Parental Caregivers' Description of Caring for Children with Intractable Epilepsy

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PARENTAL CAREGIVERS‘ DESCRIPTION OF CARING
FOR CHILDREN WITH INTRACTABLE EPILEPSY

a dissertation

by

MARY POYNER REED

submitted in partial fulfillment of the requirements
for the degree of
Doctor of Philosophy

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Abstract

PARENTAL CAREGIVERS’ DESCRIPTION

OF CARING FOR CHILDREN WITH INTRACTABLE EPILEPSY

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The objective of this study was to describe the parental perspective of caring for a child with intractable epilepsy. The purpose of this study was twofold: (1) to describe the caregiver transition from caring for a healthy child to caring for a child with intractable epilepsy, and (2) to study families that provide caregiving, to identify the challenges, and learn how they address the intricacies and nuances of caring for a child with intractable epilepsy. The specific research questions that guided this study were: (1) What do parents of children with intractable epilepsy find helpful or challenging during transition from caring for a healthy child to a child with intractable epilepsy? (2) How do parents of children with intractable epilepsy cope with caregiver strain during transition from caring for a healthy child to a child with intractable epilepsy? (3) What factors enable parents to transition from caring for a healthy child to a child with intractable epilepsy?

The research design used qualitative descriptive design and was based on naturalistic inquiry. This methodology was used to describe parental experiences using their own words and not interpret these experiences. Research participants were recruited
from a Level 4 National Association of Epilepsy Center at a Children’s Hospital in the Northeast. A purposive sample of twelve parental caregivers participated. Themes that emerged from the interviews included (1) Journey to Diagnosis, Connecting the Dots, (2) Drunken Sailor, Medication Management, (3) Negotiating and Advocacy for Education (4) Provider Challenges, Communication and Partnering and (5) It Takes a Village: Siblings, Family Members and Friends. Nurses play a significant role in educating, advocating, and guiding families through the initial diagnosis to dealing with activities of daily living and future planning. This research study serves as a foundation for future intervention studies regarding how best to support parents of children with intractable epilepsy.
Acknowledgements

First, I would like to thank the families that welcomed me into their homes to tell me about their journey from caring for a healthy child to one with intractable epilepsy. Their love, commitment, and level of advocacy are admirable. These twelve parents were some of my best teachers. Also, I would like to acknowledge Cheryl Cahill and Thelma Stockdale for providing inspiration and being expert role models in how to advocate for their sons.

I would like to thank Dr. Judith Vessey, my mentor, advisor, and dissertation chair. Dr. Vessey has always been there to support, guide and share her wisdom, knowledge and expertise. Thank you to Dr. Allyssa Harris, Dr. Nancy Kline and Dr. Sandra Mott and librarian Alison Clapp who guided me, and who were great resources, teachers, editors and supporters for this qualitative research study.

Thank you to Eileen Sporing, Patricia Branowicki, Susan Shaw, and Dr. Patricia Hickey for building a nursing culture at Boston Children's Hospital of lifelong learning, coaching, and support. Thank you to the many neuroscience nurses and my fellow doctoral students whom I have worked and studied with in the past and present and who make an ongoing difference in the lives of patients and families. Thank you, to Dr. Joanne Hickey, who paved the way in neuroscience nursing as an academic, practitioner, researcher and writer.
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CHAPTER 1

Overview of the Study

Introduction

Epilepsy is a chronic condition in children that can affect the child’s care and parents’ everyday life. Although caregiving is a normal part of being a parent, this role takes on a distinctly different significance when a child experiences functional, physical, and cognitive limitations and possible long-term dependence on the caregiver (Raina, et al., 2005). Such is the case when parenting a child with intractable epilepsy. What is not known is information regarding parents’ experience transitioning from caring for a healthy school-age child to one with a lifelong chronic condition in terms of role adaptation, changes in parenting style and behaviors, and modifications in family functioning.

The overarching goal of this study is to learn from the caregivers what strategies they find helpful or burdensome and to discover creative ways to reduce the caregiver strain they experience. The population of school-age children recently diagnosed with intractable epilepsy was selected because the school-age period is generally a time when children are becoming increasingly independent and parental caregiver roles are changing. With a diagnosis of intractable epilepsy, parental caretaking does not change in developmentally anticipated ways. Rather, parents transition to a role that is marked by the need for increasing vigilance, uncertainty, and new personal and family stressors. This study helped identify the nuances of parental caregiving during this transition and
the resources needed to help parents cope with and manage both normal developmental changes and newly emerging, specific situational stressors encountered when parenting children with epilepsy.

**Statement of Problem**

An estimated 29 million adults in the United States currently provide informal care, for example unpaid care to relatives and friends who are ill or disabled (Arno, 2006). This figure includes caregiver recipients of all ages with a range of chronic health conditions. A 2009 report on caregiving in the United States stated there are an estimated 16.8 million unpaid caregivers who provide care to a child with special needs under the age of eighteen (National Alliance for Caregivers, 2009). Recognition of informal caregivers’ contributions has heightened recent estimates of the economic value of their services at $450 billion (Feinberg, Reinhard, Houser & Chaula, 2011), up exponentially from $306 billion in 2006 (Arno, 2006). With ongoing public and private sector efforts to limit post-acute and long-term care payments, the health care system’s dependence on informal caregivers will inevitably swell with increased numbers of seniors with chronic conditions, more disabled war veterans, and improved survival rates of premature infants with long-term sequelae, including those with neurological and other congenital deficits/diseases (Navaie-Weliser, Feidman, Gould, Levine, Kuerbis & Donelan, 2002).

Epilepsy is defined as a disorder resulting in seizures that are caused by abnormal electrical discharges in the brain. Epilepsy affects three million Americans of all ages, at an estimated cost of 17.6 billion dollars in direct and indirect costs (Epilepsy Foundation,
Three hundred thousand people experience their initial seizure each year; 120,000 of them are under the age of 18 years. The statistics reveal that 75,000 to 100,000 children under the age of five years experience a first-time seizure yearly (Epilepsy Foundation, 2012). A child with intractable epilepsy can have a shortened life span due to complications such as frequent seizures, compromised airway management, and trauma during seizure activity.

A small subset of this population will have intractable epilepsy, defined as having failed medication management and poor responses to adjunct therapies such as dietary modifications (e.g., ketogenic diet), vagal nerve stimulation (VNS) and/or epilepsy surgery (Epilepsy Foundation, 2012). Many children with intractable epilepsy can, with adequate support, partake in normal age group activities such as school and recreational sports while others remain dependent on caregivers and multiple support services integrated into the home environment. These children require care around the clock because they need constant supervision to ensure their safety. The health and well-being of the caregiver is paramount in order to provide care to the affected child while striving to advance and achieve the goal of obtaining “normalcy” with respect to the family unit.

Caregivers of children with epilepsy have their own individual set of concerns regarding care delivery, maintaining the health of their child with epilepsy, and ensuring the well-being of the caregiver and family unit. The experience of parental caregiving for a child with intractable epilepsy is multidimensional, depending on the child’s health status, number and type of seizures a month, developmental status, and educational
potential. The parental caregiver of this child may undergo major life changes including but not limited to marital strain, financial stress, and disrupted coping strategies that all interfere with the management of daily activities of life and healthy family function. The primary goal of this study is to better understand the transition from being a parent of a healthy child to adapting to the role of becoming a parental caregiver of a child developing intractable epilepsy. The parents have to adjust their parenting from care of a normal child moving toward independence to increased vigilance in caring for a child with unique safety, developmental, and behavioral needs and whose long-term developmental attainment is in jeopardy.

It is challenging at best to care for a child with intractable epilepsy in the home setting. Caregiver strain needs to be better addressed and understood so nurses can provide hope, condition-specific education and, anticipatory guidance, while suggesting supportive coping strategies to sustain the parental caregiver, child, and other family members. Many children with intractable epilepsy live for decades with survival surpassing their parental caregiver(s), thus requiring long-term planning that begins in childhood. Since there are limited resources for home care, special education, respite care, counseling, and advocacy for family needs, it is beneficial to know which of these best support caregivers in making an initial healthy transition to caring for their child with newly diagnosed, lifelong, and constant health care needs (Arno, 2006). Caregivers’ initial adaptations help predict long-term behaviors (Woolley, 2006). Because nurses interact with children and their families across the continuum of care, they are positioned
to assess and develop an action plan to address caregiver strain using family-centered approaches.

**Gaps in the Literature**

Different causes of strain in the caregiver responsible for caring for the pediatric patient are not clearly identified in the existing literature. In addition, there has been a lack of exploration of the discrepancy between the perspectives of professionals and those of family caregivers regarding what defines support. Most commonly the professional’s view of support focuses on provision of health care services, but that is not necessarily how families define support (Stoltz & Uden, 2004).

If nurses can improve the parental caregivers’ ability to cope and educate caregivers in best practices of caring for a child with intractable epilepsy, the well-being of both caregiver and child can be improved. Since children with intractable epilepsy face multiple developmental challenges over the continuum of their life, the experience of their caregivers and the nature of their care differ from that of adults who require care; only adult needs are well documented in the care-giving literature (Butcher, Holpup & Buckwalter, 2001). There is an abundance of research on the stressors related to the caregiver for the elderly population, for example, care of patients after a stroke and those with Alzheimer’s disease but much less about the pediatric population with chronic conditions (Thompson, Spilsbury, Birks, Barnes & Adamson, 2007).

In 2002, the National Institute of Nursing Research (NINR), the National Institute of Child Health and Human Development (NICHD), and the National Institute of Mental
Health (NIMH) invited applicants to submit proposals for research grants to advance the science of informal caregiving by focusing on the caregivers of individuals with chronic illness, disability, or functional impairment that required partial or full dependency on others. This call for proposals invited targeted studies of informal caregiving processes, caregiving effectiveness, and health outcomes with the goal to advance science-based knowledge of informal caregiving with the focus on the caregiver. Outcome studies were needed to improve the quality of informal caregiving; prevent or manage the caregiver’s physical or mental health problems related to caregiving; reduce the burden of caregiving; test the effectiveness of advances in caregiving processes, including new technologies; and determine the impact of formal and informal support systems on caregiving outcomes and caregiving transitions from health to illness states (NINR, 2002).

Of the nine research teams that received grants only two focused on the pediatric population. One centered on parents of children with cancer and factors influencing their treatment decision-making roles (Pyke-Grimm, Stewart, Kelly & Degner, 2006). The other focused on the risk of psychological difficulties among children raised by custodial grandparents (Smith & Palmieri, 2007). The findings of these studies, while useful, do little to address large gaps in the pediatric caregiving literature.

The need for further research on family caregiving was underscored in the National Institute for Nursing Research (NINR) Strategic Plan for 2006-2010 which calls for research to “develop interventions to improve the quality of caregiving” and “evaluate
factors that impact the health and quality of life of informal caregivers and recipients” (NINR, 2007). The vision requires initial qualitative work to address the journey of the parental caregiver and examine the complexity, experiences, challenges and needs of parental caregivers transitioning from caring for a well-child to a child with intractable epilepsy (Linger, 2008).

Very little is known about all the challenges that parental caregivers of pediatric patients with intractable epilepsy deal with on a daily basis and over time. In order to achieve the future goal of developing an intervention, there needs to be an understanding of the issues parental caregivers face. By asking parents to describe their experiences, it is anticipated that the issues facing them as caregivers can be better understood by nurses and other professionals. Thus professionals can gain a better understanding of how best to help families achieve their goals.

Purpose

The purpose of this study is twofold: (1) to describe the caregiver transition from caring for a healthy child to caring for a child with intractable epilepsy, and (2) to study families that provide caregiving, to identify the challenges, and learn how they address the intricacies and nuances of caring for a child with intractable epilepsy. Knowledge regarding the best ways to care for these children and provide for the needs of their caregivers is essential. Listening and learning from those providing care is an ideal way for nurses to learn how best to facilitate caregiving and support the caregiver. Caregivers' input will provide nurses with greater understanding of the issues and result
in nurses’ ability to provide guidance, support, case management, and counseling to other caregivers at times of stress.

Parents must meet the multiple challenges that are ongoing, for example, the child who has nocturnal seizure activity. The basic issues of providing a safe environment and monitoring the airway, breathing and circulation are in the forefront of parental concerns on a daily basis. However, the commitment and perseverance that parental caregiver’s exhibit goes beyond simple safety. Holistic parental caregiving focuses on helping the child reach his or her full educational potential while attaining optimal social, emotional, and physical development (Austin & Dunn, 2000). The path to achieving these outcomes is complex and challenging. The balancing act between caring for an ill child while juggling family expectations, maintaining the marital relationship and a career are monumental tasks requiring energy and great stamina (Austin & Dunn, 2000).

The child’s initial hospital stay is focused on diagnosis and achieving the best clinical outcome before discharge. However, it is the daily caring, commitment and nonstop focus on safety, quality of life, and quest toward normal activities that caregivers of children with intractable epilepsy exhibit that needs to be explored. It is essential to learn from caregivers what is important and helpful, what facilitates their mission and what interferes with their efforts. It is important to then share this knowledge with neuroscience nurses so it can influence care. This information will provide the first step in a program of research whose long-term goal is to identify and create helpful interventions.
**Research Questions**

The specific research questions that guided this study are: (1) What do parents of children with intractable epilepsy find helpful or challenging during transition from caring for a healthy child to a child with intractable epilepsy? (2) How do parents of children with intractable epilepsy cope with caregiver strain during transition from caring for a healthy child to a child with intractable epilepsy? (3) What factors enable parents to transition from caring for a healthy child to a child with intractable epilepsy?

**Operational Definitions**

*Intractable pediatric epilepsy* is defined for purposes of this study as a condition in a child who presents with three or more seizures a month despite the administration of two or more anti-seizure medications and has failed other treatment modalities such as epilepsy surgery, ketogenic diet, and/or vagus nerve stimulation (VNS).

*Parental caregiver* is defined as a person in the caregiving role who is both a biological parent and a primary provider of care for the child, from prior to the onset of seizures until a period of at least two years after intractable epilepsy was diagnosed.

*Caregiver strain* is defined as the constant work of assisting, advocating, monitoring, and caring for a child between the ages of six and twelve years who has intractable epilepsy.
**Transition** is defined as moving from one change state to another change state. For this study it refers to parental adjustment in caring for a previously healthy child to one now diagnosed with intractable epilepsy.

**Resiliency** is defined as successful adaptations to unpredicted negative life events, trauma, stress and other forms of risk.

**Uncertainty** is defined as the lack of knowledge especially about an outcome or result.

**Summary Statement for Chapter 1**

An overview of the study is provided in the preceding pages. Chapter Two integrates the literature on the subjects of caregiver strain, parenting a child with a chronic condition, resiliency, and transitions. Chapter Three defines the methods to conduct the study including; the research design, data collection and analysis, procedures, recruitment and protection of research participants, and confidentially and storage of data. Chapter Four describes the study findings. Chapter Five discusses the findings with respect to published works and suggests implications for nursing practice and further research to better support the caregiver of the child with intractable epilepsy.
CHAPTER 2

Review of the Literature

Overview

A thorough review of the current literature was conducted to identify the gaps, ensure the research questions have not been answered previously, and provide guidance for this study. The aim is to add to the scientific knowledge base, and not duplicate published findings. A literature search was conducted with the assistance of a research librarian using three search engines, Cumulative Index of Nursing and Allied Health Literature (CINAHL), PsychInfo, and Medline from 1984 to 2013. Key search terms included; parents, caregivers, epilepsy, intractable epilepsy, refractory epilepsy, caregiver support, caregiver burden, and quality of life. Inclusion criteria stipulated that articles must have been published in nursing, medicine, or interdisciplinary journals or were dissertations. Articles were excluded from scientific review if they were published in languages other than English. The 91 articles reviewed focused on specific aspects of pediatric epilepsy and caregiving such as behavioral manifestations, social issues, homecare, and family, sibling, and friend relationships.

There is an abundance of literature on caring for children with chronic conditions but not specific to caring for a child with intractable epilepsy or parental role transitions for caregivers following diagnosis. J. K. Austin is a prolific nurse researcher and studies children with epilepsy. Her work however focuses on behavioral aspects of the condition
and does not include the needs of the parental caregiver (Austin, Dunn, Johnson & Perkins, 2004; Austin & Dunn, 2000; Austin, Mc Nelis, Shore, Dunn, Musick, 2002). There is minimal literature available on the daily challenges of raising a child with intractable epilepsy, providing a safe environment, fostering optimal education, or embracing social relationships. A paucity of literature also exists that discusses transitions over time; for example, from diagnosis to parental planning for the child's future related to education, guardianship, financial issues, sibling relationships, and social adjustment. Research describing the daily life experience of the parental caregiver was completely absent. In sum, the overall body of literature lacks descriptive qualitative information that is pivotal to revealing the daily experience and ongoing adjustments in family functioning related to parental adaptations in caring for a child with epilepsy.

**Previous Intervention Work and Limitations**

Since 1980, a small body of intervention studies (N=4) attempted to explain approaches to improve the life of parents of children with intractable epilepsy and of the children using deductive approaches (Table 1).
**Table 1**

*Summary of Intervention Studies*

<table>
<thead>
<tr>
<th>Research Team</th>
<th>Research Design</th>
<th>Research Sample</th>
<th>Intervention</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Huang, Lin, &amp; Huang, (1998)</td>
<td>Pre/post test educational intervention</td>
<td>129 parents</td>
<td>Nurse-provided education about febrile seizures to decrease parental anxiety and increase knowledge</td>
<td>Anxiety stayed constant, knowledge of first aid increased (p&lt;0.0001)</td>
</tr>
<tr>
<td>Lewis, Hatton, Salas, Leake, Chiofalo, (1991)</td>
<td>Randomized controlled trial</td>
<td>365 parents/children</td>
<td>Counseling and education provided by nurses to improve decision making</td>
<td>Knowledge increased, anxiety decreased Taylor Manifest Anxiety Scale (p&lt;0.01)</td>
</tr>
<tr>
<td>Shope (1980)</td>
<td>Pre/post test control group</td>
<td>156 maternal child dyads</td>
<td>Medication compliance educational intervention provided by a social worker</td>
<td>Medication compliance increased (p&lt;0.0077)</td>
</tr>
<tr>
<td>Snead, Ackerson, Bailey, Schmitt, Madan-Swain, Martin, (2004)</td>
<td>Pre/post psycho-education intervention</td>
<td>7 adolescents</td>
<td>Psycho-education intervention over 6 weeks provided by psychologists</td>
<td>Outcome measurement improved scores on QOLIE_AD_48 (p&lt;0.01)</td>
</tr>
</tbody>
</table>
The studies reviewed used both educational and counseling interventions. Reported findings included increasing parental knowledge about epilepsy, assisting parents in acquiring advocacy skills, and increasing the parents’ network of support resources. Their contribution to new knowledge, however, is compromised due to the insufficient methodological rigor including, but not limited, to limited power, researcher-designed instruments, without adequate psychometric properties, and lack of adequate controls.

Two of the studies focused on improving child and or caregiver knowledge. Lewis, Hatton, Salas, Leake and Chiofalo (1991) and Snead, Ackerson, Bailey, Schmitt, Madan-Swan and Martin (2004) used quantitative self-report instruments including the American Epilepsy Life Quality Scale and Taylor Manifest Anxiety Scale and the Children Depression Inventory. Although useful and valid, these instruments provided only numeric scores of quality of life, anxiety, and depression, but lacked the rich descriptive data that contributes to understanding the caregivers’ ability to provide care to their child with intractable epilepsy. These two intervention studies used discussion groups as the vehicle to educate caregivers in issues of general knowledge of epilepsy, improved decision making, advocacy, and medication compliance.

Shope (1980) used a pre/post-test design with a control group to study 156 mother-child dyads. Medication compliance was improved by using a social worker to intervene with a one-time educational program regarding medications and the rationale for compliance. Medication compliance significantly increased following the intervention. Huang, Lin and Huang (1998) used a pre/post-test research design 129
parents after an educational intervention. The nurse-delivered intervention provided education regarding febrile seizures with the goal of decreasing parental anxiety and improving knowledge. The outcome revealed that anxiety remained constant but knowledge of first aid increased.

The studies summarized in Table 1 yielded specific outcomes but did not evaluate whether the impact of the intervention was sustained over-time. Using only a quantitative approach does not allow the researchers to gain the caregivers’ perspectives. This literature focused on specific educational interventions and lacked a focus on the family life transitions post diagnosis and the daily management of extraordinary caregiving demands on family, spousal, sibling, social and professional relationships. In sum, these interventions were based on a limited perspective of caregiving and do little to advance nurses’ knowledge of parental caregivers’ needs.

**Parenting a Child with a Chronic Condition**

Parenting a child with a chronic condition goes above and beyond that of raising a normal healthy child. ―Special needs parenting‖ is the additional care required that is often unique to the disease and its manifestations in the child. These special needs frequently include the following; (1) navigating the health care system to ensure the child‘s health care issues are fully addressed, (2) advocating for appropriate educational resources and confronting administrators within the educational system when necessary, and (3) balancing spousal and family life including providing for the needs of siblings,
maintaining relationships with extended family members and friends, and self-care of the caregiver (Ray, 2002).

The United States and Maternal Child Health Bureau (MCHD) estimates that 18 million children diagnosed with chronic illness are living in the United States (Coffey, 2006; Maternal Child Health Bureau, 2003; Perrin, Bloom & Gortmaker, 2007). Most of these children are cared for at home by family members, sometimes with nursing, personal care assistant, or respite help. The sentinel definition for chronic illness by Jessop and Stein (1985) stated that it is an illness that is long-term and either not curable or has residual features that results in the limitation in daily living necessitating special assistance or adaptation in function. In 2010, Allen, Vessey and Schapiro expanded the definition to capture the full range of chronic conditions in children. They described ongoing health conditions in which one or more of the following are present at the time of diagnosis or during the trajectory of the illness: (a) limitation of function, (b) disfigurement, (c) dependency on medication, (d) special diet and/or residual technology, (e) special ongoing treatment at home or in school, and (f) need for medical care above the normal need for ongoing health maintenance.

Themes that are prevalent when reviewing the demands and stressors of care for parents of children with a chronic condition are: (a) managing the condition; (b) identifying, accessing, and coordinating resources; (c) maintaining the family unit; and (d) maintaining self (Sullivan-Bolyai, Knafl, Sadler & Gillis, 2003). Managing the condition refers to understanding any underlying disease or degenerative processes,
treatment plans, and other day-to-day management issues (Farley & McEwan, 2000). Parents need to provide and coordinate care, problem solve, and teach others how to provide care. Other providers such as teachers, family members, and respite care providers along with the parental caregivers must develop an emergency plan in partnership with the health care team to address emergencies and complications. It is vital that the parent is able to seek and accept help from health care agencies, social programs, and respite care agencies and nurses, other health care professionals, and friends and family members.

Maintaining the family unit refers to balancing demands of the child’s condition with family demands. The meaning of the condition to the child, caregivers, and family members is always in transition as it influences their developmental milestones and goal attainment. Economic issues such as paying for health insurance, medication, special programs, and tutoring also need to be addressed. Often forgotten is the need for the parental caregivers to maintain their physical, emotional, spiritual and mental health. Several studies have emphasized the importance of identifying coping strategies to relieve stress and provide designated time for the caregiver to focus on personal goals and nurture relationships and friendships (Ray 2002, Sullivan-Bolyai, Sadler, Knafl & Gillis, 2004).

Carnevale (2006) noted that caregivers of technology-dependent children were consumed with devoting extraordinary care and attention to their children. These caregivers struggled with the emotional strain of living with the constant threat of death.
plus the physical and psychological dependence of the child and impact on the family and social relationships. While striving for normalization and family cohesion, they had to neutralize societal reactions that devalued the child’s life and questions on whether the child’s life was worth maintaining. There was a temptation to live in isolation because of the child’s complex medical needs, society’s lack of understanding, and the realization that neither extended family nor friends nor the health care system could support the families’ respite needs. Parental caregivers described their life as a very unfair situation that they could not change. They questioned the moral order of how “good things” and “bad things” are determined in the world. However, despite enormous difficulties they also reported deep enrichments and rewarding experiences that they could not imagine living without (Carnevale, 2006).

Theoretical Basis

The theoretical and conceptual underpinnings for this study are drawn from three interrelated theories or models: resiliency, transition, and caregiving. Each of these is described below.

Resiliency

Overview of the Resiliency Theory. The one distinguishing characteristic in the literature repeatedly used to describe caregivers was resiliency. Merriam-Webster's Collegiate Dictionary 11th Ed (2005) defined resiliency as “the art of rebounding or springing back after being stretched or pressed, or recovering strength, spirit and good humor.” The term “resiliency” is reserved for markedly successful adaptations to
unpredicted negative life events, trauma, stress, and other forms of risk. The term resilience is often used interchangeably with positive coping, adaptation and persistence. Multiple disciplines including psychology and sociology have contributed to the expanding knowledge base for comprehending the phenomenon of resilience (McCubbin & McCubbin, 1993). The research on resilience focuses on good outcomes despite adverse conditions. It is noted in the literature that theoretical and operational definitions of both terms, “good outcomes” and “adverse conditions,” are inconsistent (McCubbin & McCubbin, 1993; Peterson & Bredow, 2004). A good outcome is usually defined positively as outcomes that meet or exceed expectations. Adverse conditions are defined as threats or risk factors that occur in the context of war, illness, community deficits, or family adversity (McCubbin & McCubbin, 1993). How the term adverse condition is operationalized varies with each research study. Examples include (1) a current or past negative occurrence, (2) predictor of poor outcomes, and, (3) a single exposure to variables or cumulative combinations of a variety of factors (McCubbin & McCubbin 1993; Peterson & Bredow, 2004).

The literature on resiliency includes concepts such as psychological resiliency (Rutter, 1987), hardiness (Kobasa, 1982), self-efficacy, and learned resourcefulness (Bandura, 1977; Rosenbaum, 1983). Individually and collectively, these concepts were analyzed to explain positive adjustment to illness and the means for providing effective interventions. Positive outcomes demonstrating resilience include improved self-esteem, self-transcendence, self-efficacy, hope, coping, psychological equilibrium, enhanced
quality of life and well-being (McCubbin & McCubbin, 1993; Peterson & Bredow, 2004).

The study of resilience was identified by the Committee on the Future Direction for Behavioral and Social Sciences as a research priority for the National Institute of Health (NINR, 2011). An understanding of resilience is important for nurses in order to (1) guide development of interventions leading to positive outcomes, (2) improve outcomes for at-risk populations, (3) prevent the likelihood of poor outcomes, and (4) influence public policy related to individuals, families, and communities (McCubbin & McCubbin, 1993; Peterson & Bredow, 2004). Researchers have used both qualitative methods and quantitative methods to study resilience. The evolution of the study of resilience has shifted from first seeking to describe personal qualities that predict success to defining resilience as a process that promotes resilience as a motivational life force to be fostered in all individuals. Evidence now supports the conclusion that resilience is a commonly occurring phenomenon that is a basic function of adaptive systems (McCubbin & McCubbin; Peterson & Bredow, 2004). Thus, the concept of resilience is a useful premise on which to study caregiver characteristics for parenting children with intractable epilepsy.

**The Resiliency Model of Family Stress Adjustment and Adaptation.** The Resiliency Model of Family Stress, Adjustment, Adaptation (McCubbin & McCubbin, 1993) provides a framework for exploring caregiver response to caring for a child with intractable epilepsy and originates from the family stress and coping work of Hill (1958),
the Double ABCX Model of Family Adjustment and Adaptation (McCubbin & Patterson, 1983), and Typology Model of Family Adjustment and Adaptation (McCubbin & McCubbin, 1989). McCubbin and McCubbin's research focused on families that had a member with a newly diagnosed head injury. Assessment of family resources, both economic and psychological; the family's appraisal of the head injury; and the family coping patterns that facilitate adjustment to head injury were studied. The outcome was the Resiliency Model that builds on the importance of family adaptation to crisis rather than specific adjustment to head injury (McCubbin & McCubbin, 1993).
Figure 1: The Resiliency Model of family Stress, Adjustment and Adaptation

The Resiliency Model is complex; it explores the interrelationship between stressors and resources and is made up of six components of stressors that threaten resilience and two phases that describe the process of demonstrating resilience (McCubbin & McCubbin, 1993). The six broad categories of stressors are as follows: (1) Hardships associated with caring for a child with a chronic condition over time; including the ambiguity surrounding the diagnosis and prognosis, marital and or sibling relationship strain, parent–child conflicts, and emotional and financial hardships; (2) Normative transitions that occur in any family such as child growth and development, adult career development, extended family changes (births, deaths), and predictable family changes such as school graduations and retirements; (3) Prior strains accumulated over time and never totally resolved that create negativity and subsequent buildups of stress; (4) Intra-family and social ambiguity occurring post diagnosis; (5) Readjustment of family roles and responsibilities; (6) New requirements of financial resources plus related role adjustment and lifestyle changes.

The adjustment and adaptation phases describe the process of demonstrating resilience. In the adjustment phase, families attempt to maintain “normalcy” in the short run. Maintaining patterns of usual interaction, roles, rules, and day-to-day family activities is the goal. Components that shape the family process and outcomes include (1) residual problems in the member with the illness or injury as a family stressor, (2) family vulnerability to stress, and (3) family functioning patterns or types. Family adjustment varies across the continuum from bonadjustment to maladjustment. Bonadjustment refers to the maintenance of established family functioning patterns, a
sense of control and new patterns of coping and adaptation. Maladjustment is noted as the deterioration of individual family member development and ability to accomplish life tasks (Patterson, 1988).

When the stressor is prolonged and not easily resolved, adjustment is inadequate and crisis continues. The family moves to the adaptation phase in order to stabilize and find a new equilibrium. The hardships of having a child with a chronic condition can cause changes in family roles, priorities, goals, rules, finances, and social relations/activities (McCubbin & McCubbin, 1993). The family adaptation phase is central to modifying behaviors and finding a new equilibrium and balance for the family unit over time. The adaptation phase occurs over time; the family’s stress from the initial crisis segues into a process of reevaluation, assessing strengths, resorting of roles and responsibilities, dealing with financial concerns, appraising family and social support resources, plus reviewing problem solving and coping strategies. This process ends with family reaching bonadaptation, maladaptation, or somewhere in between (Patterson, 1988).

Specifically, bonadaptation is characterized by positive physical and mental health of individual family members, the continued promotion of individual family members, optimal role function of members, accomplishment of life-cycle tasks, maintenance of family integrity, and a sense of control over environmental influences (McCubbin & McCubbin, 1993). Family maladaptation is noted as the continued imbalance of family functioning levels; individual to family, family to family, family to
community or deterioration of the individual member's health and/or development and crisis (Patterson, 1988).

**Meleis’s Theory of Transitions**

Meleis’s middle range theory of transitions provides a framework that is useful for understanding the caregiver role for children with intractable epilepsy. Caregiving strain has been associated with considerable demands on the caregiver who is responsible for providing physical and emotional care to a child with epilepsy. Currently with advances in the treatment of intractable epilepsy, children are living longer and being cared for by their parents in their own home. The physical stress, financial constraints, marital discord, and social isolation experienced by parents caring for children with such complex medical needs can affect the quality of life and physical and emotional health of the caregiver (Kuster & Merkle, 2004).

**Themes of Transitions**

Meleis’s work advances emerging middle range theory of transitions (Smith & Liehr, 2003). This theory addresses the component parts consisting of types of transitions, facilitating and inhibiting conditions, process indicators, outcome indicators, and nursing therapeutics (Meleis, Sawyer, Im, Messias & Schumacher, 2000). The framework of the middle range theory of transitions (Figure 2) provides a useful visualization of caregiver strain in a child with a chronic condition over the trajectory of the life span of the caregiver.
Figure 2. Model of Meleis’s Theory of Transitions


Messias, a colleague of Meleis, studied parents of children with congenital heart defects (CHD) and identified many life transitions (Messias, Gillis, Sparacino, Tong, & Foote, 1995). She categorized transitions as illusions of normalcy, rude awakenings, managing uncertainty, creating new meanings, and taking stock of costs and benefits (Messias, Gillis, Sparacino, Tong, & Foote, 1995). Such transitions are likely to be similar when focusing on the needs of the parental caregiver of a child with intractable epilepsy.

Transitions are defined as having flow from beginning, midpoint and endpoint (Meleis, Sawyer, Im, Messias & Schumacher, 2000). Anticipation, perceptions and demonstration of the change exist through a period of instability, confusion and distress. Thus, change results in an ending with a new beginning or period of stability or equilibration. Critical points and events are defined by a marker event such as the diagnosis of an illness and followed by experiences and episodes of uncertainty, fluctuation and stabilization. The three steps of Meleis’ transitional framework are described below.

**Step One: Nature of Transitions.** Types of transitions that nurses encounter in working with patients and families have been identified as developmental, health and illness, situational, and organizational. Patterns refer to whether the caregiver is experiencing a single transition or multiple transitions and the interactions that occur among them. Properties of the transition experience include awareness, engagement, change and difference, time span, critical points and events. Awareness is defined as the
perception, knowledge and recognition of the transition experience. Engagement is defined as the degree to which a person demonstrates involvement in the process inherent in the transition. Change and difference is defined as change that can be related to critical or dis-equilibrating events or disruptions in relationship routines. Differences are characterized by feeling different, being perceived as different, or seeing the world and others in different ways.

**Step Two: Transition Conditions, Facilitator and Inhibitors.** Humans have initial perceptions of, and attach meanings to, health and illness situations. These perceptions and meanings are influenced by the conditions under which a transition occurs and in turn influence the transition. Each caregiver has his or her unique environment and conditions that facilitate or hinder progress toward the attainment of health. Meanings attributed to an event can either facilitate or inhibit a healthy transition. Personal, community, social, educational, economic, cultural, and religious influences can facilitate or impair transitions. For example, cultural beliefs and attitudes can affect transitions due to stigmatization or feelings of shame. Social status can affect the experience and means to deal with transitions. Preparation and knowledge are helpful in anticipating what to expect during a transition and which techniques are used in management of the transition.

A community is needed that is inclusive of role model support, and advice from knowledgeable health care providers and who can answer questions is helpful to the caregiver. Societal conditions can be a facilitator or inhibitor of transitions. Beliefs embedded in a specific culture can represent a transitional event as stigmatized and
attribute stereotyped meanings. Gender inequality, marginalization and cultural norms can all inhibit transitions. In other words, each transition is an individual experience based on context and an individual’s personality.

**Step Three: Pattern of Response Process Indicators.** Feeling connected is defined as making new contacts and continuing old connections with family and friends. A new and emerging relationship can be developed between the caregiver and the care recipient. The relationship might be multidimensional, being both supportive and non-supportive in nature. One of the characteristics of transitions is the creation of new meanings and perceptions. Caregivers, exhibit growing confidence and coping as they come to better understand the diagnosis and treatment, and learn to live with certain limitations. Also important in the transition process is the caregivers’ awareness of the level of resources.

**Outcome Indicators.** Mastery of skills in the caregiving situation include assessing symptoms, implementing a plan of care, adjusting the plan when needed and working collaboratively with health care providers. Reformulation refers to the fluid dynamic shift of the caregiver’s interaction with the social, political, economic and cultural environments. Life situations that can trigger a transition can be developmental or situational such as marriage, pregnancy, illness or a change in employment.

**Transition Framework used in the Pediatric Population.** Wong (2004) used the transition framework to study the chronically ill pediatric population. Findings revealed parents’ feelings of being physically overburdened and emotionally in turmoil. Family dynamics, shifts in responsibility, and continuing with the primary role of parenthood
were further complicated with the need to adopt the new role of child advocate necessitated by multiple professional interactions with health care providers, social workers and educators. Preparation and knowledge of the disease process, caregiving skills, and advocacy, all elements of Meleis’s Transition Model, were all experienced by the families studied (Wong, 2004). Socio-economic adjustments also were noted as a transition when caring for a child with a chronic disease. Transitions theory was useful in providing a general understanding of the caregiver’s journey over-time and the changes they undergo.

**Schumacher’s Transactional Model**

Schumacher, Beildler, Beeber, Gambino et al. (2006) have developed a model of caregiving skill. The model includes concepts of the demands of the illness situation, patterns of care, caregivers’ responses, and patients’ responses. The model focuses on caregivers and care recipients and the process or transaction that occurs in the caregiving role. Schumacher, who studied under Meleis, used concepts from symbolic interaction and structural role theory in the formation of the transactional model of family caregiving skills. Schumacher’s model is rooted in Meleis’ transition framework but is specific to the study of caregiving. Schumacher conducted 107 interviews using the Family Caregiving Skill Interview, a semi-structured interview guide to assess what caregivers do and how they provide care (Schumacher, Stewart, Archbold, Dodd & Dibble, 2000). The pilot study included family caregivers of individuals receiving treatment for cancer. Grounded theory techniques as described by Strauss and Corbin (1990) were used to
analyze data and conceptualize relationships. The main goal of the study was to assess family caregiving skills so that skill-building interventions could be offered when needed.

Results suggested that caregiving is a process of transactions. Caregiving processes are made up of cognitive, behavioral, and interpersonal processes. The sub-processes include monitoring, interpreting, making decisions, taking action, and making adjustments. The needs to access resources, provide "hands-on care", work together with the care recipient and navigate the health care system are integral sub-processes of caregiving. The transactional model demonstrates the interaction of collaborative care between the care recipient and caregiver and how it is driven by the demands of the illness. The care recipient strives for independence and ability to provide self-care. In times of need, the caregiver steps in to help with the transaction of providing care. This process is interactive and collaborative in nature. Schumacher, Beidler, Beeber and Gambino (2006) state that demands of the illness include symptom management, nutritional support, response to illness behaviors, modification of usual activities due to illness, and interpersonal care. Other contributing care factors include implementation of the treatment regimen, management of acute illness episodes, use of community resources, and navigation of the health care system.

Schumacher, Beidler, Beeper and Gambino (2006) define caregiver response as the processes that take place in response to illness demands. The qualities that influenced a caregiver's response included emotional reaction, physical and cognitive abilities, knowledge and previous experience about caregiving, and affinity for caregiving.
Caregiving processes are complex in nature and how the caregiver and care recipient collaborate and work through the process or transaction is an integral part of a good outcome.

The transactional model of family caregiving skill and the middle range theory of transitions are complementary. The transitions model addresses the process of transition experiences, facilitating and inhibiting conditions, process and outcome indicators, and nursing therapeutics. Meleis, Sawyer, Im, Messias and Schumacher (2000) identified essential properties of the transitions experience as awareness, engagement, and change over-time, and critical events. Both Schumacher and Meleis worked on the central concept of transitions in nursing. Schumacher takes the transitions process to the next evolutionary stage of transactions (Schumacher, Stewart, Archbold, Dobb & Dibble, 2000). Both the transition model and the transactional model of family caregiving skills are useful frameworks to guide the study of the relationships and needs of the caregiver and care recipient.

Transition theory offers a way to recognize the changes across the caregivers’ and care recipients’ life span. Resiliency theory provides further clarification regarding whether transitions are likely to be successful, or not. The theory of transitions and the transactions model help to guide the understanding of how best to care for the caregiver of the child with intractable epilepsy.
Summary Statement for Chapter 2

Resiliency Theory, Meleis’ Theory of Transitions and Schumacher’s Transactional Model provide theoretical support for understanding parental caregiving. All three focus on the changes in parenting function and relationships created by the diagnosis and the new role of caregivers. Although the process of reconciling these imposed changes and integrating the new roles and expectations are emphasized, none of the three specifically address the challenges of combining the roles of parenting and caregiving. However, in combination they add structure and background for the current study of the parental caregivers‘ daily experiences and long-term challenges.

An understanding of the complex daily needs of caring for a child with epilepsy is essential for better case management and support of the caregiver by the health care providers. A qualitative approach of asking questions and listening to parents‘ perceptions regarding situational and developmental transitions provides a useful way of understanding parental concerns and parents‘ responses to transitioning from caring for a seemingly healthy child to one with intractable epilepsy.
CHAPTER THREE

Methodology

Introduction

The purpose of this study was to describe the experiences of being a parental caregiver of a child with intractable epilepsy. Specifically to: (1) to describe the caregiver transition from caring for a healthy child to caring for a child with intractable epilepsy, and (2) to study families that provide caregiving, to identify the challenges, and learn how they address the intricacies and nuances of caring for a child with intractable epilepsy. This was done from the parental caregivers‘ perspective.

Study Design

A qualitative descriptive design was used to explore the following research questions:

1. What do parents of children with intractable epilepsy find helpful or challenging during transition from caring for a healthy child to caring for a child with intractable epilepsy?

2. How do parents of children with intractable epilepsy cope with caregiver strain during transition from caring for a healthy child to a child with intractable epilepsy?

3. What factors enable parents to transition from caring for a healthy child to a child with intractable epilepsy?
Qualitative descriptive design is directed toward discovering who, what, and where of events and their basic nature or shape (Sandelowski, 2000). It is intended to convey the subjective experience of the participants without interpretation by the researcher, until the data analysis phase. This approach is useful in describing day-to-day care management and its perceived effect on quality of life for the child, parent and family members. Because there is little known about the caregiving experience, it was necessary to first gain a general description and understanding of the experience. A qualitative descriptive design was the best method by which to broadly explore the experiences of a heterogeneous group of caregivers.

**Setting**

Parents were recruited from the Boston Children’s Hospital epilepsy program. This program consists of a 29-bed neuroscience unit and an outpatient clinic program. Six inpatient beds are designated as a long-term epilepsy monitoring unit and are specifically used for epilepsy surgery workup, diagnosis, and brain mapping of seizure foci captured via 24-hour electroencephalogram (EEG) video monitoring. This unit is highly specialized and cares only for epilepsy patients. The unit is designated by the National Association of Epilepsy Centers as a level 4 epilepsy center and is a referral center for the Northeastern United States. The outpatient epilepsy clinic sees 4,200 patients annually and is made up of an interdisciplinary health care team whose primary focus is the management and care of children with epilepsy. The rationale for using this
site was the multidisciplinary team’s expertise and ability to recruit participants who are parenting children with intractable epilepsy.

**Sample**

A purposive sampling method was used to select the subjects. The parental caregiver of a child with intractable epilepsy was defined as a person in the caregiving role who was both a biological parent and a primary provider of care for the child, from prior to the onset of seizures until a period of at least two years after intractable epilepsy was diagnosed. Inclusion criteria for this study were as follows: 1) the biological parental caregiver who provided a minimum of twelve hours of care each day in the home to a child between six to twelve years of age with intractable epilepsy who has failed medication management and any adjunct therapies (e.g., vagus nerve stimulation, ketogenic diet, and /or epilepsy surgery), and 2) the child must have had a past history of normal health status prior to an insult such as a central nervous system infection, meningitis, degenerative disease, encephalitis, or high fever which caused going from being a “well child” to one with intractable epilepsy. Exclusion criteria were (1) a non-English speaking parental caregiver since the researcher’s primary language is English, and (2) a parent who lived outside a 100-mile radius of Boston, unless the subject consented for the interview to be conducted at the hospital.

A purposive sample of twelve parental caregivers who care for children with intractable epilepsy was recruited from the epilepsy clinic with the help of the nurse epilepsy coordinator. The final sample size was achieved when data saturation was
reached. Saturation was defined as the point when no new information was being obtained from additional interviews (Morse, 1995). Redundancy of data assumed saturation of data and comprehensiveness of data collection (Morse, 1995). Basic demographics of participants including gender, race, and employment status, family composition, current age of child, gender of child, and age at diagnosis were collected.

**Protection of Human Subjects/ Recruitment**

Permission for the research study was obtained from the Institutional Review Board (IRB) at Boston Children’s Hospital and Boston College prior to the initiation of the study. (Appendices C, D) Adherence to the Health Insurance Portability and Accountability Act (HIPAA) was followed.

Names of potential participants who fit eligibility criteria were obtained through the epilepsy nurse coordinator. These names were further screened by the health care team prior to subjects being approached by the principal investigator at the time of the child’s clinic visit. Potential research participants were given a letter of consent to learn more about the study and were contacted within 72 hours following the clinic visit by telephone. At this time the principal investigator offered to answer any questions or provide additional information. For those who wanted to participate, a mutually agreed upon date, time and place were arranged. At that time the informed consent was reviewed, questions answered, and signatures obtained. Participants did not receive compensation for their time.
Data Collection

In depth open-ended unstructured interviews were conducted with every study participant (Appendix B). Questions were reviewed for content validity by subject matter experts, specifically the nurses and physicians who care for children with epilepsy. Each interview lasted approximately 60 minutes. Both parental caregivers were interviewed together, if available. Twelve interviews took place, eleven in the family’s home, comprising five couples, one stay-at-home mother and another mother preferred to be interviewed in a private office at Boston Children’s Hospital. The interviews were audiotaped with a digital tape recorder and a backup digital tape recorder, and data were transcribed verbatim by a HIPAA, CITI certified transcriptionist. The transcribed data were reviewed and shared with the parental caregiver for any needed clarification. For example, one Indian couple was contacted for clarification due to a language accent that on occasion was difficult to understand. The interview tapes were coded by pseudonym and stored in a locked file cabinet in a private office to which the principal investigator has sole access.

Data Analysis

Tapes and transcripts were reviewed by the principal investigator to ensure that the interviews were transcribed verbatim. Data were analyzed by conventional content analysis, meaning coding categories are derived directly from the text data. The transcripts were read multiple times to obtain a general sense of the content and then the process of coding from in vivo codes to categories, and then either subcategories or
patterns, took place (Lincoln & Guba, 1985). The Hyper-RESEARCH 3.03 qualitative software computer program was used to arrange and analyze data. The data were coded by using the participants’ own words. These in vivo codes remained close to the data and comprised all the descriptive phrases, expressions and meaning units that were specific in nature to the experience of the caregiver of a child with intractable epilepsy. The in vivo codes were compared both within and across documents and similar codes were clustered together into categories and relabeled and defined. Lastly, the categories were examined, and based on the data either combined to define emerging patterns that described the experience of caring for these children in general terms or subdivided into sub-categories to account for the particular aspects that defined each category (Lincoln & Guba, 1985).

An example of the coding process is documented in Table 2.
Table 2

Sample of Coding Process

Worksheet #2 Medication

<table>
<thead>
<tr>
<th>CODES</th>
<th>CATEGORY</th>
<th>THEME</th>
</tr>
</thead>
<tbody>
<tr>
<td>videos of sitting on her—screaming at the top …I mean like a crazy person”</td>
<td>side effects</td>
<td>navigation meds</td>
</tr>
<tr>
<td>—drunken sailor” → she would fizzle out”</td>
<td>physical/behavioral</td>
<td>medication: drunken sailor”</td>
</tr>
<tr>
<td>—just look physically destroyed”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>—he’s like a drunken encephalopathy pt.”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>turned into a psycho</td>
<td></td>
<td></td>
</tr>
<tr>
<td>he wanted to kill himself</td>
<td></td>
<td></td>
</tr>
<tr>
<td>lost attention</td>
<td></td>
<td></td>
</tr>
<tr>
<td>math, reading difficulty</td>
<td></td>
<td></td>
</tr>
<tr>
<td>loss balance, coordination</td>
<td></td>
<td></td>
</tr>
<tr>
<td>cause behavior issues, vomiting, sedation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>increase side effects of meds</td>
<td></td>
<td></td>
</tr>
<tr>
<td>he was an unholy mess”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>cumulative meds effects</td>
<td></td>
<td></td>
</tr>
<tr>
<td>multiple med changes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>navigating meds</td>
<td></td>
<td></td>
</tr>
<tr>
<td>brought in healthy child got one back who’s sleepy &amp; with a walker</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
assessing the pt. in the moment—you’re getting a snapshot”

advocating for meds being pushy in a nice way

constant challenges of medication changes
decrease meds=increase seizures
increased meds=increased sedation
ongoing titration medications
med changes affect child, school, interactions, friends, well-being

medication station

belly up to the bar to take his meds

need to reach therapeutic levels

long-term side effects-conceiving for females
concerns long term effects of meds esp. in girls

medication station

managing meds/drug levels

long-term side effects/female
medication regimen is not settled yet
no long lasting effective drugs
powerful drugs
advocating for meds

This coding technique was repeated with two other research advisors during numerous meetings to reach mutual agreement on the concise coding scheme, themes, and subthemes. The process of primary researcher and two research advisors mutually rereading text, deciding on coding, themes, and subthemes brought overlooked text to the foreground and recoding took place. Consensus regarding frequent themes, non-frequent themes, indexing, synthesis, and interpretation occurred.

Rigor

The transcripts were analyzed and independently coded by the research advisor(s) trained in qualitative research and the principal investigator to determine inter-rater reliability in terms of data analysis, coding, rigor, and adherence with the qualitative descriptive method. Having three readers read the raw transcripts, identify mutually agreed upon themes, and interpretation enhanced trustworthiness (Lincoln & Guba, 1985). This process occurred over six meetings and by electronic mail communication establishing credibility and includes listening to the voices of the participants and being accurate in description of the data with representative group of participants. The rigor of
the study was ensured by asking the appropriate introductory question and reviewing or modifying interview questions, as needed. Review of data, coding techniques and recoding were analyzed and rechecked for appropriateness of fit and relationship. After the interviews were analyzed there was a member check conducted with five research participants (Lincoln & Denzin, 2005). The researcher contacted parents by telephone and reviewed narrative accuracy checks and interpretive validity. The five parents from different interviews affirmed that the narrative and summaries accurately reflected their experiences and viewpoints. The results, in their entirety, also were reviewed by a physician and two advanced practice nurses who practice in neuroscience to ensure credibility.

Audit Trail

An audit trail was documented. This technique establishes dependability, confirmability and objectivity (Lincoln & Guba, 1985), thus yielding credibility and authenticity while providing validation of the findings. Written field notes provided a richer description of family/parental dynamics, environment, relationships and family/parental functioning. Field notes were useful in understanding how parental caregivers function and cope on a day-to-day basis. Written field notes in a form of a chronology helped characterize the parental caregivers’ day-to-day challenges in caring for their child. The audit trail was inclusive of all transcribed data, written field notes, coding decisions made and the rationale for them. The process is analogous to
bookkeeping and keeping a systematic tracking mechanism for data collection (Lincoln & Guba, 1985).

**Summary Statement for Chapter 3**

This study is designed to describe the experience of being a parental caregiver of a child with intractable epilepsy. The qualitative descriptive design is key to answering the research questions and collecting raw data from the parental caregivers without interpretation from the researcher.
CHAPTER 4

Analysis of Data and Findings

Descriptive Characteristics of the Study Sample

The sample included parents from seven families - two families were represented by mothers only; for five families, both mothers and fathers participated. The interviews took place in the child’s home except for one interview that took place in a private office at the hospital. All study participants lived in the suburbs of eastern Massachusetts within a 40-mile radius of Boston. Of the twelve parents interviewed all were employed except for one who was a „stay-at-home‘ mother. All parents were married and living together with their children. The sample consisted of five males, seven females, all Caucasian except for one married couple of Indian decent. Demographic information for the sample is presented in Tables 3.
<table>
<thead>
<tr>
<th>Family Members*</th>
<th>Sex</th>
<th>Marital Status</th>
<th>Residence</th>
<th>Race/Ethnicity</th>
<th>Education Level</th>
<th>Occupation</th>
<th>Current Age</th>
<th>Age of Onset</th>
<th>Siblings</th>
<th>Current Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bob</td>
<td>Male</td>
<td>Married</td>
<td></td>
<td>Caucasian</td>
<td>College</td>
<td>Grocer</td>
<td>10</td>
<td>4</td>
<td>12 y/o sister</td>
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<tr>
<td>Bob’s Father</td>
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<td>Caucasian</td>
<td>College</td>
<td>Business</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bob’s Mother</td>
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<td>High school</td>
<td>Business</td>
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<td>Business</td>
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<td>9</td>
<td>24 y/o sister</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
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<td>Shared suburban home</td>
<td>Caucasian</td>
<td>High school</td>
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<td>Caucasian</td>
<td>College</td>
<td>Business</td>
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<td>4</td>
<td>13 y/o sister</td>
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<td>Nurse</td>
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<td>Nancy</td>
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<td>Business</td>
<td>11</td>
<td>4</td>
<td>13 y/o sister</td>
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</tr>
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<td>Nancy’s Father</td>
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<td>Business</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<td>Physical therapist</td>
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<tr>
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<td>5</td>
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<td>Caucasian</td>
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</tr>
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<td>Technical school</td>
<td>Homemaker</td>
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<tr>
<td>Peter</td>
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*use of pseudonyms
**Data Analysis**

The interviews revealed the complexity and dynamics of family life and life transitions. Parents described the real life context of living with a healthy child and the transition to caring for a child with documented intractable epilepsy. Analysis of the data collected revealed five themes. Theme one, titled “Journey to Diagnosis, Connecting all the Dots”, revealed the transition from caring for a well-child to an ill child and formulating a working diagnosis of epilepsy. Theme two, titled “Drunken Sailor” symbolized the ongoing need for medication management, titration, dealing with side effects and the perseverance to get the medication regimen right. Theme three was titled “Negotiating and Advocating for Education” and dealt with issues around dealing with school administrations and ensuring that children received an appropriate and quality education. Theme four was titled “Provider Challenges, Communication and Partnering.” This theme was further divided into three subcategories: 1) knowing the child, 2) partnering with the health care team, and 3) the journey of transitioning from initial diagnosis to a child with intractable epilepsy. The fifth and final theme was titled “It takes a Village: Siblings, Family Members, and Friends” and symbolizes the support network of the family. The analysis for each of these themes is explained below.

**Theme 1: Journey to Diagnosis: Connecting All the Dots**

Epilepsy presents in many different ways, it can be dramatic as in a grand mal seizure with the child experiencing airway compromise and cyanosis to the other extreme of a brief lapse of concentration as seen in absence seizures. Seizures can have a pattern,
e.g., revolving around nocturnal sleep cycles, as specific as seizures occurring on awakening or no pattern at all. The presentation of epilepsy can be sudden, it can present with diverse symptoms that can easily be missed by the parents over an extended time period. This theme speaks to the process that included making the right diagnosis after subtle or large changes in the child’s seizure presentation. One parent stated:

So, I didn’t understand sort of what I was looking at, or what I was now in retrospect looking at was my son sort of deteriorating and gradually becoming really full-blown encephalopathy by the time he was five? I had no frame of reference.

Another parent sought out medical consultation from a neurologist and a sleep medicine physician for her seven year old child who presented with significant night terrors and sleep disturbances. The physician stated that these were night terrors and that she would grow out of it. The mother was told to follow a strict bedtime routine and promote good sleep patterns. She stated that when she initially brought her new baby home from the hospital she thought her infant’s sleep patterns were abnormal.

I knew something was wrong I knew it, and I felt that the doctors kept calling me crazy, and I felt that they just dismissed me, and that’s expected because they weren’t with her all the time, but I always say the mom knows, they know.
Throughout the interviews, parents clearly articulated the need to persistently advocate and to seek medical consultation for their child, knowing something was seriously wrong. The parent of a seven year-old child stated:

Something’s not right, and then for doctors to just kind of blow me off and I mean, I felt like they were telling me I was crazy. So, for five years I fought and fought for that girl, and finally found somebody that would listen which was great, which was really good.

Seizure activity during sleep can be misdiagnosed or labeled night terrors or sleep walking. One parent would hear their nine year old child during the night, “He would run up and down the hall and then he’d go back to bed; he’d never wake up,” so we called the pediatrician. The mother stated the physician’s impression was:

Oh it's sleepwalking, like well, okay, he’s doing it, he's yelling, he's screaming. Like, well okay, it's night terrors and we found him outside in the car. So he’d gone from his room, out the door, into the car which was open because it was midnight, and we heard the door open and we called the pediatrician, oh, it's just sleep walking, night terrors….that strangeness goes on.

Abnormal behavior changes can be indicative of the onset of epilepsy. Another parent stated that at home their eight year old son’s behavior was becoming increasingly abnormal.
He’d pee in different places and you’d just ask him why, and he’d say well, I didn’t want to miss the commercial….I didn’t want to miss the show, or something. It was almost like he was going backwards brain-wise, judgment-wise.

In this case, parents consulted a psychologist, who collaborated with a psychiatrist regarding the child’s behavior issues.

Well, from March of last year until July, we were pretty much asking for an EEG because we were sort of explaining the symptoms, but I guess we didn’t use the word seizure soon enough. No, but once we started using it and it looked like it, then we were taken more serious. At first it looked like sleepwalking, then dropping and shaking, and then it just went to shaking. So, it was almost like it was morphing over-time.

The psychologist thought the child was having seizures, the psychiatrist disagreed. The pediatrician was consulted, and it was decided that the child should undergo a sleep study.

As noted in the example above, epilepsy can present in subtle ways. Another set of parents described their son playing videogames, and stated:

He’s not answering us; he’s just zoning out being a typical adolescent and a behavioral issue. I would be sitting next to him while he is doing his homework and notice that he was on the same problem five minutes later.
One day, I noticed his pupils dilated and I'm talking to him and then he
came back and I'm like, my God, he doesn't even know I'm here.

The same boy would be playing soccer and actually physically stop in the game and not
know where he was. One parent recounted:

The coach said –Get the ball, and once again in retrospect he was
having a seizure. We’re like this kid does not pay attention.”

Another mother stated that on three different occasions during playgroup
meetings she noticed her five year old –daughter walking funny, like she was dizzy.”
The child’s EEG was normal and the working diagnosis was migraine headaches, as there
was a family history of migraine headaches. Later the child presented with a high fever
and multiple seizures. Following further evaluation including an MRI and a long-term
monitoring EEG, the child was diagnosed with temporal lobe epilepsy.

Another uncommon presentation of seizure onset was in a six year old child who
blinked her eyes then dropped her chin to her chest. The child resisted going to the dining
room table to eat her food because her seizure activity often would result in her spilling
her milk and she would become very upset. The father stated, –That was a mental sort of
phobia she developed.”

One seven year old boy presented with his first grand mal seizure on awaking
from sleep. His father was caring for him while his mother was on a business trip
two-half-hours from home. The father stated, “I mean I heard him kind of gurgling, making that kind of a funny noise. I went to check on him and he was convulsing. His mother stated “I could not get home fast enough at that point. I’m crying the whole way home.”

Theme 2: Drunken Sailor: Medication Management

One of the challenges revealed in all the interviews was the constant challenge of medication management. In order to decrease the number of seizures, a child is often initially prescribed a high dose of anticonvulsants; a common side effect is sleepiness and sedation. Titrations of medication(s) present an ongoing struggle to balance the child’s ability to function and participate in activities of daily living while simultaneously maintaining seizure control. Sometimes the choice has to be made between giving a lower dose of medications and tolerating mild seizure activity or increasing a medication dose that results in sedation of the child but decreased seizure activity. The theme “drunken sailor” speaks to the choice that parents have to make with medication: did they want their child awake and alert but having seizure activity, or sedated but seizure free? For parents this presents a difficult troubling decision.

The interviews revealed that the quest for finding the right medication(s) and dose can be an ongoing effort and affect the child’s school participation, interactions with friends, and general well-being. One mother stated:
The daycare told me that they were now worried, and not even sure if he could really stay in school anymore because they said he can't do anything in the school, and I said what do you mean he can't do anything? He really learned by doing and they described he’d go out in the playground and he’d prop himself against the fence and just sort of lean over and sort of stand there and look off into space and drool. He had gone from a child with lots of friends, vivacious, busy, a physical tactile child to a child who could not participate in school and playground activities.

The same five year old child was witnessed sitting down in nursery school at circle time. He would “sort of keel over onto the student next to him and, then he would be dead asleep and they could not pick him up.”

One eight year old child had fallen asleep during the morning bus ride to school and then fell over lying across the seat. At school all the children had exited the bus except this child who was reported missing and the teacher had to find the missing child. For many parents, this was why they found it “potentially dangerous” for their child to ride the bus. The solutions presented to the parents, were for the child to ride on the special needs bus or for the parents to drive their son to school.

Experimenting with medications to find the right medication, dose, and fewest side effects is at times a long-term process. Parents stated that common side effects were behavioral agitation, rashes, vomiting, and sedation. Antiepileptic medications require sufficient doses to reach a therapeutic drug level. Tolerance of side effects, while finding
the best antiepileptic medication and reaching therapeutic levels is often a trial and error process. Moreover, just because a drug is effective in the short run does not mean it will remain effective over time, thus requiring constantly adjusting the child’s medication regimen. The majority of parents interviewed stated that finding an effective medication regimen was an ongoing and often lengthy process. One parent noted that when starting their son on the first round of medications:

It was horrendous, absolutely horrendous. He had every symptom in the book. He couldn’t walk two doors down to his friend’s house without throwing up. Just the motion sickness was absolutely horrible. He couldn’t ride in a car. We had trash bags everywhere, stuffed in every orifice of the car just to get him somewhere.

When the child reached his therapeutic level it was —like a light switch, he hit his level. The dizziness stopped, the nausea stopped.”

Behavioral side effects of antiepileptic medications can be problematic. One parent stated her six year old daughter experienced significant mood swings.

It turned her into like a psycho. I don’t know how else to put it. It was horrible. It turned her into… I mean I have videos of like a hundred and forty pounds sitting on this monster. She’s fifty-five pounds and she is bucking me off of her. Running down the street, screaming at the top… I mean like a crazy person.
Another ten year old child was reported by his mother to be aggressive towards his father, threatening his sister, and on one occasion when the family was all attending a social function the son threatened to blow up the car because he was not happy with the situation. In school, the same child stated that he wanted to kill himself.

An ongoing concern of the twelve parents interviewed was the long-term effects of the medications and the ever-changing adjustments to keep the seizures under some degree of control. One parent stated in regard to her daughter’s learning style:

She has a decreased attention span, and math and reading are difficult. Her balance and coordination isn’t quite there. She used to be a three year old determined to learn to ride her bike. These are powerful drugs for a little girl. What is going to happen overtime and as her body changes and develops, what long-lasting effects will occur, are there going to be side effects when she conceives and grows up? As a parent we do worry where her future lies and challenges she will face medically because I think since the time of detection of her seizures until now, one thing that baffles me is still her medication is not settled as yet.

Theme 3: Negotiating and Advocating for Education

Some of the interviews revealed a need for special educational programs. Parents were confronted with learning a new terminology (i.e., Individual Education Plan (IEP), 504B, 101A). One mother stated:
I had a vague idea about IEP’s, like I knew they existed. I didn’t know the difference between a 504B and an IEP. I didn’t know why I would need one or the other, and I certainly didn’t know the array of services that the school might provide, and as I said I was lucky because the school kept saying well, I think you should add this, and how about this, and he needs a 101A, and here we are loaded up with one of every flavor, and I obviously heard from other families that just even getting the school to sort of want to be on board can be problematic.

Learning terminology associated with a diagnosis of epilepsy and specific needs of each child is part of the transition parents undergo, and they need support in this from the health care team. Communication with educators is especially important as numerous decisions regarding a child’s educational needs must be considered. These include but are not limited to whether to pursue ‘mainstreaming’ and /or special education and support. One mother thought the public school was trying to accommodate her seven year old child’s needs but that her daughter was just ‘getting pushed along’ and that she needed more a ‘one-to-one’ focus from the teacher to address her educational needs. This mother inquired about a private school that specially addressed children with special learning needs but the cost was $65,000 a year. She did not think the town would pay for these services unless she advocated and sought legal assistance.

One set of parents interviewed moved to the adjacent town since the public funding for special needs education was more favorable. Another parents’ child began in
a parochial school that was not well equipped to handle the child’s behavior outbursts. He transferred to a private school where he later was asked to leave. The father stated his son would bolt out of the school building and it would get to the point where the school principal would threaten to call the police.

They didn’t, but the nurse or someone would catch him and we’d get the phone call all the time, you need to come pick up your son, so you would have to leave work and I don’t know what to do with him. He’s got this great personality. When he’s on he’s on, but when things fall apart, he’s just another person.

Eventually, he attended a public school system that was able to address his needs, and he thrived. The public school had an “adjustment counselor” assigned to the classroom. So when there was a behavioral problem, he was not suspended but they dealt with the issue in real time. “That was a hard pill to swallow. He can’t even function in a regular classroom.”

Parents had the need to strike a balance between how much one-to-one attention their child received and how much time was spent in-group learning in the larger classroom setting. One father stated:

We prefer that she does not study in isolation, only doing special education and doesn’t get to socialize. I feel personally, that she will not reach her fullest potential if she is isolated in a special needs classroom.
Parents expressed that partnering with the school nurse and educating teachers regarding their child’s seizure type, onset, known triggers, plan of action, safety precautions, and education of fellow students was at times labor intensive. Parents stated that teachers and nurses had different comfort levels when dealing with their child and since the student navigated through the different classrooms and later to different schools, the process of educating, advocating, and negotiating seemed to be never ending. One school nurse called a mother with an actively seizing child and stated:

I walked by and peeked in the classroom from the hallway, he looks pretty good and I said you know, I’m thinking it will be hard to assess his mental status from across the room, would you mind going back and just asking him a few questions to see if he’s confused in any way? But that was when I knew we were in trouble because I think she would have preferred to see Paul across a crowded room all the time. It was her own fear.

On transferring to a new school the school nurses were comfortable with seizures, had experience with children with epilepsy, inquired about a seizure action plan and questions around safeguarding the student. –So if you knew exactly whatever kind of seizure activity was going to look like and you could rest easy and the problem of course is that’s not the way it goes, and it is an evolving picture.”

Having the support of a knowledgeable school nurse and a well-informed teacher who both knew the signs and symptoms of a seizure resulted in this parent having a good
comfort level with the school’s ability to meet her child’s needs. Communication was key to a good relationship with the school nurse and teacher, having to be away from him for eight hours, it helped to know the nurse would visit the classroom and make sure he was okay.”

Another parent was asked to accompany her eight year old child on a school trip because the school nurse needed to stay at the school to care for the other children. If the parent could not accompany the child, he would have to either not participated in the trip or there would be the need to hire another school nurse to accompany the child. I’m like oh, all right I guess I’m going on the field trip now and I don’t know how long that will happen for but that’s one of the little things that we have had to adjust too.” One school nurse was amazing” with her plan of care, education of staff and fellow students, and the plan for privacy when administering rectal diastat in the classroom. Overall, open communication with the school teacher, the nurse and having a seizure plan was effective if all the team is educated, and had a comfort level of how to safeguard and care for the child.

**Theme 4: Provider Challenges, Communication and Partnering**

The parents’ capacity to provide care for their child is dependent on good communication and partnering with the health care team. The ability to get information, access, and collaborate with physicians, nurses, and administrative personnel is paramount to achieving the best care possible. Partnering with the health care team and its ability to know the patient and their family’s wants, needs, desires, and expectations is
critical to formulation of a strong partnership. A solid, working partnership between the family and health care team is needed to provide care, guidance, and education over the course of treatment, but especially during the transition from the onset of seizures, to diagnosis, to eventual ongoing management.

Finding the right fit is a prerequisite to successful partnering with a health care provider. One mother who is a nurse stated:

I’m interested in participating in my son’s care, and on the other hand I don’t want to do anything to get in the way or to get myself confused. What would you recommend in terms of my reading, because I really would like to get pulled together here and the physician said, “Oh, ma’am I recommend that people don’t read anything.”

This example is extreme but it shows that finding the right pediatrician and neurologist with the ability to listen to better guide a parent is paramount.

A family that lived overseas in London for a few years experienced a “laid back attitude” from providers. The mother stated that the new British physician made her feel like a hypochondriac and the physician would say “Just relax, calm down, these are fits.” Her daughter was having more and more seizures and the physician kept saying - “Increase the medication, increase the medication, and I was like that’s not working.” Throughout all the interviews parents made it clear that there was a need to obtain a second opinion and build a health care team including a primary care pediatrician,
epileptologist, nurse, and sometimes a psychiatrist or behavioral therapist to care for the child.

The parents expressed that after their child’s diagnosis, communication with the health care team could be challenging. Parents were confronted with questions such as when to report seizure activity, what was the norm for the child, what changes were likely to be problematic. One mother’s view was:

I thought I was just supposed to collect great data for the physician. So we cleared up that confusion that we had and I took her at her word that we should now call, and the whole next year was sort of a study, and my child kind of slowly going downhill; the hard part about how often are we to communicate, and do we communicate all that we know?

Being able to deal with a consistent medical team and that knew the patient was a recurrent concern in the interviews. For example, one parent stated:

We didn’t see the same doctor and that was really frustrating because we had to tell the whole story all over again, every single time, and it felt like we were starting over again. We weren't working with someone who knew our son. I think that was kind of the biggest frustration in the beginning.

If the team listened to, and understood, the parent’s story, this helped decrease frustration. Another parent stated, “We couldn't seem to get anybody to listen to what
we had to say or at least help us put the pieces together; people were working in vacuums.” System issues arose with how health care practices were designed. One mother had trouble navigating the practice when telephoning the physician’s secretary. The timeliness of the secretary accessing the physician or triaging the issue to a member of the nursing staff was problematic. One parent stated:

I am calling… I’m calling all the time, and I’m trying to just report the clinical information. I kept calling and then the rigmarole would ensue, so in desperation I had my father who is a physician fax over a request for permission to speak with him, physician-to-physician to help convey the clinical picture.

Another barrier was learning how to navigate the health care system. Most parents revealed that experiences in using the emergency department was not ideal since the team was not knowledgeable about the child’s situation and specific needs and nuances of care. However, parents needed guidance in how to access the health care system for quick consultation if emergency department visits were to be avoided. One parent stated:

If I take him to the emergency room, they’re going to have no context; they’re not going to know what to do, and they’re not going to understand.

A physician after caring for a child over a period of time told a parent, we always have an on-call person who can examine kids. You know if you
were worried why didn’t you bring him in? I said because no one ever
told me that that was an option.

Another parent stated, “You needed to be informed, use websites, get organized and have
all your questions listed in preparation for your health care appointment.”

Understanding and ensuring care access is problematic for parents. One working
parent stated it was very labor intensive negotiating with insurance companies and that
finding the right health care providers was a fulltime job. Access to the health care
provider in a timely manner was crucial to the management of care. “I like the fact that I
could call the nurse at any time during their hours, and I knew somebody was going to
get back to me at work. If they couldn’t get me at work, they called my house.”

Another parent stated:
When he was having problems with the medication, the nurse’s hotline
was great because I knew there was someone knowledgeable that I could
just go to and they talk to you like a normal person, which is great.

Theme 5: It Takes a Village: Siblings, Family Members and Friends

The very important role that family and friends played was clearly articulated by the
parents.

**Siblings.** Interview data indicated that siblings were of great support in caring for a
child with epilepsy; however they had their own special requirements. One thirteen-year-
old sibling appreciated visiting her brother when he was in the hospital. She wanted to
visualize the setting and to meet the health care providers caring for him. She even requested an appointment with her brother’s physician to ask questions. The mother stated, “I wanted her to not be scared by what she didn’t know and have permission to sort of ask questions.” Also important was carving out time for the well sibling, “like volunteering at my daughter’s dance or drama class, having my daughter be the big deal,” said one mother. One parent explained how important it was for her “well child” to have the time to talk about having a brother with epilepsy and to focus on what was normal as much as possible.

One sister, two years younger than her ten-year-old brother with epilepsy, was noted to be his guardian. When the siblings would go for a walk around the neighborhood, the sister would “bring him home by the shirttails if he wanted to walk into someone’s house without permission.” Her parents stated, “I guess she gave us a break too—she was the only one.” Another set of parents noted that their daughter was very protective of their son stating:

She does tell us things that happen when we’re not around in terms of when they’re outside playing with friends. They are fifteen months apart in age. He thinks he has a lot of friends, but he doesn’t. I think they tolerate him in the neighborhood because when you get my daughter you get my son. I think that school… as he gets older, I’m getting more and more concerned for him just because what’s it going to be like. Is he going to be bullied? Will he have friends?
One parent stated that the daughter sometimes “gets the raw end of it, not doing things, not going places. Her brother is not behaving well so she’s missed out a little bit. So we feel bad for that.” This couple implemented “girl’s night out,” plus father and daughter dinner dates.

One eventful moment described by a set of parents occurred when one of the siblings had a birthday party and the child with epilepsy had a grand mal seizure. “It was in a movie theater for her sister’s birthday party, very traumatic for not just her and us but for the kids who were at the party too.” One younger sister was called the parents “little helper.” The parents said, “she was always my-stand-by; she was always there and very helpful.” When the seizure frequency increased, it was noted by the parents that the sister was able to verbalize and talk about what went on and how it affected her as well. “I mean we are very open about it. We talk about it. We don’t treat it like’s…. friends, everybody knows about it.”

Another set of parents stated that it was nice when the child with epilepsy has a sibling to communicate with and support her.

Communication with us is different than when the two girls of the same age are communicating. So, it helps when she is playing with her and talking with her and discussing any game or whatever they are doing.

Families. Family support is crucial to caring for a child with intractable epilepsy although more difficult when family members were separated by significant geographic
distance. It was noted that all the parents interviewed had families that would help with respite care when needed. One mother said:

I think what’s harder is the ongoing grind of this, because all of us can rally under the worst of circumstances…it’s more sort of constant stress that I think is actually the harder one to bear up under because it’s a little bit like the trauma scenario, like in actual assaults. You muster your resources, but it’s every day you’re a little bit on guard, and you’re hyper-vigilant and it’s just wearing you down. Your resources begin to get a little thin, that is when family is your lifeline.

One mother stated that it is hard to get babysitters, and said, “I don’t like to leave her, but then when I do, they don’t understand. So it’s usually a family member.”

Family members also become tired and could only offer so much support. One of the young boys who frequently visited his grandparents before the onset of epilepsy was not encouraged to visit following diagnosis since the grandparents regarded his care as too much work; they didn’t want to deal with the numerous safety concerns and his unpredictable behavior. When parents were unable to obtain family support, they relied on each other. One 73-year-old grandmother stated that she grew up next to a boy who had seizures all the time; there were no medications, and she was horrified by the experience. This grandmother who was very frightened because her grandson developed epilepsy turned out to be the most dedicated and vigilant person to look after the boy. The boy’s parent said, “Yes, she over reacted a little bit. She was diligent about what
happened and who watched him. I mean if she could have held his hand in the pool, God love her, she would have…” One father stated that his mother-in-law was a nurse, encouraged the entire family to get cardiopulmonary resuscitation (CPR) certified and basic first aid training.

**Friends.** One parent said —*friends are irreplaceable, from the friend that takes care of your well child while your ill child is hospitalized, to church families that deliver food to your home and provide a network of support.”* One set of parents stated the importance of finding a good support system; you definitely have to have a spouse or a friend who can help you out. —*We have friends that are nurses and one that is a pharmacist. It’s nice to bounce off ideas and frustrations to friends that are health care providers for clarification.”*

Knowing families that are going through the process is helpful. One father stated he worked with a man whose son had complex seizures and was on his fifth medication for epilepsy treatment. One father developed a close friendship with his son’s soccer coach and so the coach was very aware of the child’s seizure history and knew what to look for in regard to symptoms and behavioral issues. When one parent spoke with his child’s karate teacher, the teacher said that his stepson had had a-four-minute seizure and actually ended up in the emergency department. The teacher felt comfortable teaching a child with epilepsy. The parent said, —*mean the medications are working, and it was under control but ten-year-old kids at karate or soccer or whatever, they get embarrassed*
real easy, and the soccer coach and the karate teacher understood.” The parents said
"We've been actually lucky with the people that have been surrounding him are very
aware and very cognizant of his ailments and they are naturally caring people, like that
when anything happens, they will let us know.”

Parents reported that from the child's perspective it was sometimes difficult to
foster friendships or keep them. One young boy who needed to change schools because
of behavioral issues would call his friends at his old school to play baseball, but he would
not get any response and he felt stigmatized by being rebuffed. He eventually made new
friends at his new school and did not want to live in the past.

On a positive note, another parent stated his son and his friends who ride their bikes
together were very supportive. "They are so aware of what is wrong with him; it is
actually funny to think that ten year olds are like we got it, we can do it.” The friends
answered:

If anything weird happens, we will come and get you and they're very
open to having that as a responsibility which I found very funny to begin
with…that kids that age would take such care of one another.

Transparency about the potential situations that can occur with a child with epilepsy and
education of friends is needed. Another set of parents stated that they were "very lucky
to have people around them who help out with the situation that allows us to give the
freedom that he can have at ten which is nice.”
Summary Statement for Chapter 4

The themes that emerged from the interviews reflected a thorough description of parents’ views on caring for their child with intractable epilepsy. There appeared to be a quest for finding the diagnosis and the need for ongoing medication adjustments, sometimes with positive outcomes, sometimes unsuccessful. The journey taken by parents to support and protect their child became successful only after optimal communication was established with health care providers, educators, and coaches. Lastly, support the parents received from siblings, friends and extended family members was essential.
CHAPTER 5

Significance of the Findings

The purpose of the study was to present the parental caregivers’ description of caring for children with intractable epilepsy. A qualitative descriptive approach was chosen as it allowed the participants to express themselves regarding the transition from parenting a healthy child to one with intractable epilepsy. In this way, the participants’ voices could be heard without judgment from the researcher. The researcher analyzed the data using components of the Resiliency Theory (McCubbin & McCubbin, 1993), Meleis’s Theory of Transitions (Meleis, Sawyer, Im, Messias, & Schumacher, 2000), and Schumacher’s Transactional Model (Schumacher, Beidler, Beeber, & Gambino, 2006). In this chapter, the themes that were presented in Chapter 4 are discussed in the context of existing research and theory. Limitations of the study are reviewed and the implications for education, practice, and research are presented.

Discussion of Major Themes

Theme 1: Journey to Diagnosis, Connecting the Dots

This theme described the transition from a healthy child to a child newly diagnosed with epilepsy. The children presented with varying degrees of epilepsy from absence seizures or loss of concentration, to nocturnal seizures, to grand mal seizures. Some of the parents sought immediate medical assistance, and a definitive diagnosis was established. Others experienced a circuitous and painful course, which resulted in delayed diagnosis and treatment. Families had to ask the right questions of the right
health care team member in order to establish a diagnosis, formulate a plan of care, and reevaluate the comprehensive plan over time to flexibly adjust to the ever-changing needs of the child.

Components of the Resiliency Model for Family Stress, Adjustment and Adaptation were evident when the family sought to maintain an established family functioning pattern, and a sense of control while developing new patterns of coping and adaptation. As depicted in the model on page 22, illness is a significant stressor faced by families, requiring adjustments of caregiver roles and family resources. In this study, the family’s perspective of the illness was an important factor in determining their resiliency in needed role adjustments. The diagnosis and comprehensive treatment plan had to be perceived as a manageable family challenge rather than a domestic catastrophe; this perspective allowed for careful appraisals of challenges and better family adaptation over-time (McCubbin & McCubbin, 1993). The twelve parents interviewed in the study exhibited strong family ties, shared values and goals, and a ‘can-do’ attitude; this promoted their willingness to and success in adapting and negotiating changing roles and responsibilities as well as the needed perseverance, while remaining committed to maintaining family integrity. Of interest, the families in this study all demonstrated successful adjustment and adaptation. This is not always the case as the literature indicates that families of children with chronic conditions often have initial difficulties adjusting to the diagnosis, and this may affect long-term adaptation (McCubbin & McCubbin, 1993).
The “Journey to Diagnosis, Connecting the Dots” represents a transitional state. When viewed through Meleis, Sawyer, Im, Messias and Schumaker’s (2000) work on the middle range theory of transitions, it is clear that parents’ discourses reflected the themes of key theory constructs. These include illusions of normalcy, rude awakening, managing uncertainty, and creating new meanings. Seeking and acquiring a diagnosis of epilepsy is a transitional process that causes instability, confusion and distress and progresses to a period of stability or new equilibrium.

**Theme 2: “Drunken Sailor”, Medication Management**

This theme clearly identified the challenge of antiepileptic drug (AED) management. The constant battle of trying to find the right medications and right doses, and minimize side effects was an ongoing challenge for parents. Parental approach to medication dosing ranged across the spectrum. Some families strictly adhered to the prescribed regimen while others, after developing expertise in evaluating the medications’ effects, altered the dosing without prior consultation with the medical team. There was a thread of uncertainty in parents’ statements regarding medication, which was related to the medications, effectiveness (how long the medication would work), and the duration of side effects. Parents also expressed uncertainty in their ability to manage the next medication dose adjustment hurdle. Parents spoke of needing to find the “right cocktail” of medications, which included the titration and constant surveillance for medication side effects. Drug titration is a complex process with the goal of achieving the lowest frequency of seizures while managing the side effects of sedation, behavioral
problems, skin rashes, and gastrointestinal disturbances that are often challenging for the child and the parents.

Resilience was important to successfully care for the child and understand the disease process, plan of treatment, and day-to-day management. Crepeau, Moseley, and Wirrell (2012) studied safety and tolerability in the use of anticonvulsant medication in children. They reported that the choice of an anti-epileptic drug (AED) depends on seizure type/electro-clinical syndrome, potential adverse effects, and ease of use. In the pediatric population, age-dependent pharmacokinetic effects and the impact of potential interactions with other medications, as well as their direct or indirect effects on development must be considered (Katzung, Masters, & Trevor, 2012).

The caregivers in this current study expressed concern regarding AEDS and their numerous side effects, and felt they needed to understand the goals of treatment, potential common and rare adverse effects of AEDs, other concurrent medications, and appropriate therapeutic drug levels in order to best care for their child and promote his or her healthy development. These parental caregiver responses mirror the findings in Crepeau and colleagues (2012) review of pediatric AED therapy; they reported that a close therapeutic partnership between the child, family members, and the treating physician was key to successful therapy.

Schachter and Yerby (1997) studied the management of epilepsy and pharmacological therapy and quality of life issues. They found that persons with epilepsy have cognitive, vocational, and psychosocial needs that may exceed the scope of the
primary care physicians’ responsibilities. They also stated that a team approach of health care and social services professionals are needed to address needs. By establishing and maintaining effective communication among the patient, family members, and management team there is the opportunity to maintain or improve the child’s quality of life through safe and effective pharmacologic treatment.

**Theme 3: Negotiating and Advocating for Education**

This theme captured the need for the parent to advocate for the most appropriate academic setting and for the development of an Individual Education Plan (IEP), including the challenges of partnering with teachers, nurses, and coaches. Meta-analyses and integrated reviews regarding parenting a child with a chronic condition indicated that “special needs parenting” requires additional care which is often unique to the disease and its manifestations in the child (Barlow & Ellard, 2004; Coffey, 2006; Drotar, 1997; Dunst, Trivette, & Hamby, 2007; Grant & Brito, 2010). Across these meta-analyses and reviews, there is strong evidence that children who’s health care needs are met are less likely to miss school days due to illness and better able to focus in the classroom, and perform in school. There are multiple diverse factors which that affect a child’s opportunity for successful learning, for example, clinical intervention and managing chronic health conditions. Other factors, such as socioeconomic status, neighborhood characteristics, quality of education resources, and availability of quality school nursing, are not easy to control (Grant & Brito, 2010).
Frequently, this involves advocating for appropriate educational programming system as well as navigating the health care system (Ray, 2002). The parents in this current study described the need to shop for the right school in the right community, one that was both committed to providing educational services with the necessary resources for meeting the educational needs of children with special needs. Requisite resources included the right classroom setting and appropriate nursing support. The literature indicates that this is a concern for all families, but is heightened when a child has a chronic condition (Grant & Brito, 2010).

Miller, Condin, McKellin, Shaw, Klassen, and Sheps (2009) found that systemic and organizational barriers to continuity of care are common, including across the trajectory of educational services. Key developmental transition points of childhood were often described by parents as events that cause change in how services were organized. This results in fragmentation of care, causing parental distress. Children would “age out” of eligibility for certain educational, rehabilitative, and supportive services, leaving a lack of comparable services for adolescents and young adults, or lack of coherence between the earlier and later programs. Although Individual Transition Plans are mandated by federal law to help bridge these gaps (U.S. Department of Education, 2000), no parent mentioned them, as their children were not yet at an age where these are commonly implemented.

The ongoing reassessment is required as part of the Individual Educational Plan process (as a consequence of transitions, aging and development of the child) is critical
and requires new knowledge, ongoing effort, and adaptation by all involved parties. Developmental milestones are loosely defined as toddlerhood, and entering school. Each transition was unique in its success and challenges for the child with a chronic condition. This was supported by the literature, Schumacher, Stewart, Archbold, Dodd, and Dibble (2000) stated that meaning, expectations, level of knowledge, and planning affect emotional and physical well-being of the parental caregivers. Nurses can make an impact by educating parents to the disease process, current treatments and anticipatory guidance.

Parents in the current study found they faced an abundance of new tasks after their child was diagnosed, including having to learn terminology associated with a seizure disorder, understanding the intricacies of an Individual Education Plan (IEP), and the intricacies associated with accessing special educational programming for the child. Unfortunately, parents' difficulty in understanding the intricacies of special education laws and programs has been documented since their advent in the late 1970s and remains an issue today (Cuban, 1996). The need for resiliency and perseverance was apparent in the parents' continuous effort to advocate for their child's needs.

Optimal communication between teachers, administrators, and school nurses is an ongoing challenge as the child progresses through the school years. Comprehensive health care services need to be continuous, and coordinated. Early identification and intervention for developmental and mental health conditions are associated with better social and academic outcomes (Grant & Brito, 2010). Miller, Condin, McKellin, Shaw, Klassen, and Sheps (2009) found that compartmentalization often occurred even though
it was problematic to helping the child reach his or her academic potential; achieving seamlessness across services was problematic. The parents studied by Miller and colleagues (2009) often described that excellent continuity was provided by groups of providers in specific health or educational settings, but not across these settings. The parents in this study echoed the findings of Miller and colleagues (2009) who reported that there were poor linkages between the child’s school and health care services. The participants’ in this study clearly indicated a need for an over-arching plan that comprehensively addressed their child’s medical, learning, and behavioral challenges and the difficulty in achieving this goal.

When there was a failure of the educational system to meet the child’s special educational needs, parents’ expressed a need to advocate for their child by seeking legal counsel. This is a problem for many families with children with special needs and is clearly addressed in the literature (Siegel, 2011). Legal efforts usually are needed to obtain approval from the local town for tuition for a private, specialized school, and school systems are highly reluctant to support such requests due to the expense (Siegel, 2011; Stoner, Bock, Thompson, Angell, Heyl, & Crowley, 2005). In other cases, the families chose to relocate to a new community that was better able to address the child’s needs (Siegel, 2011). Families in this study pursued both these options—pursuing legal redress and relocating the family. All these solutions are labor intensive, emotionally draining, and financially costly. It was evident that the parents in this study needed to be resilient, address educational obstacles, and be tenacious in advocating for their child.
Theme 4: Provider Challenges, Communication and Partnering

The demands and stressors associated with the care for parents of children with a chronic condition include: (a) managing the condition; (b) identifying, accessing, and coordinating resources; (c) maintaining the family unit; and (d) maintaining self (Sullivan-Bolyai, Sadler & Gillis, 2003; Sullivan-Bolyai, Knafl, Tamborlane & Gray, 2005). All these require high quality, ongoing communication. The parents in this study stressed the need for optimal communication and partnering with the health care system. For example, one barrier to access was the health care team members‘ inability to appropriately triage phone calls in a timely fashion. Parents found that establishing a trusting partnership with providers as well as determining the appropriate way to navigate the on-call system and/or emergency department during off hours was essential. Parents soon learned that they needed to know how the health care system worked and how best to —present their case.” The need for better patient-centered care coordination is now a priority as noted in policy statements and other forums (Clancy, 2012; U.S. Department of Health and Human Services, 2012).

In addition, parents in this current study faced ever-changing obstacles that included negotiating and re-negotiating with insurance companies to maximize benefits to meet the child‘s needs or dealing with an upgrade in insurance coverage or change in an insurance carrier. This is highly challenging in today’s insurance market, which is in tremendous flux due to the passage of the Patient Protection and Affordable Care Act
(Obama, 2008; Oberlander, 2008). The parents in this current study showed resilience in the ability to adapt, cope and persist with the ongoing demands of accessing appropriate financial coverage for their child’s health care needs. Some of the families’ insurance companies had nurse case managers who helped the child receive needed care while helping minimize costs incurred by the family. Case managers, who have a thorough knowledge of the child’s medical condition and other needed supports, have been found to be extremely important to parents (Miller, Condin, McKellin, Shaw, Klassen & Sheps, 2009; Haggerty, Reid, Freeman, Starfield, Adair & McKendry, 2003; Reid, Haggerty & McKendry, 2002); this was true in this current study. Moreover, the role of case management in coordinating care is taking on greater importance in today’s value-driven health care arena due to its proven cost effectiveness (Porter & Teisberg, 2006).

Three dimensions of continuity are described: relational continuity, which refers to an ongoing therapeutic relationship with patient and providers; informational continuity defined as the use of information from prior events to adequately update current plan of care; and management continuity, defined as the timely provision of services that complement each other across a shared management plan across organizational and service boundaries (Miller, Condin, McKellin, Shaw, Klassen & Sheps, 2009).

In summary, healthcare, school, and insurance providers need to partner, coordinate, communicate and manage a plan of care that transitions with the child’s changing developmental needs. Miller and colleagues, (2009) reported that parents work
to ensure continuity; they play an indispensable role in compensating for the systemic lack or breakdown of continuity. They provide information across geographically dispersed school, social and clinical systems and between service sectors, acting as a conduit between providers and institutions.

Theme 5: It Takes a Village: Siblings, Family Members, and Friends

Positive resilience outcomes may include increased self-esteem, self-transcendence, self-efficacy, hope, coping, psychological equilibrium, enhanced quality of life and well-being (McCubbin & Patterson, 1983; McCubbin & McCubbin, 1993; Peterson & Bredow, 2004). The relationships and contributions of siblings, other family members, and friends are paramount in helping parents and their children become more resilient (Skinner, John, & Hampson, 2000; Hamlett, Pellegrini, & Katz, 1992).

The parents in the study indicated that siblings go through a transition of adjustment and adaptation that is consistent with the resiliency model. Parents stated that siblings found discussions with the ill child’s physician to address their brother’s or sister’s condition and care to be helpful. Safeguarding the sibling’s personal time with each parent and receiving special attention were critical to sibling well-being. Parents wondered about the impact of their child’s chronic illness on their relationship with their other well children. This is consistent with the existing literature, in which different authors (Meleis, Sawyer, Im, Messias & Schumacher (2000); Haase, 2004) reported that feeling connected and positively interacting with each other resulted in positive coping for individual family members. These factors also are known to contribute to
individuals' resilience (McCubbin & McCubbin, 1993). Chronic illness has an impact on the whole family including extended family relationships. In this study, managing the child's epilepsy took on a greater part of the parents' energy and time. Often the siblings began to assume some of the responsibilities of the parents, sometimes to their parents' dismay.

In the current study, adequate planning was a prerequisite for successful family events. While anticipating the best scenario, parents found that they needed an abortive back-up plan given the potential for seizure activity, behavioral issues, and unexpected side effects of medication. Family support and respite care were necessary for parents. Epilepsy was shown to have an impact on the whole family including extended family relationships. These findings are supported in the literature (Austin & Dunn, 2001; Austin, Dunn, Johnson, & Perkins, 2004).

The interview data suggested that specific family members developed into trusted alternative care providers, exhibited different degrees of comfort with the diagnosis and care, ranging from enthusiastic to resistant, while some members expressed fear of providing respite care. Overall, most extended family members wanted to be involved in caring for the child with epilepsy and helped support and guide parents through the transition and adaptation periods from well child to a child needing special support. The family support allowed the parents to take time away from the "ongoing grind, constant stress, and need to always being on guard," as stated by one parent.
This was supported in a study by Raina et al., (2005) who studied the health and well-being of caregivers of 468 families with chronically ill children. The methodology consisted of developing a stress process conceptual model and applying structural equation modeling with data from a large cohort of caregivers. The results suggested that social support provided by extended family, friends and neighbors was secondary to that of the immediate family working closely together. Family function and social support positively affected health directly, self-esteem, and stress management.

The ability to develop a support system, whether it includes extended family members, friends, or the child’s sibling is vital. A network of people that have good listening skills and knowledge of the child, the disease process, and safety concerns is important. A supportive social network of friends and family can make the difficult times bearable, alleviating some of the burden of the daily challenges and sustained journey inherent in the life of parents caring for a child with epilepsy. Schumacher, Stewart, Archbold, Dodd, and Dibble (2000) also state that the well-being of relationships is a factor in obtaining emotional and physical well-being.

**Limitations of the Study**

The small sample size of twelve parents was rich in data, but the results of this study are limited in scope and transferability. The participants were Caucasian, except for one Indian couple, and all had private insurance and resided in suburban neighborhoods of metropolitan Boston. Attempts were made to interview families from low socioeconomic backgrounds, but ultimately, they were not recruited. Although many
expressed a desire to participate, all were overextended with multiple jobs and caretaking responsibilities for children and elders. Therefore, the views of the participants in this study may not represent those of parental caregivers from different ethnic groups, without private insurance, living in a rural or inner city settings, or from lower or high socio-economic backgrounds.

The twelve parents interviewed were very forthright and anxious to tell their story during one-hour interview. The research questions were not designed to investigate in depth the totality of potential concerns that are unique to patients with epilepsy. These include stigma associated with epilepsy; neurological impairments affecting information processing and retention; or potential consequences of epilepsy in terms of sudden death, lifestyle modifications, or childbearing issues; or the goal for the child to transition to independent living when reaching adulthood.

**Implications for Parental Education**

Nurses caring for children with intractable epilepsy can provide education regarding diagnosis, management and treatment plans, and advocacy on legal matters and the educational system. In addition, parental caregivers are often overwhelmed when the initial diagnosis is made and are unaware of the resources that might be available in their community. Nurses are often familiar with the community’s resources and by keeping comprehensive lists of support groups, specialists, lawyers, educational resources, and online informational web sites can provide parents with needed resources without having to conduct research in a time of stress. The literature supports this finding in that
preparation and knowledge facilitates developing confidence and coping in parents with a child with a chronic condition (Meleis, Sawyer, Im, Messias & Schumacher, 2000).

All parents in this study endorsed education regarding symptoms, medication, behavioral management and child development, as well as information on how to cope with the transitional periods of childhood. Parents with daughters all mentioned concerns surrounding hormonal changes and potential long-term side effects of epileptic medications during future childbearing years. Education regarding hospital policies and procedures in age-appropriate language was a concern that was expressed. Ray (2000) found that there is a need for appropriate educational resources to meet the needs of parental caregivers of chronically ill children. Anticipatory guidance about procedures including magnetic resonance imaging (MRI); electroencephalogram (EEG); positron emission tomography (PET), and Wada sodium amytal testing is necessary and important. Consideration should be given to meeting the health literacy needs of the parent and the child. Farley and McEwan (2000) described the importance of the need to understand the child’s disease process, treatment plan, and day-to-day management issues. Additionally, parents requested bringing the education to the bedside; bulletin boards in the hallway with posted information were not advantageous since parents did not want to leave their child’s bedside.

The parents found that basic education on neurological assessment was valuable. In order to provide information to the health care team they shared that it was useful for them to record data such as seizure frequency, duration, time of day, unilateral or
bilateral movements, eye movements, facial expressions, loss of consciousness, and loss of speech. Additional information communicated during office visits included medication doses and side effects, close monitoring of lab critical values, correlation of seizure activity and monitoring of behavior (e.g., disruptive outbreaks, loss of focus, sleepiness and sedation). Questions during the visit need to be addressed, for example: (1) how often do seizures improve upon addition of a particular medication for a particular seizure type? (2) Do seizures improve when switching or combining medications? (3) How often is a recognized seizure associated with a missed medication dose? Observational research cannot confirm cause and effect, but may be useful in generating hypotheses for an interventional study. The parent’s ability to communicate and record accurate data to share with the health care provider is paramount in managing seizures.

**Implications for Nursing Practice**

The ability to navigate health care systems and partnering with the team for best outcomes are achieved through good communication. Schumacher, Stewart, Archbold, Dobb, and Dibble (2000) suggested that a good working relationship between parents’ and providers’ is an indicator of healthy transition. Their findings revealed that requests from parents included designated physicians and other providers providing continuity of care, open paging hours, “just in time” access to nurse consultation, “face time” with nurses using iPhone or Skype on an “as needed” basis. Parents also requested periodic in-person conferences with all providers and a coordinated care plan. They requested system information on how to navigate the health care system during “off hours” and
how best to communicate with emergency department staff regarding seizure history and medication management to achieve a good outcome. One parent also requested a “fast track” ticket to admission to the neuroscience unit that “knows” their child and can “listen and act on parents’ concerns.”

Strong connections, partnering among the primary team of health care providers (physicians, nurse practitioners, primary nurses, and social workers), were all frequently mentioned throughout the interviews. Preplanning for vacations and out-of-state trips away from the safety net of the primary health care team required planning and effort by the parents. The need to “doctor shop” and find the right hospital, right health care team, right location, and right insurance required effort and persistence, meaning that parents would often travel to more than one institution prior to finding the one that suited all of their needs. Nurses through anticipatory guidance can support the parents’ efforts with planning and assessing potential health care needs of the child.

Parents stated they wanted the health care team to listen to their concerns and issues as they knew their child best and did not want team members to be judgmental of their best efforts. The parents valued the health care professionals’ expertise; however, they wanted their experience and knowledge of their child’s care recognized. One parent stated that education was needed about how hospitals work, the “pecking order” and hierarchy, in the physician team from intern to attending and how to navigate a complex “crazy” system that does not always lend itself to meeting and listening to the parent and child and understanding their needs.
Many parents said it is imperative to work with the child’s school and provide information regarding a new epilepsy diagnosis (Austin & Dunn, 2001; Grant & Brito, 2010). This was important in establishing an optimal educational environment. Discussions with the school nurse regarding seizure type, frequency, rescue medication, treatment plan, and parental permission to discuss care with the primary health care team are essential. Anticipating behavioral issues and planning effective responses must also occur. The need to educate families regarding educational terminology (e.g., IEPs), potential transitions from a regular classroom to a special needs classroom, and the use of a behavioral therapist, speech therapist, and/or occupational therapist should be discussed. Anticipatory guidance regarding the need to transition to a new school, or to a different teacher and classroom, is important to the success of the child and comfort of the parent. The level of planning is indicative of a healthy transition (Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000).

Carnevale (2006) found that parental caregivers of chronically ill children were consumed with devoting extraordinary care and attention to their children; this was evidenced throughout the twelve interviews. Nurses can help parents find support by promoting networking with other parents who are making the journey from initial diagnosis of intractable epilepsy to reaching the goal of seizure control and a higher quality of life for their child. Parents stated they felt “lost and overwhelmed” and benefited from family support groups, networking with the National Epilepsy Foundation; local community support; church support and honest and thorough conversations with teachers, coaches, neighbors, friends, and family members of the daily
responsibilities, safety, and behavioral concerns that can dominate hours of parental worry. Nurses need to confer with families about which of these resources may be beneficial to them. Studies have emphasized the importance of identifying coping strategies to decrease stress and the importance of focus on personal goals and nurturing relationships and friendships (Ray, 2002; Sullivan-Bolyai, Sadler, Knafl & Gillis, 2004). The parents stated that they need to be able to plan for respite care to give them time to recover from the constant day-to-day challenges and commitments required to care for a child with frequent seizures. Nurses can assist parents to identify their support network.

All parents stated that being transparent and sharing their safety concerns while addressing the comfort levels of coaches, teachers, the school nurse and families and friends were paramount in ensuring their child’s safety and building a personal connection with the community. Sharing stories revealed the totality of the situation and the need for health care providers not to be judgmental of parents’ efforts to safeguard the child even if it seems extreme to some people, for example sleeping in the child’s room on a blow-up mattress when there is an increase in seizure frequency. Parents revealed that there are “good days and bad days, good years and bad years” and there is an ongoing transition and progression and sometimes even resolution of the disease.

Carnevale (2006) found that despite enormous difficulties, parents’ also reported enriching and rewarding experiences that they could not imagine living without. One mother in the current study strived to “normalize” the situation and said that many people have disabilities or “different abilities” and “to belly up to the kitchen bar to take your
medication every morning and evening” can all be accepted into the family structure only if the dynamics of education, guidance and community support are integrated. All the parents exhibited resiliency, perseverance, and learned how best to advocate for their children. One mother stated, “It’s tough; honestly it’s exhausting being his parent at times. There are times when it’s fabulous, what a great kid and then there’s other times…Oh my God really … you don’t know what to do.”

**Implications for Future Research**

The results of this qualitative descriptive study can inform future research. Potential areas of investigation include exploring the effects of case management approaches, the use of electronic medical seizure diaries, interventions to increase medication compliance and improve knowledge of antiepileptic drugs. In March 2012 the Institute of Medicine (IOM) released the report, Epilepsy across the Spectrum: Promoting Health and Understanding. The report noted that expanding early identification and screening for learning impairments in children, evaluation and promoting effective innovative teaching strategies, assessing the information needs of people with epilepsy and capturing trends in knowledge, awareness, attitudes, and beliefs about epilepsy overtime and specific subgroups will advance the field of epilepsy and better the lives of people with epilepsy (Hesdorffer, et al., 2003). Future research in this area will contribute to this effort.
Conclusion

The purpose of this qualitative descriptive study was to describe caring for children with intractable epilepsy from the perspective of the parental caregiver. A qualitative method was used to elicit the parent’s voice regarding the transition from parenting a healthy child to parenting a child with intractable epilepsy. Information regarding role adaptation, changes in parenting style, and behaviors and modifications in family functioning were elicited.

Immersion in the qualitative descriptive data revealed the complexity and ongoing challenges of caring for an ill child, and by listening to parents; health care providers can gain insight into ways to improve health care delivery and interventions for a specific population. Using the qualitative descriptive method allowed the researcher to reach the actual sources of data, in this case the parents, and document verbatim the parents’ interviews. This research study revealed the need to focus on partnership with parents, providing continuity of care, case management and education for providers, children with epilepsy and their families, and the public. This knowledge will provide the first step in a program of research whose long-term goal is to create and implement interventions to improve the care delivery model, develop parental resiliency and educate nurses.
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Appendix A: Letter of Participation

Children’s Hospital, Boston, MA

Investigator: Mary Reed RN, PhD

You are invited to be a participant in a study because you are the parent and caregiver of a child with intractable epilepsy. The purpose of the study is to learn from the experts, those providing care, what is involved in caring for these special children. I also want to learn how we as nurses can be of help to parents through the process from diagnosis to daily care. Caregivers who choose to participate in this study will be interviewed in their home at their convenience by Mary Reed, a nurse and doctoral student at Boston College School of Nursing. The interview will be approximately one hour and consist of a few questions asking for your perspective of the experience of being a caregiver of a previously healthy child who now has intractable epilepsy.

Some questions are thought provoking and you may consider of a personal nature. Please be assured all answers are keep confidential and anonymous. In other words the research data cannot be traced back to an individual caregiver. If you feel uncomfortable about a question or want to withdraw from the study at any time you may do so. This study may or may not benefit you. The purpose is to analyze how caregivers provide care giving well so I can create an intervention to help other caregivers in the future deal with the daily challenges of caregiving. All participation is confidential. The written data and audiotapes will be in a locked file cabinet in a private office at Children’s Hospital, Boston. At the end of the study all written and audiotape data will be destroyed. Your
name will not be used in any scientific reports of the study. You are free to choose not to participate in this study. In addition, if you choose to participate you can withdraw at any time without consequence. Whether you participate or not will not affect your child’s care. Please feel free to ask any questions concerning the consent form.

I have received a copy of the consent form.

Signature: _________________________________________________________

Date:_____________________________________________________________

Email: mary.reed@childrens.harvard.edu

Phone: 1-617-355-7590
Appendix B: Interview Tool

Central Question: Please tell me what it is like to be the parental caregiver of a child with intractable epilepsy?

Potential Probes

1. Tell me more

2. Give an example

3. Clarify comments

4. Can you describe a typical day?

5. What were your first thoughts when ____ was diagnosed with intractable epilepsy?

6. How has life changed from those early days/weeks after diagnosis?

7. What would make life easier/better for you?

8. How do you define support?

9. What interventions will prove beneficial in increasing coping/strategies for you?

10. How do you manage the roles of parent and caregiver on a daily basis?

11. What do you identify as challenges, barriers or facilitators for providing care?

12. How do you define caregiving well?
Appendix C: Boston College IRB Letters

BOSTON COLLEGE
Institutional Review Board
Office for Research Protections
Wiggin House, 3rd Floor
Phone: (617) 552-4773, fax: (617) 552-4988

IRB Protocol Number: 12.110.01

DATE: November 22, 2011

TO: Mary Reed

CC: Judith Vassey

FROM: Institutional Review Board – Office for Research Protections

RE: Parental Caregivers' Description of Caring for Children with Intractable Epilepsy

Notice of IRB Review and Approval

Expedited Review as per Title 45 CFR Part 46.110, FR 80368, FR. # 6 & 7

The project identified above has been reviewed by the Boston College Institutional Review Board (IRB) for the Protection of Human Subjects in Research using an expedited review procedure. This is a minimal risk study. This approval is based on the assumption that the materials, including changes/corrections that you submitted to the IRB contain a complete and accurate description of all the ways in which human subjects are involved in your research.

This approval is given with the following standard conditions:

1. You are approved to conduct this research only during the period of approval cited below;
2. You will conduct the research according to the plans and protocol submitted (approved copy enclosed);
3. You will immediately inform the Office for Research Protections (ORP) of any injuries or adverse research events involving subjects;
4. You will immediately request approval from the IRB of any proposed changes in your research, and you will not initiate any changes until they have been reviewed and approved by the IRB;
5. You will only use the informed consent documents that have the IRB approval date stamped on them (approved copies enclosed);
6. You will give each research subject a copy of the informed consent document;
7. You may enroll up to 12 participants.
Boston College
Use of HIPAA Protected Health Information

Project Title: Provider-Completed Description of Care for Children with Intellectual Disability
Project Number: IRB00000160
Principal Investigator: Nancy Amy Kandall

Please complete the form and submit it with your IRB application if you will be working with health information in a HIPAA-covered institution.

The Health Insurance Portability and Accountability Act (HIPAA) requires the confidentiality of protected health information (PHI), which includes being and disclosing that information in patient education, treatment, and payment of services provided to patients involved in any electronic transmission related to their health care.

Definition of Protected Health Information (PHI)

- Information that is a subset of health information, including demographic information, collected from an individual, including his or her personal or future physical or mental health condition or treatment status.
- Information that is individually identifiable (see HIPAA guidance in Attachment 2 of IRB proposal) to the extent that:
  - There is a reasonable basis to believe that the information could be used to identify the individual, and
  - The individual is a member of a group or subgroup in which confidentiality needs to be maintained.

All applicants to the IRB who will be working with health information are expected to complete the certification below as part of the IRB application process. Any individual who fails to complete this certification or the application as a whole will be denied access to the IRB of any voluntary affiliation or authorization granted by the IRB of any covered entity and may be referred to provide additional information as part of the IRB approval process.

I certify that the use of any understanding, the project does not involve any protected health information (PHI) beyond any ongoing research project to determine if this is any harmful part of the data for the research, but I am immediately, including the HIPAA and the Federal privacy act, and will be subject to the regulations for confidentiality of records filed with the HIPAA and the Federal privacy act.

The data from the institution, a description of the information collected in the research proposal, and

A. The data categories of information is not (eg., diagnosis, treatment, dates, insurance status, demographics, contact information, please select):

B. The specific categories of information collected (eg., diagnosis, treatment, dates, insurance status, demographic information, contact information, please select):

C. The data categories of information collected (eg., diagnosis, treatment, dates, insurance status, demographic information, contact information, please select):

Date: 2/2/2021

Reviewed: Dec 21, 2020
If you have not been cleared by the Person Responsible of the current entity, please submit a copy of the active authorization/HRSA authorization agreement for this research protocol. If the researcher does not have written approval, please complete the appropriate form below.

☐ If consent will be obtained with written HRSA authorization from participants, please complete the written consent form with the participant.

☐ If consent will be obtained verbally on HRSA authorization, please complete the HRSA Authorization Form.

☐ If the project involves children as participants (under HRSA guidelines), please complete the HRSA Authorization Form.

☐ If HRSA authorization is required for all participants (whether or not HRSA guidelines apply), please complete the HRSA Authorization Form.

☐ If HRSA authorization is required for specific activities (such as research involving children, use of confidential health information, etc.), please complete the HRSA Authorization Form.

☐ If HRSA authorization is required for any aspects of the project (such as the use of confidential health information), please complete the HRSA Authorization Form.

☐ If HRSA authorization is required for the completion of the project (such as the use of confidential health information), please complete the HRSA Authorization Form.

☐ If HRSA authorization is required for any aspects of the project (such as the use of confidential health information), please complete the HRSA Authorization Form.

☐ Other (please specify)

Principal Investigator: ____________________________

Applicant/Chair or Sponsor: _______________________

[Handwritten signatures]

[Handwritten date: 12/01/2011]
Appendix D: BCH IRB

Children's Hospital Boston
Office of Clinical Investigation
300 Longwood Avenue
Boston, MA 02115
phone 617-355-7052 fax 617-730-0226

Principal Investigator: Mary Reed
Protocol Number: IRB-P00001690
Protocol Title: Parental Caregivers' Description of Caring for Children with Intractable Epilepsy
Date: September 26, 2011

NOTICE OF EXPEDITED APPROVAL
IRB Approval Date: 9/1/2011
IRB Activation/Release Date: 9/26/2011
IRB Expiration Date: 8/31/2012

The Committee on Clinical Investigation has approved the above referenced protocol through expedited review procedures. We are now able to release this approval to you since you have adequately responded to the Committee's questions and concerns.

Risks were determined to be minimal with potential for direct benefit.

The approved consent form is available on-line through the CHB Informed Consent Library. To obtain the consent form, please go to http://chbcfapps/research/consent/. The ICLibrary should be accessed each time you need a consent form to ensure that the current version of the consent is always used. Do not store the consent forms on your computer or make copies for future use. Note that the activation/expiration date on the consent form can only be changed or modified by the staff of the Clinical Investigation Office. Please also note that subjects cannot be enrolled in a study if the consent form has expired. A copy of the signed consent should be kept in your files. It is our understanding that consent forms will be stored in the research record. The subject/family must also be given a signed copy.

The occurrence of unanticipated problems should promptly be reported to this office. Any revisions, amendments, or changes to the protocol require prior Committee approval. The Committee has asked this office to notify investigators that clinical investigation protocol files are subject to audits at some future time.

Sincerely,

[Signature]

Robleinscky Dominguez, IRB Administrator
For the Committee on Clinical Investigation
Nursing Research Council – Scientific Review

7/27/11

Re: Review of Protocol: Parental Caregivers Description of Caring for Children with Intractable Epilepsy

Dr. Mary Reynolds, RN, PhD
Nurse Researcher

Your protocol titled: Parental Caregivers Description of Caring for Children with Intractable Epilepsy was reviewed by the scientific protocol review subcommittee of the Nursing Research Council. At this time the decision of the subcommittee is to approve your protocol. However, we ask that you make two revisions before submitting it to the IRB:

- Please delete the ‘Specific Aims and Objectives’ section on page 2 of Form B. This is a qualitative proposal and your well-stated research questions on page 6 are more appropriate to the design.
- Please add reference citation(s) on page 5 in your summary of the gaps in the literature.

We wish you success in your endeavor as it is an important study that will enable nurses to be more aware and responsive to the unique needs of these parents as they combine care and parenting responsibilities.

If you have not already initiated the IRB electronic application, please do so at this time. Once the committee has received a request for review, we will upload your Nursing Research Council approval letter and complete the sign off signaling IRB review.

Respectfully,

[Signature]

Jane Anne Carter, DNP, RN, CCRN
Chair, Nursing Research Council

The first place for children
Appendix E: Consent Form

Why is this research study being conducted; What is its purpose?

The purpose of this study is twofold: (1) to gain an understanding of the parents’ experience in transitioning from being a parent of a healthy child to becoming a parent and caregiver for a child with intractable epilepsy and (2) to understand the parental perspective of caring for and living with a child who has intractable epilepsy; to learn how they address the intricacies and nuances of caring for this child.

This study will be a first step in the effort to learn how parents modify their parenting activities to accommodate the unique needs of their child who has intractable epilepsy. Nurses and other health care providers can best serve future parents in similar situations if they first learn from experienced parents what resources they find helpful and what ones burdensome.

Who is conducting this research study, and where is it being conducted?

Research participant recruitment will be obtained from the population of a single site Level 4 National Association of Epilepsy Center at Children’s Hospital, Boston, MA. The principle investigator for this study is Mary Poyner Reed, RN PhDc and there is no current sponsor for the research.

How are individuals selected for this research study? How many will participate?

A purposive sample of 8-12 parental caregivers will be recruited with the help of the nurse epilepsy coordinator. Inclusion criteria are (1) parental caregiver who provides the majority of care to a child with intractable epilepsy in the home environment, (2) the child will be between 6-12 years of age who was previously healthy and now has intractable epilepsy, (3) children will have a variety of seizure frequency and be on a variety of medications. The exclusion criteria are (1) non-English speaking (2) parent lives greater than 100 miles radius of the researcher, (3) child has been diagnosed with >2 concurrent acute/chronic co-morbidities.
What do I have to do if I am in this research study?

You will partake in a 60-90 minute open-ended unstructured interview regarding the transition to and current experiences of caring for your child with intractable epilepsy. Ideally both parents will participate in the interview. The setting will be in your home or site of your choosing. The interview will be audio taped. You will not be identified, as pseudonyms will be used. All data will be stored in a locked cabinet in a private office to which the investigator herself alone has access.

What are the risks of this research study? What could go wrong?

The risk of an adverse event is highly unlikely; parents may experience sorrow or become upset when talking about the care their child requires or changes that have occurred since the child’s diagnosis. If this were to happen, a counselor is available to assess and/or provide resources as needed. The other risk could be accidental disclosure of parent information. Strict precautions and safeguards will be taken to ensure confidentiality. Data will be de-identified and pseudonyms will be used.

What are the benefits of this research study?

Parents who share their experience might realize a therapeutic effect to the process. What is learned from the parents’ experiences may be helpful to nurses when caring for future parents with a child with intractable epilepsy. The new knowledge could lead to improved family-centered care.

Are there costs associated with this research study? Will I receive any payments?

☐ There are no costs associated with this study.
What will happen with the information obtained as part of this research study? What about confidentiality?

The interview will take place in the privacy of the parents‘ home or other place of choosing. Data will be transcribed by a certified Health Insurance Portability and Accountably Act (HIPAA) transcriptionist. The data will be de-identified using pseudonyms and stored in a locked cabinet in a private office that I alone have access to. Identifiable data, consents and audio tapes will be stored in separate locked cabinet accessible only by me.

If I do not want to take part in this research study, what are the other choices?

Participation in this study is voluntary and parents can withdraw from the study at any time. The alternative to participate in this study is to not participate. The current or future care that you receive at Children’s Hospital Boston will be the same, regardless of whether or not you choose to partake in the study.

What are my rights as a research participant?

Study participation is voluntary, and refusal to participate or withdraw will in no way affect the medical care patients receive at Children's Hospital. I will provide you a copy of the consent for your records and answer any questions you have regarding the study.

Why would I be taken off the study early?
I do not foresee any reason that you would be taken off the study early except if you withdraw yourself on a voluntary basis.

**What information do I need to know about the Health Insurance Portability and Accountability Act (HIPAA)**

During this research, information about your child or your child’s health will be collected. In general under Federal law, information about patients is private, but there are exceptions and you should know who would have access to this information and might see it.

Researchers may be collecting information about you or your child from medical records. They may also learn things from procedures that are part of the research itself such as tests, office visits, questionnaires and interviews.

The following people will be able to see this information:

- Medical and research staff at Children’s Hospital, including people listed on your informed consent.
- Medical staff that are directly involved in your care that is related to the research or arise from it.
- People, who oversee, advise or conduct research at Children’s Hospital, and people who oversee or evaluate research and care, including the Committee on Clinical Investigation, staff working on quality improvement, and other clinicians and administrative staff of Children's Hospital.
- People from agencies and organizations that provide independent accreditation and oversight of research.
- Sponsors or others involved in funding the research.
- Federal agencies that oversee or review research information.
Government agencies and sponsors.
If some law or court requires us to share the information, we would have to follow that law or final ruling.

You should be aware that the federal privacy rule does not cover all of these possible uses. This means that once some of the above mentioned users receive your health information they do not have to follow the same rules. Other laws may or may not protect sharing of private health information. If you have a question about this you may contact the Children's Hospital Privacy Officer at 617-355-5502.

There is no set time for destroying this information and no time limit for its use. Researchers continue to analyze data for many years and it is not possible to know when they will be done.

You do not have to sign this form. If the form is not signed, however, you won't be able to participate in the study. Not signing will not affect your care or your child's care at Children's Hospital in any way now or in the future. Also, there will be no penalty or loss of benefits if you choose not to sign and participate.

You also have the right to withdraw from this study at any time. You have the right to end your permission for Children's Hospital to use or share the protected information about you or your child that was collected as part of the research.

Researchers may also continue to use information already collected to protect the integrity of the study. This means that your withdrawal won't make the whole study useless. Once you remove your permission and you are no longer in the study, no more private health information will be collected. If you wish to withdraw you will need to do so in writing. If you decide to share private information with anyone not involved in the study, the federal law designed to protect privacy may no longer apply to this information.
Although there are some legal limitations, you have the right to get protected information resulting from this research that relates to your treatment or to payments. This information is available after the study analysis is done. To request the information, please contact the Hospital’s Privacy Officer at 617-355-5502. If you have questions, please be sure to ask for answers.

**Research at Children’s Hospital:** Children’s Hospital has recently developed a web-based, interactive educational program for parents called “A Parent’s Guide to Medical Research.” To find out more about research at Children's Hospital, please visit the program at [www.researchchildren.org](http://www.researchchildren.org).

Children's Hospital is interested in hearing your comments, answering your questions and responding to any concerns regarding clinical research at Children's Hospital. If you would like further information about the type of clinical research performed at the hospital or have suggestions, questions or concerns regarding clinical research you may send an email to cci@childrens.harvard.edu or call 617 355-7052 between the hours of 8:30 and 5:00.

I understand that I may use the following contact information to reach the appropriate person/office to address any questions or concerns I may have about this study. I know:

<table>
<thead>
<tr>
<th>I can call …</th>
<th>At …</th>
<th>If I have questions or concerns about …</th>
</tr>
</thead>
</table>

Investigator: [Mary Poyner Reed, PhDc, RN]  
Phone: [617 355-7590#]
Pager: 617-355-7243[0929 #]

- General questions about the study.
- Research-related injuries or emergencies.
- Any research-related concerns or complaints.
- Any research-related concerns or complaints.

Office of Clinical Investigations
Rights of a research subject.

- Use of protected health information.
- Compensation in event of research-related injury
- Any research-related concerns or complaints.
- If investigator/study contact cannot be reached.

Phone: 617-355-7052

- If I want to speak with someone other than the Investigator, Study Contact or research staff.
I have been satisfactorily informed of the above-described procedure with its possible risks and benefits. I have been provided with the applicable Privacy Rule provisions under the Health Insurance Portability and Accountability Act. I give permission for my/my child's participation in this study and for use of the associated protected health information as described above.

I understand that participation in this study is voluntary. If I refuse to participate or choose to drop out of the study at any time, I understand there will be no penalty or loss of benefits to which I am otherwise entitled, and this decision will not affect present or future care by the doctors or the hospital. I am signing this consent form before participating in any research activities. I have been given a copy of this form.

Date (MM/DD/YEAR)  If subject 18yrs or older: Signature of Adult Participant

INVESTIGATOR'S AND/OR ASSOCIATE'S STATEMENT:

I have fully explained to all involved parties (participant/parent/guardian as applicable) the nature and purpose of the above-described procedures and the risks involved in its performance. I have provided the subject/family with the Privacy Rule if requested. I have answered and will answer all questions to the best of my ability. I will inform the participant of any changes in the procedures or the risks and benefits if any should occur during or after the course of the study. I have given a copy of the consent/authorization form to the subject/family.

Date (MM/DD/YEAR)  Signature of Investigator or Associate
Appendix F: CITI

Main Menu

1. This is the email address you have for.
   If this is not correct, click to edit your email address and other account information including your security question and answer.
2. You are affiliated with participating institutions on the CITI website. You will have at least one grant book per institution to track your progress in meeting the institution’s coursework requirements (see below).

Add/Next institution | Change linked information | Click here to apply for CITI/CLEU Credits.

Boston College

You have enrolled for the following courses:

<table>
<thead>
<tr>
<th>My Courses</th>
<th>Status</th>
<th>Completion Reports</th>
<th>CITI/CLEU Credits</th>
<th>Volunteer Satisfaction Survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biomedical Research, Referee Course</td>
<td>Passed - 06/28/11</td>
<td>Print CITI/CLEU Credit</td>
<td>Completed</td>
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