, 2011; Nolon et al., 2006; Wirrell, et al., 2007), participants in the current study found the duration of seizure activity a particularly difficult and frightening concern. They were acutely aware of the association between uncontrolled seizure activity and negative cognitive and other developmental outcomes (Shields, 2000). This was particularly true for several participants in the current study who had observed firsthand the developmental deficits that occurred in their own children as a consequence of even a single severe or prolonged seizure.

### **Mobilizing Resources: A Constant Preoccupation and Effort**

Living with catastrophic epilepsy is expensive. Participants in this study recognized the need to mobilize a diversity of resources to care for their child and were challenged by the expense of caregiving for a child with epilepsy and accompanying severe disabilities. They were grateful for the sources of external support available to their children including palliative care, state-supported programs, and health insurance, though they found it both daunting and taxing to

qualify for, organize, and work with the various organizations and agencies associated with such resources.

Several previous studies affirmed the need for substantial resources in caring for a child with debilitating epilepsy. Findings from a survey of 100 caregivers of individuals with epilepsy, for example, confirmed the multiplicity of resources needed to address the complexity of epilepsy (Westphal-Guitti, et al., 2007). A sample of 339 mothers who were recruited to examine the impact of health-related quality of life in children with epilepsy highlighted the need for resources not only to care for the affected child, but also to meet family needs (Ferro, et al., 2011).

People of any age living with epilepsy experience increased direct and indirect health care costs, but this is especially true for children with catastrophic epilepsy. As might be expected, a controlled national study revealed that children with epilepsy had a comparatively increased use of health care providers and medication (Jennum et al., 2011), thus increasing the epilepsy-associated expenses within this population. In another study, Dean (2011) noted that the cost of medications and frequent health insurance co-payments posed a financial stress for families with children living with uncontrollable seizures.

### **Providing Daily Care: An Often Overwhelming Responsibility**

According to the findings associated with the current study, the daily all-encompassing care that participants provided for their affected children was around-the-clock, without respite, exhausting, frustrating, purposeful, satisfying and viewed by participants as often overwhelming. Consistent with the extensive care required by chronically ill children in general, the participants perceived it necessary to remain at home (Hatzmann, et al., 2008) to organize, oversee, and

provide such care. Care provision for their affected child, particularly those whose children had limited or no mobility, affected the quality of life and physical health of the study participants.

A recent review of pediatric epileptology confirmed the devastation of childhood epilepsy (Sahin, et al., 2011) and affirmed the extensive care required by children with special needs such as catastrophic epilepsy (Buelow et al., 2006; Cushner-Weinstein, et al., 2008; Dean, 2011; Farnalls & Rennick; Ferro, et al., 2011; Kraft & Kraft, 1998; Rodenberg et al., 2007; Wirrell et al., 2008). Twenty parents of children with epilepsy and intellectual disabilities, for instance, participated in qualitative interviews that explored the sources of stress and psychosocial care needs of parents of children with both epilepsy and intellectual disabilities. This study confirmed the extensive care involved in meeting the daily needs of a child who has both epilepsy and intellectual disabilities (Buelow, et. al., 2006) particularly since, according to a study by Mohammed (2006) and affirmed by participants in the current study, children with intractable epilepsy were perceived by their mothers to be less adaptive and more demanding.

For the participants in this study, childhood epilepsy involved a commitment to extensive care, treatment, and therapy for multiple serious intellectual and physical issues in addition to the seizures experienced by the child. Striving to manage the seizures alone was challenging for participant caregivers. The seizure treatment they described included not only the administration of daily and emergency medication, but also in some cases, planning and providing special dietary interventions or engaging in emergency procedures, each of which required a significant level of ongoing commitment on the part of the parent.

The administration of daily and emergency medication exemplified participants' level of commitment to their child and her or his care. Several of the participants' children took more than one antiepileptic medication that participants administered several times a day. They

explained that providing medication involved more than administering each drug according to the prescribed dosage, route, and schedule, and monitoring the child for evidence of efficacy, side effects, mood changes, or issues that impacted absorption such as vomiting or swallowing problems. It also entailed having the child evaluated by a health care provider to obtain a prescription or adjust dosage, pharmacy visits to obtain the medication, monitoring and maintaining a home supply of the medication, dealing with insurance companies and health care providers to arrange for insurance coverage, and making budgetary adjustments and expenditures for insurance co-payments. The study participants explained the challenges of introducing a new medication in terms of a heightened need to observe the child for side effects and monitor the child for evidence of efficacy, including its impact on seizure activity.

A cross-sectional study of sixty-five parents of who completed a parenting stress index, child depression inventory, and behavior and demographics form confirmed the extensive care involved in adjusting medications and monitoring seizure activity (Cushner-Weinstein, et al., 2008) similar to that described by the current study participants. A prior study involving in-depth interviews with 22 participants explored the experiences of parents with children who received a new treatment for severe intractable epilepsy. They described seizure monitoring and treatment in terms of a need to “stay on top of things” and “balance hope with realism” (Farnalls & Rennick, 2003, p. 4).

Several participants in this study described an additional daily care activity as the endless and often seemingly elusive task of helping their child achieve what participants perceived to be a state of contentment. Alterations in the child’s mood could occur for various reasons each day such as different medication, seizure activity, or environmental changes. In order to help their

child attain a sense of calm and contentment, participants described seeking ways to entertain or soothe their child.

Each study participant described planning and organizing their child's care as essential, time consuming, exhausting. Their efforts were inclusive of a continuing need to research and understand a complex neurological diagnosis and prognosis, the various treatment options available, and treatment options and side effects, including side effects from medication currently administered to their child.

Not only did participants have to work with meeting their child's immediate needs, they also had to consider and plan for their child's future needs. Participants in the current study devoted significant time and energy to the process of information seeking regarding their child's condition in an effort to stay abreast of the current knowledge and engage in planning for the future. They explored treatment alternatives by researching issues and options on the Internet, talking to and advocating for their child with healthcare providers; maintaining relationships with other families going through similar circumstances; and planning and scheduling appointments with countless specialists, evaluations, therapies, and clinics.

Although the care required by a child with epilepsy in general and catastrophic epilepsy in particular has been documented to a limited degree in the existing literature, the findings that emerged from the interviews with the participants in this study contributed a complex, holistic view of care and the everyday challenges faced by mothers who provided such care. The participants offered their rich descriptions of caring for a child with catastrophic epilepsy and extended the recognized scope of care to include their investment in the here-to-fore unrecognized parental preoccupation with and efforts related to mobilizing resources. Such mobilization involved the processes of organizing, planning, scheduling, transporting,

documenting, and researching in an effort to address their child's immediate and anticipated needs.

The participants in the study scheduled, transported, remained attentive to, and were educated about each of their child's various daily therapies. Like parents of children with disabilities who participated in early intervention programs (Leiter, 2004), participants in the current study worked actively and hands-on with their children to implement a wide range of therapy recommendations in order to ensure as much developmental support as possible and to prevent regression of the even small improvements their child had made. Consistent with the findings of a survey of 114 parents that analyzed the efficacy of services for their disabled children, participants in this study wanted to be involved in their child's therapy and their children were involved in many types of therapies (Case, 2000). In addition to various therapies, several studies have described how children with chronic conditions were exposed to many testing procedures and specialists (Beleza, 2009; Farnalls & Rennick, 2003; Jennum, et al., 2011; Sahin, et al., 2011). The parents of children with catastrophic epilepsy in this study also reported repeated testing undergone by their children. The multifaceted, multidisciplinary care provision that involved parents as key providers of therapies for their children characterized the participants in this study.

### **Effects of Care on Caregiving Parents: "Confined to a Helpless Situation"**

Several studies have addressed the losses incurred by parents of children with chronic, life-altering conditions (Buelow, et. al., 2006; Cushner-Weinstein, et al., 2008; Farnalls, S. & Rennick, J. 2003; Kraft, S. & Kraft, L., 1998; Westphal-Guitti, et al., 2007). As documented in parents of children with Dravet syndrome, a type of catastrophic epilepsy (Granata, 2011), the participants in the current study grieved the loss of the dreams and aspirations they held for their

child before the onset of symptoms that would eventually result in a diagnosis of catastrophic epilepsy. The participants also spoke about losses related to themselves, such as a loss of their personal goals, careers, freedom, spontaneity, and social interactions. Their child's seizures or mood changes often prevented them and their families from attending social engagements or addressing routine family needs. Participants tended to become increasingly isolated.

The isolation experienced by study participants and described in previous research (Hatzmann, et al., 2008; Wirrell, et al., 2007) could result from such issues as their general state of physical and emotional exhaustion, feelings of sorrow that could contribute to the exhaustion, their child's lack of adaptability to different environments and consequent parental and family confinement to the home, lack of employment for the parent caregiver, and feelings of being alone and confined to a helpless situation. Importantly, support from family and friends varied, with some individuals opting out of assisting with childcare due to their discomfort in caring for a child with seizures and complex needs.

In addition to countless personal concerns, it was the future that weighed heavily on participants' minds. The study participants expressed a range of emotions when discussing their child and her or his future. The duality of emotions they expressed during the interviews included joy, love, optimism, and gratitude, as well as exhaustion, sadness, sorrow, loss, isolation, and fear. Several of them expressed that it was frightening to think about the future, due to the unknown life expectancy of their child or wondering how their child would be cared for if they as parents and primary caregivers were no longer alive.

In reflecting on their personal experiences of parenting a child with intractable seizures and consequent profound intellectual disabilities, Kraft and Kraft (1998) related feelings of grief and sorrow that they contended reflected Olshansky's (1966) concept of chronic sorrow. Clearly



representing the experiences of participants' in the current study, Kraft and Kraft described Olshansky's view of chronic sorrow as:

Long-lasting sadness that accompanies the diagnosis of retardation that can be attributed to the permanence of the child's disability, fear for the child's future, the child's continued dependency on the parents, and the extraordinary stress and demands of the caregiving role. (Kraft & Kraft, 1998, p. 60)

While experiencing persistent sadness reflective of chronic sorrow and the relentless demands of care provision, participants also celebrated the great joy that their child brought into their lives and the positive influence their child had in shaping them as a person. The participants relayed that they had gained a deeper understanding of others going through life's trials and could more readily reach out to others going through difficult situations. Parenting a child with catastrophic epilepsy provided them with a sense of purpose in their lives and they were proud, grateful, and joyful about having their child in their lives.

As Kearney and Griffin suggest, the literature does not often give credence to expressions of joy by parents caring for severely impaired children. Their phenomenological study of six parents of children with disabilities revealed parental sorrow but also, like the participants in the current study, the parents "emphasize [d] their experience as being positive [...] and spoke of them [their children] with admiration, love and optimism. [...] It was clear that their children were a source of joy" (Kearney & Griffin, 2001, p. 586).

A marriage can be a support system or fail due to the intensity of the situation. A previous study addressed how family and friends can impact caregivers (Ferro, et al., 2011). The public reaction to a child with catastrophic epilepsy may be to look away, stare, smile or engage the parent in a conversation with concern for the child. A previous study addressed how disabled

children attract attention in public places mainly in the form of staring at affected children (Case, 2000).

### **Caregiver Coping: “Celebrating the Child While Mourning the Losses”**

Some study participants adopted the simple notion of providing care for their affected child as, “It is what it is.” They recognized the reality of having little control over the child’s condition. Their reality of parenting a child with catastrophic epilepsy, particularly a child who was immobile, was that it could be physically and emotionally demanding and challenging and lead to chronic ongoing physical and emotional issues for the caregiver. For the participants in the current study, the problem of such issues was compounded by the reality of exhaustion that arose in response to many issues, including the child’s own insomnia due to medication or neurological condition. The demanding schedule of parental caregiving and lack of sleep has been noted in the literature related to children with intractable epilepsy (Ganata, 2011; Kraft & Kraft, 1998).

Coping skills come in a variety of forms for parents of children with catastrophic epilepsy. Like participants in other studies of parenting children with intractable seizures (Buelow, et al., 2006; Wirrell, et al., 2008), the study participants discussed their own investment in learning about their child’s condition as a means of coping with the condition. A qualitative study involving interviews with twenty-seven parents of chronically ill children also found that seeking an understanding of their child’s condition served as a positive coping strategy for them (Hummelinck & Pollock, 2006).

Social media has made it easier for parents to communicate with an increased number of parents experiencing similar situations. Networking with other families going through similar circumstances was a coping strategy for all of the participants in this study. Seeking out support

by means of social media, family, or friends was presented in several previous studies (Buelow, et. al., 2006; Dean, 2011; Ferro, et al., 2011; Rodenburg, et al., 2007; Wirrell, et al., 2008) as an important strategy in coping with epilepsy.

The development of coping strategies for parents of children with epilepsy has been addressed in previous studies (Cushner-Weinstein, et al., 2008; Rodenburg, et al., 2007). Parents can acquire internal coping strategies that can include striving to maintain a positive outlook on their situation. The findings associated with the current study included participants' identification of the internal coping strategy taking full responsibility and of serving as an advocate and "leading force" in the child's life. They accomplished this with the understanding that, as the parent, they could not control their child's seizures or the condition, but could control of some aspects of their child's life. They learned to take charge of those aspects that were within their control.

## **Conclusion**

Catastrophic epilepsy begins in children under the age of five and typically evolves into a continuing struggle with uncontrolled seizures and global disabilities during the child's often shortened life. The prognosis is poor. The child's caregiver cares for a child who typically has profound developmental disabilities. Participants' perceptions of the intensive care required by children with catastrophic epilepsy are presented in this study.

Epilepsy is an unpredictable condition that leaves the parent and child at the mercy of its unpredictability. The condition controls the daily activities for many children and their families. This study explored and described maternal experiences and perceptions of living with and witnessing their beloved child struggle daily with the effects of this devastating condition. The

essence of parenting was, for the participants in this study, one of commitment to a beloved child in a seizure-centered life.

Concerns about the symptoms that ultimately prove to be catastrophic epilepsy tend to be initiated by the parent or pediatrician early in the child's life. Developmental disabilities are evaluated and extensive therapies begun. Referrals to countless specialists address the issues that stem what becomes diagnosed as a catastrophic form of epilepsy. Issues of feeding and attempting to administer daily medication arise, often leading to gastrostomy placement to ensure adequate nutrition and intake of medication. Seizure-related global disabilities affect the physical and cognitive development of the child, leaving the children immobile and with profound intellectual disabilities. Lack of speech and other means of communication can lead to frustration and behavioral issues with the child. Behavioral issues in the child can also stem from effects of her or his neurological condition as well as medications that are administered in an effort to reduce seizure activity. A lack of mobility adds an extra burden for caregivers in lifting and carrying the child and continually repositioning the child. Limited or lack of mobility and other problems affect many of the child's body systems. For example, the child might experience impaired gastrointestinal tract function and thus have issues with bowel movements. Seizure activity and intellectual disabilities require that the child be constantly monitored. Prolonged seizures require the administration of emergency medication and the child's intellectual disability requires monitoring to insure the child's safety. The child requires continuous and complete care every day to meet her or his complex needs. In the case of this study, the study participants served as the primary providers of that care.

Parenting a child with catastrophic epilepsy necessitates that numerous decisions be made. Parents are constantly weighing the benefits and risks of new seizure medications, many

of which had not yet been tested on children. There were decisions about starting a diet that may decrease seizures and committing to the use of a strict and complicated diet that could have negative as well as positive effects on the child. Parents made difficult decisions about surgical options some of which were invasive procedures performed on the child's brain in an effort to reduce or control seizures. The parents make decisions about specialists, therapies and educational opportunities for their child. They were constantly on the phone or on the go to an appointment on behalf of their child. They often sought government assistance due to their child's extensive medical needs and to enable their child to receive care in the home when possible. The tasks of parenting a child with catastrophic epilepsy greatly overshadowed those of caring for a typically developing child.

The endless care and planning for their children left the parents in this study exhausted and overwhelmed, facing what they experienced as being "confined in a helpless situation." The daily, unpredictable seizures suffered by their child resulted in them as parents being on edge and constantly vigilant, while "waiting for the next shoe to drop" in anticipation of the next seizure or alteration in their child's mood or a behavioral outburst.

Study participants experienced the dichotomy of demanding yet rewarding caregiving experiences and the duality of sorrow and joy in how they viewed their child. They found joy in small developmental gains and purpose in serving as the child's "leading force" and advocate, despite the isolation, fear, sorrow, and losses that they experienced in caring for their child. Coping with the needs of a child with catastrophic epilepsy warranted their prioritization of caregiving, often to the detriment of meeting their own needs. For the mothers who participated in this study, parenting a child with catastrophic epilepsy reflected a total commitment to care with no end in sight. It was a life where seizure activity was, of necessity, a central concern and

focus of attention, the essence of their experience was that they were deeply committed to their beloved child in a seizure-centered life.

## **Implications**

### **Implications for health educators and healthcare providers.**

The theory of ambiguous loss (Boss, 2006) provides insight into the findings associated with this study. Boss contends that there are two types of ambiguous loss. One is associated with a physical absence but a psychological presence as illustrated in the case of a missing person, divorce, or immigration (Boss, 2010). The second type of ambiguous loss, one in which the person was physically present but psychologically absent, was reflected by the children of the participants in this study. A child with a catastrophic form of epilepsy is physically present but, due to intellectual disabilities and an inability or extremely limited ability to communicate, psychologically absent to varying degrees. This unique kind of loss complicates both grief and relationships and, in the case of the participants in this study, prevented the parent from coming to closure regarding the loss. The loss experienced by participants was, according to Boss (2010), unclear and traumatic and could serve as a source of much depression, anxiety, and family conflict. In the case of the parents who participated in this study, the losses associated with their child's condition were ongoing. The prognosis for their child was poor; no marked improvement in the child's condition was expected.

An ambiguous loss included a host of losses experienced by parents of children with catastrophic epilepsy. These losses included the loss of a dream to parent a typical child, loss of a career due to the demands of caring for the child, and the isolation-promoting loss of social interaction due to the inability of the child to adapt to new environments. According to Boss

(2006), the losses felt by the parents could be vague and result in an unmoving, unresolved grief process that may be alleviated only by the tangible closure of death.

A study participant described the feeling of having continuing posttraumatic stress disorder as a direct result of parenting her child with a catastrophic form of epilepsy. Ambiguous loss is “traumatic, painful, immobilizing, and incomprehensible” and prohibits effective coping (Boss, 2010, p. 139) with the precipitating situation. Boss described ambiguous loss as similar to the trauma caused by posttraumatic stress disorder and explained that, unlike some cases of posttraumatic stress disorder, ambiguous loss remained present and continued for years or a lifetime.

The desired outcome of ambiguous loss is to support the longevity of the caregiver and create the best scenario for the family. The guidelines Boss presents for ambiguous loss were meant to alleviate the ambiguities associated with the situation and enable adjustment to a life-altering event. Findings from the current study suggested that the study participants implemented some of Boss’s guidelines, but each individual varied in terms of their congruence with or implementation of each of the guidelines. Participants who cared for less severely affected children more closely reflected the guidelines that Boss presented in coping with ambiguous loss. Study findings in the context of the guidelines identified by Boss (2006, 2010) will be discussed below.

As part of the six guidelines for coping with ambiguous loss, the first was to find meaning in what, for these participants, was a difficult situation. Faith and family traditions can be helpful in a search to find meaning (Boss, 2006; Boss, 2010). The study participants found meaning in their difficult situation. Of necessity, the study participants adopted a position of flexibility in the relentless disruptions of daily living caused by seizure activity. They created a

life that was tailored to their child's needs and seizure-centered. They found meaning for themselves in their child's condition in that they expressed that their child had a) given them a purpose in their lives, b) made them a better person and one who was more compassionate and empathetic toward others, and c) committed them to being a "leading force" in their children's lives, including serving as an advocate for their child.

The second guideline for coping with ambiguous loss was to strive to be comfortable with a vague sense of loss (Boss, 2006; Boss, 2010). Some of the participants sought balance in accepting that which could not be controlled and taking charge of that which could be controlled related to their child's condition. They were in the process of creating a balance in their lives and learning to live with a duality of joy as well as sorrow and loss. Each person was at different stages of acceptance of the losses associated with having a child with severe health and developmental issues. Their lack of control of anything related to their child's condition posed issues for the participants, leading to many of them feeling helpless and overwhelmed in the face of catastrophic epilepsy. Thus, the sense of loss they experienced was on going and both chronic and acute.

Boss's (2006; 2010) third guideline was to embrace the role that, in this case, was parenting a child with this condition, and allow the experience to shape the individual into a new person. Evidence of participants' embracing their role was evident in the passion and energy they devoted to mobilizing resources for care on behalf of their children and the advocacy role in which they actively engaged regarding epilepsy awareness and education, particularly for health care professionals. While the participants embraced their child, they would not use the word embrace to describe how they perceived their exhausting, demanding experience as caregivers.



Any experience related to their child beyond care provision was limited for the participants due to their investment of all of their energy into meeting the daily needs of their child.

The fourth guideline offered by Boss (2006, 2010) to cope with ambiguous loss was to normalize feelings of ambivalence. Such normalization was evidenced by study participants in that they were open about the guilt, anger and other negative emotions they felt and had engaged in learning how to deal with emotional ambivalence. The participants expressed sadness, anger, and frustration about their child's excessive seizures, comorbidities as a result of seizures, and their child's global disabilities. They each were at different stages of coping with the feelings of ambivalence that they collectively shared.

The fifth guideline offered by Boss was revising attachment which, in the case of participants in this study, was attachment to their child by "accepting rather than resisting the ambiguity" of the circumstances associated with their losses (Boss, 2010, p. 144). All of the participants may have accomplished some elements of revising attachment by celebrating the child, but continuing to mourn the loss of a typical child in that they accepted and allowed these emotions to surface.

The last guideline in coping with ambiguous loss was discovering hope by understanding that life is comprised of struggles to which people have to continually adapt. This is accompanied by the realization that life can continue in a different way and the realization that resilience exists (Boss, 2006; Boss, 2010). The study participants believed they had no other choice but to adapt to the needs of their child. They all explained the importance of a clear daily schedule as a means of striving for normalcy, despite the fact that it would be disrupted daily with seizure activity and dealing with their child's complex medication and other issues. Their

daily routine may represent an effort to bring order to the disorder and thus served a means of adapting to the on-going seizure activity.

Ambiguous loss is often a “cruel and unending torment” for families who experience such a loss (Betz & Thorngren, 2006). The grief is exhausting and an uncertain future causes families to remain in a constantly responsive state. Families cannot move on and closure is nearly impossible (Boss, 2010; Betz & Thorngren, 2006). Caring for a loved one with a chronic condition can go on for years, with family and friends becoming less involved over time. Family and friends may have a difficult time understanding a loss that is unclear and undefined, which often characterizes a loss that is accompanied by social stigma such as epilepsy (Betz & Thorngren, 2006).

The healthcare community provides care for the children with this devastating condition. It is helpful for health educators and providers to clearly understand parents’ perceptions about parenting a child with a catastrophic form of epilepsy. It is anticipated that such an understanding will enable a potentially higher quality of care and more effective interpersonal interactions since such professionals may be able to be more supportive to the child, parents, and their family. Knowledge of ambiguous loss and the guidelines that Boss provides can aid in creating an understanding of the trauma that some parents of children with catastrophic epilepsy may experience. The theory of ambiguous loss also may be utilized to provide suggested coping guidelines to parents and healthcare providers.

The participants expressed disappointment and sometimes anger about the lack of epilepsy education and awareness evidenced in health care and other professionals. The lack of awareness and public support resonated in previous studies (Fernandes, et al., 2011; de Boer, et al., 2008). Participants in this study believed that people did not understand that, in the case of

their children, epilepsy was impossible to control, devastating to both child and parent, and potentially deadly. These findings were supported in the de Boer study that involved narratives of fourteen individuals with epilepsy.

The implications of these study findings for health educators and healthcare providers include the need for such professionals to be knowledgeable about epilepsy, aware of the issues and challenges that the participants in this study have articulated, and mindful of a need for empathy and support for caregivers when working with pediatric populations affected by epilepsy. A need exists for health educators and health care providers to learn about epilepsy and its many forms since epilepsy is the most common neurological problem in children. They particularly need to learn about catastrophic epilepsy and how it affects children and their parental caregivers. Healthcare educators and other professionals must understand that children with catastrophic epilepsy have seizures that are not only frequent and unable to be controlled, but are also developmentally detrimental and life threatening. Many of these children's parents are committed to and love their children and live a seizure-centered life. These children require constant, complete care, including constant seizure monitoring and treatment. The child's condition tends to not improve over time; parental goals are nevertheless focused on whatever improvement is possible and on striving for the often-elusive goal of contentment. Ultimately, they want to help their child simply be content.

In terms of interacting with children with catastrophic epilepsy who are typically non-communicative, healthcare professionals need to verbally acknowledge and recognize the child as an individual. They must use care in communicating sensitive information in front of the child since it is unknown what the child might be able to understand. The parents of children with catastrophic epilepsy not only need health educators and other professionals to extend

empathy and support, they also need to be regarded as knowledgeable collaborators in their child's care and the "leading force" in the child's life.

Children with epilepsy have higher rates of contact with all sectors of health care and have a higher rate of medication use (Jennum et al., 2011). The study participants explained that they had to call their pediatrician, neurologist, gastroenterologist, or other healthcare professional frequently and repeatedly about concerns they had regarding their child. They expressed concerns about being judged and discredited by health-related professionals due to the numerous calls they made to their healthcare providers on behalf of their child. As Sharon described, she doesn't want to be labeled "that mom" who frequently called about issues with her child, but at the same time her child and the other participants children had extensive medical issues that needed to be addressed and for which parent caregivers needed informed guidance and support.

Another side of this issue is the overloaded healthcare system whose professionals care for both typical children as well as children with special needs. At the time of this study, single pediatric medical practices attempted to address the full range of children's health issues, including the many complex health issues experienced by children with catastrophic epilepsy. The findings from this study underscores that children with debilitating forms of epilepsy have unique, frequent, and sometimes emergency needs that require oversight by knowledgeable, empathetic, and supportive health care professionals. Such professionals must effectively address the acute and chronic needs of these children and do so in a timely way, ideally using a collaborative approach with parent caregivers. The magnitude of need within this particular patient population may exceed the already overstretched capabilities of the health care providers who strive to serve them.

The level and kinds of acute and chronic needs experienced by these children and chronicled in this study suggest a need to explore alternative forms of health care provision for them.

Consideration of a more supportive, palliative care approach for all such affected children, for example, is warranted given the kinds of issues faced by these children, their parental caregivers, and the health care providers who serve them.

### **Implication for future research.**

Further research is needed explore the healthcare options for children with catastrophic epilepsy, given an overloaded health care system and existing barriers to effectively addressing the great health needs of children with severe, chronic conditions. A study is needed to further explore alternative care options such as palliative care for all children with catastrophic forms of epilepsy

The findings from the current study leaves little doubt about the enormous impact that devastating children's health conditions such as catastrophic epilepsy has on parents who serve as primary caregivers for these children. The need for support that is tailored to the context of these parents' lives is evident. Although participants in this study engaged in occasional support group meetings, used social networking sites to connect with one another, and turned to family and friends for support, further research might more pointedly address their potential need for additional or different support that they would find helpful. A different means of support might, for example, come in the form of webinars, since it is difficult for parents to find childcare for special needs children who have unpredictable seizures to attend support group meetings.

An additional research need is to explore ways to facilitate the physical and mental well being of parents immersed in a caregiving role for their child. Time for much needed self-care

such as physical exercise or the pursuit of personal interests, for example, seems to be an outstanding need for many such parents.

### **Dissemination of Findings**

The researcher will provide the final copy of the completed study to the study participants. She will submit at least one manuscript to a refereed professional journal for consideration for publication in order to disseminate findings to health educators and health care professionals. In addition, the researcher will write newsletter articles disseminating study findings directly to parents served by the Family Support Network.

### **Summary**

This qualitative hermeneutic phenomenological study explored the maternal perceptions of life with a child affected by catastrophic epilepsy. The researcher's involvement in parenting her own child with catastrophic epilepsy provided her with the interest to bring education and awareness to the phenomenon. The findings of this study were the result of two in-depth, open-ended interviews with five mothers of children with catastrophic epilepsy. A photo elicitation process used as a catalyst for the second interview added more depth to the findings.

The participants described being preoccupied and extending a great deal of effort in mobilizing resources to care for their child. They had to plan and organize extensive care, and the overwhelming responsibility in providing daily care to their child with a catastrophic form of epilepsy. The unpredictable nature of epilepsy resulted in a continuous state of being on alert and "waiting for the other shoe to drop." The participants described joy and love that parenting their child brought to them as well as the grief and loss they felt. The concept of chronic sorrow captured the sadness expressed by participants, including their concerns about the future. The theory of ambiguous loss described the loss experienced by parents whose child was physically

present but psychologically absent, leaving them with an inability to attain closure in experiencing loss related to their child with a debilitating form of epilepsy. These parents felt, in the words of one mother, “confined in a helpless situation.” They coped with their difficult situation by celebrating their child while mourning the losses they experienced. The essence of the findings for the mothers who participated in this study was that of commitment to a beloved child in the context of a seizure-centered life.

## References

- Acevedo, C. (2011). ILAE gray matters workshop report a century of achievements. *Epilepsia*, 52(5), 1025-1026.
- Andermann, F. (2011). ILAE gray matters workshop report a century of achievements. *Epilepsia*, 52(5), 1027-1028.
- Austin, J., Shafer, P., & Deering, J. (2002). Epilepsy familiarity, knowledge, and perceptions of stigma: Report from a survey of adolescents in the general population. *Epilepsy & Behavior*, 3(4), 368-375.
- Avanzini, G. (2011). ILAE gray matters workshop report a century of achievements. *Epilepsia*, 52(5), 1028.
- Beckung, E. (2000). Development and validation of a measure of motor and sensory function in children with epilepsy. *Pediatric Physical Therapy*, 12(1), 24-35.
- Beleza, P. (2009). Refractory epilepsy: A clinically oriented review. *European Neurology*, 62(2), 65-71.
- Berg, E. (2011). Epilepsy, cognition, and behavior: The clinical picture. *Epilepsia*, 52(s1), 7-12.
- Betz, G., & Thorngren, J. (2006). Ambiguous loss and the family grieving process. *The Family Journal*, 14 (4), 359-365.
- Birks, M., Chapman, Y., & Francis, K. (2008). Memoing in qualitative research. *Journal of Research in Nursing*, 13(1), 68-75.
- Bishop, E., & Shepard, M. (2011). Ethical reflections: Examining reflexivity through the narrative paradigm. *Qualitative Health Research*, 21(9), 1283-1294.
- Boss, P. (2006). *Loss, trauma and resilience: Therapeutic work with ambiguous loss*. W.W. Norton & Company.
- Boss, P. (2010). The trauma and complicated grief of ambiguous loss. *Pastoral Psychology*, 59 (2), 137-145.
- Bradbury-Jones, C., Irvine, F., & Sambrook, S. (2010). Phenomenology and participant feedback: Convention or contention? *Nurse Researcher*, 17(2), 25-33.



- Brooks-Kayal, A. (2011). Molecular mechanisms of cognitive and behavioral comorbidities of epilepsy in children. *Epilepsia*, 52(s1), 13-20.
- Buelow, J., McNelis, A., Shore, C., & Austin, J. (2006). Stressors of parents of children with epilepsy and intellectual disability. *Journal of Neuroscience Nursing*, 38(3), 147-154.
- Camfield, P., & Camfield, C. (2011). Transition to adult care for children with chronic neurological disorder. *ANNALS of Neurology*, 69(3), 437-444.
- Case, S. (2000). Refocusing on the parent: what are the social issues of concern for parents of disabled children? *Disability & Society*, 15(2), 271-292.
- Clayton-Smith, J. (2010). Angleman Syndrome. *Journal of Pediatric Neurology*, 8(1), 97-99.
- Close, H. (2007). The use of photography as a qualitative research tool. *Nurse Researcher*, 15(1), 27-36.
- Creswell, J. (2007). *Qualitative Inquiry and Research Design: Choosing from Among Five Approaches*. Thousand Oaks, CA: SAGE.
- Cushner-Weinstein, S., Dassoulas, K., Salpekar, J., Henderson, S., Pearl, P., Gaillard, W., & Weinstein, S. (2008). Parenting stress and childhood epilepsy: The impact of depression, learning, and seizure- related factors. *Epilepsy & Behavior*, 13(1), 109-114.
- Dean, P. (2011). Counseling of parents of a child with uncontrollable seizures. *Seminars in Pediatric Neurology*, 18(3), 209-212.
- de Boer, H., Mula, M., & Sander, J. (2008). The global burden and stigma of epilepsy. *Epilepsy & Behavior*, 12(4), 540-546.
- de Boer, H. (2010). Epilepsy stigma: Moving from a global problem to a global solution. *Seizure*, 19(10), 630-636.
- DHHS. (2010). *Community Alternative Program for Children Parent Handbook*. North Carolina Department of Health and Human Services: North Carolina Medicaid.
- Dowling, M. (2004). Hermeneutics: An exploration. *Nurse Researcher*, 11(4), 30-39.

- Ekinci, O., Titus, J., Rodopman, A., Berkem, M., & Travathan, E. (2009). Depression and anxiety in children and adolescents with epilepsy: Prevalence, risk factors, and treatment. *Epilepsy & Behavior, 14*(1), 8-18.
- Farnalls, S., & Rennick, J. (2003). Parents' caregiving approaches: facing a new treatment alternative in severe intractable childhood epilepsy. *Seizure, 12*(1), 1-10.
- Fernandes, P., Snape, D., Beran, R., & Jacoby, A. (2011). Epilepsy stigma: What do we know and where next? *Epilepsy & Behavior, 22*(1), 55-62.
- Ferro, M., Avison, W., Campbell, K., & Speechley, K. (2011). Prevalence and trajectories of depressive symptoms in mothers of children with newly diagnosed epilepsy. *Epilepsia, 52*(2), 326-336.
- Fisher, R., & Leppik, I. (2008). Debate: When does a seizure imply epilepsy? *Epilepsia, 49*(s9), 7-12.
- Good, W. (2009). Cortical visual impairment: New directions. *Optometry and Vision Science, 86*(6), 663-665.
- Granata, T. (2011). Comprehensive care of children with Dravet syndrome. *Epilepsia, 52*(2), 90-94.
- Green, S. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with a disability. *Social Science & Medicine, 64*(1), 150-163.
- Hatzmann, J., Heymans, H., Ferrer-i-Carbonell, A., van Praag, B. & Grootenhuis, M. (2008). Hidden consequences of success in pediatrics: Maternal health-related quality of life-results from the care project. *Pediatrics, 122*(5), 1030-1038.
- Hummelinck, A., & Pollock, K. (2006). Parents' information needs about the treatment of their chronically ill child: A qualitative study. *Patient Education and Counseling 62*(2), 228-234.
- Jackson, R., Drummond, D., & Camara, S. (2007). What is qualitative research? *Qualitative Research Reports in Communication, 8*(1), 21-28.
- Jacoby, A., Gorry, J., & Baker, G. (2005). Employers' attitudes to employment of people with epilepsy: Still the same old story. *Epilepsia, 46*(12), 1978-1987.

- Jennum, P., Gyllenberg, J., & Kjellberg, J. (2011). The social and economic consequences of epilepsy: A controlled national study. *Epilepsia*, 52(5), 949-956.
- Johns, P., & Thorn, M. (2008). Epilepsy and hippocampal sclerosis: Cause or effect? *Advances in Clinical Neuroscience and Rehabilitation*, 8(5), 16-18.
- Kraft, S., & Kraft, L. (1998). Chronic sorrow: Parents' lived experience. *Holistic Nursing Practice*, 13(1), 59-67.
- Kearney, P., & Griffin, T. (2001). Between joy and sorrow: being a parent of a child with developmental disability. *Journal of Advanced Nursing*, 34(5), 582-592.
- Kurth, T., Lewis, B., & Walker, A. (2010). Health care resource utilization in patients with active epilepsy. *Epilepsia*, 51(5), 874-882.
- Lee, P. (2011). ILAE gray matters workshop report a century of achievements. *Epilepsia*, 52(5), 1026-1027.
- Leiter, V. 2004. Dilemmas in sharing care: maternal provision of professionally driven therapy for children with disabilities. *Social Science & Medicine*, 58(4), 837-849.
- Magiorkinis, E., Sidiropoulous, K., & Diamantis, A. (2010). Hallmarks in the history of epilepsy: Epilepsy in antiquity. *Epilepsy & Behavior*, 17(1), 103-108.
- Magilvy, J., & Thomas, E. (2009). The first qualitative project: Qualitative descriptive design for novice researchers. *Journal for Specialists in Pediatric Nursing*, 14(4), 298-300.
- Meyer, S., Shamdeen, M., Gottschling, S., Strittmatter, M., & Gortner, L. (2011). Sudden unexpected death of epilepsy in children. *Journal of Paediatrics and Child Health*, 47(6), 326-331.
- Milroy, C. (2011). Sudden unexpected death in epilepsy in childhood. *Forensic Science, Medicine and Pathology*, 7(4), 336-340.
- Mitchell, W., & Irvine, A. (2008). I'm okay, you're okay?: Reflections on the well being and ethical requirements of researchers and research participants in conducting qualitative fieldwork interviews. *International Journal of Qualitative Methods*, 7(4), 31-44.
- Mohammed, J. (2006). Intractable childhood epilepsy and maternal fatigue. *The Canadian Journal of Neurological Sciences*, 33(3), 306-310.

- Nemeth, B. (2011). The diagnosis and management of common childhood orthopedic disorder. *Current Problems of Pediatric and Adolescent Health Care*, 41(1), 2-28.
- Ngugi, A., Bottomley, C., Kleinschmidt, I., Sander, J., & Newton, C. (2010). Estimation of the burden of active lifetime epilepsy: A meta-analytic approach. *Epilepsia*, 51(5), 883-890.
- Olshansky, S. (1966). Parents' responses to a mentally defective child. *Mental Retardation*, 4, 21-23.
- Patton, M. (2002). *Qualitative Research and Evaluation Methods 3<sup>rd</sup> Edition*. Thousand Oaks, California, Sage Publications.
- Peranich, L., Reynolds, K., O'Brien, S., Bosch, J., & Cranfill, T. (2010). The roles of occupational therapy, physical therapy, and speech/language pathology in primary care. *The Journal for Nurse Practitioners*, 6(1), 37-43.
- Pellock, J., Hrachovy, R., Shinnar, S., Baram, T., Bettis, D., Dlugos, D. Gaillard, W., Gibson, P., Holmes, G., Nordli, D., O'Dell, C., Shields, D., Trevathan, E., & Wheless, J. (2010). Infantile Spasms: A U.S. consensus report. *Epilepsia*, 51(10), 2175-2189.
- Rantanen, K., Eriksson, K., & Nieminen, P. (2011). Cognitive impairment in preschool children with epilepsy. *Epilepsia*, 52(8), 1499-1505.
- Riddick-Grisham, S., & Deming, L. (2011). *Pediatric life care planning and case management*, 2 ed. Boca Raton, Florida: CRC Press Taylor & Francis Group.
- Rodenburg, R., Meijer, A., Dekovic, M., & Aldenkamp, A. (2007). Parents of children with enduring epilepsy: Predictors of parenting stress and parenting. *Epilepsy & Behavior*, 11(2); 197-207.
- Sahin, M., Miller, I., Holmes, G., & Sheth, R. (2011). Pediatric epileptology. *Epilepsy & Behavior*, 22(1), 32-37.
- Sheth, R., Binkley, N., & Hermann, B. (2008). Progressive bone deficit in epilepsy. *Neurology*, 70(3), 170-176.
- Shields, D. (2000). Catastrophic epilepsy in childhood. *Epilepsia*, 41(s2), 2-6.
- Shields, D. (2006). Infantile Spasms: Little seizures, BIG consequences. *Epilepsy Current*, 6(3), 63-69.

- Shorvon, S. (2011a). The causes of epilepsy: Changing concepts of etiology of epilepsy over the past 150 years. *Epilepsia*, 52(6), 1033-1044.
- Shorvon, S. (2011b). *The causes of epilepsy common and uncommon causes in adults and children*. New York: Cambridge.
- Smith, M. (2010). Neuropsychology in epilepsy: Children are not small adults. *Epilepsia*, 51(s1), 68-69.
- Thurston, W., Cove, L., & Meadows, L. (2008). Methodological congruence in complex and collaborative mixed method studies. *International Journal of Multiple Research Approaches*, 2(1), 2-14.
- van Manen, M. 1990. *Researching lived experience- Human science for an action sensitive pedagogy*. Albany, NY: State University of New York Press.
- Vendrame, M., Alexopoulos, A., Boyer, K., Gregas, M., Haut, J., & Lineweaver, T. (2009). Longer duration of epilepsy and earlier age at epilepsy onset correlate with impaired cognitive development in infancy. *Epilepsy & Behavior*, 16(3), 431-435.
- Walker, W. (2007). Ethical considerations in phenomenological research. *Nurse Researcher*, 14(3), 36-45.
- Westphal-Guitti, A., Alonso, N., Migliorini, R., da Silva, T., Azevedo, A., & Caboclo, L. (2007). Quality of life and burden in caregivers of patients with epilepsy. *Journal of Neuroscience Nursing*, 39(6), 354-360.
- Williams, K., Jarrar, R., & Buchhalter, J. (2011). Continuous video-EEG monitoring in pediatric intensive care units. *Epilepsia*, 52(6) 1130-1136.
- Wirrell, E., Wood, L., Hamiwka, L., & Sherman, E. (2008). Parenting stress in mothers of children with intractable epilepsy. *Epilepsy & Behavior*, 13(1) 169-173.
- Wolf, Z. (2003). Exploring the audit trail for qualitative investigations. *Nurse Educator*, 28(4), 175-178.

## Appendix A: Advertisement for Study Proposal

**You are receiving this invitation because you are the parent of a child with catastrophic epilepsy. I am also the mother of a child with catastrophic epilepsy and completing my master's thesis. I would like to invite you to participate in my study that explores the perspectives and experiences of parents who have a child affected by this debilitating form of epilepsy.**

**Invitation:** You are invited to participate in two individual interviews that I will conduct for a study about parenting a child with catastrophic epilepsy. Each interview is anticipated to last from 45 to 90 minutes. Your identity will be anonymous and the information that you share will be kept confidential.\*

**When:** The interviews will take place at times that are convenient for you during the months of March and April, 2012.

**Why:** There is limited research on the perceptions of parents and the daily experiences of parenting a child with catastrophic epilepsy.

Upon publication and presentation, shared findings from the study will bring awareness and education to other parents, healthcare providers, educators and other professionals about catastrophic epilepsy.

**Where:** The interviews will be held in a private room at the family support network, or a location of your convenience.

**How:** If you are interested in being a part of this study, please contact **Chastity Case** at 828-275-6526 at your earliest convenience.

## Appendix B: Informed Consent



*East Carolina University*

### **Informed Consent to Participate in Research**

Information to consider before taking part in research that has no more than minimal risk.

Title of Research Study: The physical and emotional effects and the daily experience of parenting a child with catastrophic epilepsy

Principal Investigator: *Chastity Case*

Institution/Department or Division: *East Carolina University/ Health Education Graduate Program*

Address: *36 Old Trull Road, Candler, North Carolina 28715*

Telephone #: *828-275-6526*

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Researchers at East Carolina University (ECU) study problems in society, health problems, environmental problems, behavior problems and the human condition. Our goal is to try to find ways to improve the lives of you and others. To do this, we need the help of volunteers who are willing to take part in research.

#### **Why is this research being done?**

*The purpose of this research is to explore the experiences of parenting a child with catastrophic epilepsy. Epilepsy with intellectual delay is often termed catastrophic epilepsy. The decision to take part in this research is yours to make. By doing this research, we hope to capture and learn from the daily experiences of parenting a child with catastrophic epilepsy.*

#### **Why am I being invited to take part in this research?**

*You are being invited to take part in this research because you are the parent of a child with catastrophic epilepsy. If you volunteer to take part in this research, you will be one of about 4 people to do so.*

#### **Are there reasons I should not take part in this research?**

*I understand I should not volunteer for this study if I am not a parent of a child with catastrophic epilepsy, or under 18 years of age.*

#### **What other choices do I have if I do not take part in this research?**

You can choose not to participate.

#### **Where is the research going to take place and how long will it last?**

*The research procedures will be conducted in a private room at the Family Support Network library in the [...] Children's hospital. You will need to come to the [...] Children's hospital two times during the study. The total amount of time you will be asked to volunteer for this study is two hours over the next two months.*

#### **What will I be asked to do?**

You are being asked to do the following:

- *Participate in an audio-recorded interview to discuss parenting a child with catastrophic epilepsy. This interview will occur at a convenient day and time for you during September.*
- *Complete the Center for Epidemiological Studies Depression Scale (CES-D) that is a 20 item questionnaire that evaluates depressive symptoms*
- *Participate in a focus group that includes parents of children with catastrophic epilepsy. Written notes will be utilized to record findings of the focus group.*
- *All recorded information will be transcribed on a password-protected computer, and the audio and written recordings will be destroyed. The audio recordings will be deleted from the recording device and the written record of the focus group will be shredded.*

### **What possible harms or discomforts might I experience if I take part in the research?**

It has been determined that the risks associated with this research are no more than what you would experience in everyday life.

### **What are the possible benefits I may experience from taking part in this research?**

We do not know if you will get any benefits by taking part in this study. This research might help us learn more about *the daily experiences of parenting a child with catastrophic epilepsy*. There may be no personal benefit from your participation but the information gained by doing this research may help others in the future.

### **Will I be paid for taking part in this research?**

We *will not be able to* pay you for the time you volunteer while being in this study.

### **What will it cost me to take part in this research?**

It will not cost you any money to be part of the research.

### **Who will know that I took part in this research and learn personal information about me?**

To do this research, ECU and the people and organizations listed below may know that you took part in this research and may see information about you that is normally kept private. With your permission, these people may use your private information to do this research:

- The University & Medical Center Institutional Review Board (UMCIRB) and its staff, who have responsibility for overseeing your welfare during this research, and other ECU staff who oversee this research.
- People designated by PCMH and University Health System;

Additionally, the following people and/or organizations may be given access to your personal health information and they are: *Chastity Case, Researcher*

### **How will you keep the information you collect about me secure? How long will you keep it?**

*The audio and written recordings of the interviews and focus group will be transcribed. The original recordings will be destroyed after it is transcribed. The transcribed material will be kept on the researcher's password protected computer. The findings of the completed Center for Epidemiological Studies Depression Scale questionnaire will be kept in a locked filing cabinet in the researcher's office. The researched material discussed above will be destroyed when the thesis is completed and accepted by East Carolina University. This material will only be used for the purpose of this research study.*



**What if I decide I do not want to continue in this research?**

If you decide you no longer want to be in this research after it has already started, you may stop at any time. You will not be penalized or criticized for stopping. You will not lose any benefits that you should normally receive.

**Who should I contact if I have questions?**

The people conducting this study will be available to answer any questions concerning this research, now or in the future. You may contact the Principal Investigator at 828-275-6526 (*Monday thru Friday, between 9am and 2pm*).

If you have questions about your rights as someone taking part in research, you may call the Office for Human Research Integrity (OHRI) at phone number 252-744-2914 (days, 8:00 am-5:00 pm). If you would like to report a complaint or concern about this research study, you may call the Director of the OHRI, at 252-744-1971

**Is there anything else I should know?**

*This research project is to provide insiders' prospective about parenting a child with catastrophic epilepsy. The research purpose is to highlight epilepsy and the effects it has on a family. There are many aspects of catastrophic epilepsy discussed within the research study. The parents' experiences add value and depth to the research.*

**I have decided I want to take part in this research. What should I do now?**

The person obtaining informed consent will ask you to read the following and if you agree, you should sign this form:

- I have read (or had read to me) all of the above information.
- I have had an opportunity to ask questions about things in this research I did not understand and have received satisfactory answers.
- I know that I can stop taking part in this study at any time.
- By signing this informed consent form, I am not giving up any of my rights.
- I have been given a copy of this consent document, and it is mine to keep.

---

**Participant's Name (PRINT)****Signature****Date**

**Person Obtaining Informed Consent:** I have conducted the initial informed consent process. I have orally reviewed the contents of the consent document with the person who has signed above, and answered all of the person's questions about the research.

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**Person Obtaining Consent (PRINT)****Signature****Date**

## Appendix C: UMCIRB Approval



**EAST CAROLINA UNIVERSITY**  
**University & Medical Center Institutional Review Board Office**  
1L-09 Brody Medical Sciences Building · Mail Stop 682  
600 Moye Boulevard · Greenville, NC 27834  
Office 252-744-2914 · Fax 252-744-2284 · [www.ecu.edu/irb](http://www.ecu.edu/irb)

### Notification of Initial Approval: Expedited

From: Biomedical IRB  
To: [Chastity Case](#)  
CC: [Sharon Knight](#)  
Date: 2/20/2012  
Re: [UMCIRB 12-000192](#)  
Parenting a child with catastrophic epilepsy

I am pleased to inform you that your Expedited Application was approved. Approval of the study and any consent form(s) is for the period of 2/17/2012 to 2/16/2013. The research study is eligible for review under expedited category #6. The Chairperson (or designee) deemed this study no more than minimal risk.

Changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. The investigator must submit a continuing review/closure application to the UMCIRB prior to the date of study expiration. The Investigator must adhere to all reporting requirements for this study.

The approval includes the following items:

Name	Description
<a href="#">Case COI</a>   <a href="#">History</a>	COI Disclosure Form
<a href="#">Case Interview Guide</a>   <a href="#">History</a>	Interview/Focus Group Scripts/Questions
<a href="#">Case Thesis Proposal</a>   <a href="#">History</a>	Study Protocol or Grant Application
<a href="#">Informed Consent</a>   <a href="#">History</a>	Consent Forms
<a href="#">Invitation</a>   <a href="#">History</a>	Recruitment Documents/Scripts
<a href="#">Photoelicitation</a>   <a href="#">History</a>	Additional Items
<a href="#">UMCIRB Form</a>   <a href="#">History</a>	Additional Items

## **Appendix D: Interview Guide**

### **Interview Guide**

Research question: What are maternal perceptions about life with their child affected by catastrophic epilepsy?

- Can you tell me a little bit about your family?
  - Probe: I am interested in learning about your child.
- What is it like to be a parent of a child with catastrophic epilepsy?
  - Probe: What is it like to provide the care your child needs?
- What is typical day like for you?
  - How do people react to you and your child? (family, friends, healthcare providers, or in public).
  - Can you describe how your life is different now with a child that has catastrophic epilepsy compared to your life before your child's diagnosis?
- What challenges have you faced in parenting a child with catastrophic epilepsy?
  - Probe: Please explain how your child's condition has affected you socially, financially, emotionally, physically, mentally?
  - What has been your experience with your child's healthcare providers? (Doctors, Nurses, Therapists)
  -
- What advice would you give other parents caring for a child with catastrophic epilepsy?
  - What would you like to add?
  - What have we not talked about that you would like to be sure to mention?

### **One Shot Question:**

Can you describe how your life is different now with a child that has catastrophic epilepsy compared to your life before your child's diagnosis?

## **Appendix E: Photoelicitation Directions**

Maternal perceptions about life with their child affected by catastrophic epilepsy: a phenomenological study.

### **Photograph Activity**

#### **Directions:**

- Please take four photographs of items (other than your child) that reflect your perceptions or experiences of parenting your child with special needs.
- Please take these photos with a digital camera and email them to me at [ccase@abtech.edu](mailto:ccase@abtech.edu) two days prior to the second interview. I will loan a digital camera if you do not have one.
- The second interview will be an opportunity for you to discuss the photos that you chose.

#### **Purpose:**

This activity is an opportunity to reflect in a different and concrete way about your maternal perceptions and experiences. These photos could be of anything that means something to you with your journey as a parent of a child with catastrophic epilepsy.

## Appendix F: Sample Analysis and Interpretation Memos

Date	Analysis and Interpretation Memos
4/5	There are several forms of isolation that keep repeating throughout the interviews. Social isolation, the parents feel their participation is limited in family events and events with friends. Physical isolation, the parents spoke of being confined to their home for different reasons. Their child may just be having a bad day and not in a good mood. They may have a day riddled with seizures too numerous to count, or get over stimulated by leaving the house. One participant explained that it is easier just to stay at home. She explained, it's exhausting to get everything together and get out the door. Mental isolation, there is an immense feeling that no one else in the world understands what you are going through.
4/10	As I read through the transcripts I interpret this loss of control. Parents that are on edge, because they are not sure how their day is going to go. The nature of epilepsy is that it can strike at any moment and these parents are waiting for that to happen. Not only the epilepsy, but it maybe their child wakes in a bad mood and screams all day.
4/15	Relentless is what I see when I read through the interviews today. But, you can't give up, it's your child. It's exhausting, overwhelming and relentless. The tiniest improvement in the child can cause exhilaration and renewal to press forward.
5/1	The planning and organizing the care for the child is relentless and ongoing. There are therapies in the home and out of the home along with appointments to specialists and evaluations. I want to relate the amount of time and energy necessary to juggle making the appointments, going to the appointments and processing information provided at the appointments. Keeping up with the paperwork is a job for the caretaker.
5/12	The child is deemed medically fragile often by the pediatrician and is considered "in the system" to receive community services. The findings need to communicate the parents' perceptions of what it is like to be "in the system." There is early intervention, the school system, and various governmental programs.
5/18	The child's behavior is a point of concern for parents due to the lack of communication the child often relates their feelings in ways that can seem like behavioral issues. One participant in particular has a child that has screamed for hours almost daily for five years. The parents spoke about trying to maintain contentment for their child by providing an immense amount of one-on-one time to entertain their child striving for a happy child.

## Appendix G: Codebook

<b>Code</b>	<b>Description</b>	<b>Example</b>	<b>Non-example</b>
<b>FI</b> <b>Financial Impact</b>	<b>Statements about the financial impact for caring for a child with catastrophic epilepsy.</b>	Refers to anything economic or financial related to care and support of child or self in relation to care and support of child (i.e., therapy; psychological support).	Any statement that is unrelated to financial concerns
<b>RES</b> <b>Resources</b>	<b>Statements about finding, using, navigating through, and evaluating resources for care and support for self or child.</b>	Refers to concerns about locating, using (including “navigating”), and evaluating information, care, and support services for self or child.	Any statement that is unrelated to resources
<b>COM</b> <b>Commitment</b>	<b>Statements about the commitment of a child with catastrophic epilepsy.</b>	Refers to concerns about perceived time, effort, emotional or other commitments as well as perceived intensity of commitment related to the child and child care and support (i.e. appointments, phone calls, meetings).	Any statement that is unrelated to commitment to the child and his or her care and support
<b>NE</b> <b>Needs</b>	<b>Statements about the needs of their child.</b>	Refers to concerns about their child’s dependency for basic needs (eat, bath, diaper, etc.) to be met by the caregiver.	Any statement that is unrelated to meeting the child’s needs
<b>PHY/EMO</b> <b>Physical/ Emotional</b>	<b>Statements about the physical and emotional demands on maternal caregiver in caring for a child with catastrophic epilepsy.</b>	Refers to the concerns about the physical and emotional repercussions related to the care and support of child.	Any statement that is unrelated to physical concerns
<b>MAR</b> <b>Marital Impact</b>	<b>Statements about maternal relationship/marital impact when parenting a child with catastrophic form of epilepsy.</b>	Refers to marital concerns related to parenting of child, including communication, relationship issues, intimacy, ability to work together in addressing the child’s needs.	Any statement that is unrelated to maternal relationship/ marital concerns
<b>HCP</b> <b>Health care provider and system</b>	<b>Statements about experiences with healthcare providers and healthcare system.</b>	Refers to experiences with the healthcare community related to care of child.	Any statement that is unrelated to experiences with healthcare providers or system
<b>F&amp;F</b> <b>Friends and family</b>	<b>Statements about experiences with family and friends.</b>	Refers to experiences with family and friends related to the child, including their engagement and interactions with the child and parents	Any statement that is unrelated to reactions of family and friends
<b>PR</b> <b>Public</b>	<b>Statements about the public’s reaction to their child.</b>	Refers to experiences with public reaction to child.	Any statement that is unrelated to reactions of the

<b>Reaction</b>			public
<b>COP</b>  <b>Coping</b>	<b>Statements about maternal coping.</b>	Refers to any coping mechanism/strategy on the part of parents related to care, support, and protection of child or self. Can include strategies that the parents explicitly label as coping and more tacit coping strategies.	Any statement that is unrelated to coping mechanism
<b>REA</b>  <b>Reality</b>	<b>Statements about maternal reality relating to the care, support and future of a child with catastrophic epilepsy</b>	Refers to maternal realities relating the care, support, and future of the child.	Any statement that is unrelated to Maternal acuity
<b>ISO</b>  <b>Isolation</b>	<b>Statements about the isolation experienced by parents of a child with catastrophic epilepsy.</b>	Refers to anything related to the physical, social and emotional isolation experienced in living with and caring for the child.	Any statement that is unrelated to isolation concerns
<b>GRE</b>  <b>Maternal grief, sadness, loss</b>	<b>Statements about maternal grieving for losses experienced.</b>	Refers to anything related to the maternal sadness, depression, grief or grieving process experienced in living with and caring for the child.	Any statement that is unrelated to grieving process
<b>JOY</b>  <b>Maternal joy, happiness, satisfaction</b>	<b>Statements about maternal joy, happiness, satisfaction related to the child.</b>	Refers to anything related to the maternal joy, happiness, satisfaction experienced in living with and caring for the child	Any statement that is unrelated to joy and happiness

## Appendix H: Research Log Sample

RESEARCH LOG: Qualitative Study: Parenting a Child with Catastrophic Epilepsy				
Date	Time	Action	Comment	Plan
3/10	9:44	Phone call	Participant #3 contacted me regarding an interview	Set up a time for Participant #3 interview 1
3/13	10:33	Interview	Participant #3 interview, consent was explained, reviewed, and signed. Interview 1 was completed. The photoelicitation was explained.	Participant #3 Interview 1 Interview 2 was scheduled.
3/13	2:20	Phone call	Participant #4 contacted me regarding an interview	Set up a time for Participant #4 interview 1
3/13	8:45	Transcribe	Transcribe Participant #3 Interview 1	Transcribe and read
3/16	12:12	Interview	Participant #4 interview, consent was explained, reviewed, and signed. Interview 1 was completed. The photoelicitation was explained.	Participant #4 Interview 1 Interview 2 was scheduled.
3/18	8:03	Email	Participant #3 emailed photos	Photos will be discussed at Interview 2
3/20	12:00	Interview	Participant #2 interview, consent was explained, reviewed, and signed. Interview 2 was completed.	Photos were reviewed
3/22	10:45	Interview	Participant #3 interview, consent was explained, reviewed, and signed. Interview 2 was completed.	Photos were reviewed
2/23	9:05	Transcribe	Transcribe Participant #4 Interview 1, Participant #2 and #3 Interview 2	Transcribe and read
3/25	3:25	Email	Participant #4 emailed photos	Photos will be discussed at Interview 2



## Appendix I: Sample Reflective Journal

April 4, 2012

I have so many of the same perceptions that these parents have. It's just not fair that the awareness and support is nonexistent for epilepsy (and therefore funding). Unless you are experiencing seizures first hand or someone in your immediate family, people just don't want to address epilepsy. This is a frustrating point in dealing with the stigma that continues to surround epilepsy. People are simply not comfortable with this condition. They don't want to see it, recognize it, talk about it, support it, or fund it. It's so nice to spend time with these moms who "get it" and to know that I am not alone in this battle. But, we are the ones dealing with epilepsy affecting our children so we are exhausted. We don't have the time, energy or supports to fight for epilepsy awareness, education, funding, and research and ultimately a cure. We are the ones dealing with the devastating effects day in and day out.

I often think about how there is documentation of epilepsy occurring over 4000 years ago, and to this day we cannot stop a seizure in over a third of people affected. This is frustrating as a parent of a child completely dependent on me for care. The frustration and exhaustion was echoed by all the parents interviewed. The isolation as a result from a debilitating form of epilepsy had made an enormous impact on the parents. I have those same feelings of isolation due to my child's mood, the energy and the strength that it takes to go anywhere.