

PARENTS' EXPERIENCE CARING FOR CHILDREN WITH DRUG RESISTANT
EPILEPSY

by

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ABSTRACT OF THE DISSERTATION

Parents' Experience Caring for Children with Drug Resistant Epilepsy

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Rationale for study: Of the more than 65 million people estimated to have epilepsy worldwide, 10.5 million are children; one third of whom have drug resistant epilepsy (DRE). Although caring for a child with epilepsy impacts the lives of the child and family, parents who care for children with DRE have been found to experience more stress, as this severe form of epilepsy negatively affects the child's physical growth and mental development and is often associated with behavior disorders and disturbances. This study examined the lived experiences of parents with children with DRE to gain insight into how they described and gave meaning to their own quality of life relating to their lived experience.

Method: A purposeful sample of ten parents of children with DRE participated in the study, equally represented by men and women. The participants' ages ranged from 27 years to 56 years, with a mean age of 45 years. Using distinct interview guides to facilitate conversation, three interviews were conducted over the course of a four-month period. Time for reflection occurred between each interview, with field notes and journal reviews done by the researcher. The transcribed interviews were also reviewed at the beginning of each subsequent interview to ensure accuracy of the stories shared.

Results: The semi-structured interviews and narrative analyses portrayed parents' life stories pertaining to what it is like to care for a child with DRE. Narrative life patterns emerged and culminated in five shared areas: what is best for my child, functioning in silos, maintaining balance, living with uncertainty, and finding meaning and purpose.

Conclusions: A composite narrative told the story that represented the patterns of parents' experience caring for a child with DRE, which provided a deeper insight into their lived experience. Understanding their experience provided valuable information, such as, the type of support they need and how best to assist them as they care for their children.

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Chapter 1: Introduction and Theoretical Perspective

The Concern to be addressed

Epilepsy is the term given to a variety of mixed conditions that present as classic seizures (Hart, 2012). The International League Against Epilepsy (2014) defines epilepsy as (a) two or more unprovoked seizures occurring at least twenty-four hours apart in time; (b) one seizure with a high probability of a further seizure; and (c) diagnosis of an epilepsy syndrome. Epilepsy has an unpredictable nature and creates uncertainty regarding seizure occurrence (England et al., 2012). For most people who develop seizures, the long-term prognosis is good, often being free of seizures for up to five years (Hart, 2012). However, there is a greater risk of sudden unexpected death (Devinsky, Hesdorfferr, Thurman, Lhatoo, & Richardson, 2016; England et al., 2012) as well as school-related challenges, uncertainty regarding social interactions, and the potential for employment in this population. Achieving autonomy may also be difficult with limitations on driving and independent living uncertain (England et al., 2012).

Organized into syndromes, determined by clinical characteristics such as age and seizure type ranging from behavioral arrest to full body shaking, as well as the electrophysiological characteristics, epilepsy is a common chronic condition, (England, Liverman, Schults, & Strawbridge, 2012; Fisher & Kobau, 2017; Hart, 2012) with peak incidence in children under the age of 18 and adults over the age of 65 (England et al., 2012; Russ, Larson & Halfon, 2012; Zack & Kobau, 2017). While precise estimates of epilepsy occurrence are scant, (Zack & Kobau, 2017) epilepsy has been noted as the fourth most common neurological condition affecting 65 million individuals worldwide (England,

et al., 2012). Nevertheless, precise estimates are challenged by variations in methodology, coupled with mixed inclusion criteria and diagnostic criteria (Angus-Leppan & Parson, 2008).

Many people who live with epilepsy will often have co-morbid conditions, for example, high blood pressure, pre-diabetes, obesity, chronic obstructive pulmonary disease, migraines, painful conditions such as arthritis, and a history of stroke, more common in adults with epilepsy (Keezer, Sisodiya, & Sander, 2016). Health and well-being can be affected, impacting quality of life of both the individual and their family in many ways (England, et al., 2012). For the person living with epilepsy, there is an increased risk of injury, mortality, cognitive decline, and negative mental health outcomes (Kerr, 2012).

In addition to physical co-morbidities associated with epilepsy, psychosocial problems exist at higher rates than the general population. Issues with stigma, social isolation, anxiety, (Harsono, 2016; Sung-Pa, 2013) and depression (Zack & Kobau, 2017) are experienced more often in the epilepsy population (Harsono et al., 2016; Kwon & Park, 2013). As a result, and because this is often overlooked, the evaluation of the psychosocial impact of epilepsy for individuals and their family is crucial for development of a comprehensive plan of care (Modi, Ingerski, Rausch, & Glauser, 2011).

There is a vast burden created from epilepsy on the individual, family, and society. The impact of epilepsy involves more than seizure control (England et al., 2012). There is a need to improve the overall quality of life for individuals living with epilepsy and their

families (Modi et al., 2011). Epilepsy, especially severe forms, can take a toll on families and can create both financial and emotional strains (England et al., 2012).

Severe forms of epilepsies are those refractory to treatment known as drug resistant epilepsies (DRE). Kwan et al. (2010) defines DRE as the failure of two adequate trials of appropriately chosen anti-epileptic medications used to achieve sustained seizure freedom. Although most people living with epilepsy can achieve good seizure control, about one-third has inadequate control of seizure activity (Kwan & Brodie, 2000; Laxer et al., 2014). Those with DRE have additional concerns. There is an increased cost associated with the care of an individual with epilepsy refractory to medication, with visits to emergency departments and hospital admission contributing to the overall cost (England, et al., 2012). There is also a greater risk of death seen in this population, with sudden unexplained death in epilepsy (SUDEP) 24 times higher than that of the general population (Ficker, 2000; Laxer et al., 2014).

In the United States, there are an estimated 125,000 to 150,000 newly diagnosed patients with epilepsy annually (England et al., 2012; Fiest et al., 2017). Although seizures may happen at any age, epilepsy most often occurs in children and older adults (England et al., 2012; Russ, Larson & Halfon, 2012; Zack & Kobau, 2017). Worldwide, over 65 million people are estimated to have epilepsy, including approximately 10.5 million patients of which are children (Ji, T. et al., 2019).

Children suffer from epilepsy, experiencing seizures that are more frequent, unpredictable, and of higher severity (Miller, Palermo, & Grewe, 2003; Modi et al., 2009; van Andel, Zijlmans, Fischer, & Leijten, 2009), with medication side effects that negatively

impact their quality of life (Berg, Levy, Testa & Shinnar, 1999). Approximately, 80% of children with epilepsy have at least one other health-related issue (Aaberg et al., 2017). They are at greater risk for neurological behavioral problems (Austin & Caplan, 2007) and lower academic achievement throughout school years (Ibrahim et al., 2014). When seizures occur at the time of brain development, impaired cognitive and social functioning can result (Hamiwka & Wirrell, 2009).

The impact of childhood epilepsy may depend on the severity and ability to control the seizure frequency. Ferran et al. (2005) state that in addition to the severity of epilepsy; the complex nature including treatment, management and the support available for parents, it is also important to understand the meaning of the illness for the parents. Illness represents a disruption of daily living and the understanding of how health and wellness are viewed by an individual (Riessman, 1993). Although there are reports of decreased quality of life for parents of children with DRE (Ferran, Zerwij, Wibur, & Larson, 2005), little is known about how the parents describe this lived experience.

The Phenomenon of Interest

Quality of life is generally defined as a person's level of physical, psychological, spiritual, and social well-being (Ferrell, 1995), and is an important aspect of healthcare that needs to be addressed in persons with chronic illnesses (Megari, 2013). Advances in medicine have improved overall life spans; however, it has resulted in increased chronic illnesses requiring disease management (Han, Lee, Lee, & Park, 2003). More individuals live with chronic illness than in previous decades as a result of advances in medicine (Megari, 2013). Over 117 million Americans live with at least one chronic illness (Ward,

Schiller, & Goodman, 2014). For those with long-term or chronic illness, quality of life may be affected. Living with a chronic illness such as epilepsy impacts the physical, emotional, spiritual, and psychosocial quality of life of an individual (Suurmeijer, Reuvekamp, & Aldenkamp, 2001).

Adults with epilepsy do not live in isolation and frequently rely on caregivers. Caregivers are usually family members who aid a loved one without pay and frequently have a personal tie to the individual in need (Pierce, & Lutz, 2013). Epilepsy has a significant impact on quality of life for the individual, those close to, and caring for them (Gibson, 2014; Hocaoglu & Koroglu, 2011; Thompson & Upton, 1992); this remains unchanged over time. Caregivers may see an impact on their own quality of life (de Oliveira, Neto, de Camargo, Lucchetti, Espinha, & Lucchetti, 2015; England, et al., 2012). Additionally, an emotional toll exists for the families of individuals with epilepsy. Physical, psychological, and social aspects of quality of life have been examined for those family members (van Andel, et al., 2009). Family caregivers of patients with DRE exhibit lower mental health, social function, and role function within the psychological, social, and physical aspects of quality of life (van Andel et al., 2009). Both mental and physical components appear to be related to the burden of providing epilepsy care (van Andel, et al., 2009).

For children with epilepsy, parents are the primary caregiver. Depressive symptoms have been reported more in mothers of children with epilepsy compared to mothers of healthy children, resulting in a negative impact on the child's overall quality of life (Ferro, Avison, Campbell, & Speechley, 2011a). All children require supervision and care provided by their parents. In addition to the parenting role, parents of children with a

chronic illness require even greater support. Little is known about the parents' lived experience, which emphasizes the need to explore the parent's experience providing care for these chronically ill children.

Ferro, Avison, Campbell and Speechley (2011a) found that parents' quality of life correlated to their child's quality of life in physical, psychological, and social areas. Parents of children with DRE experience more parenting stress such as increased isolation from others, having less social support, and more role restriction with sacrificing a sense of self to care for their child (Wirrell, Wood, Hamiwka, & Sherman, 2008) compared to those with less severe epilepsy (Camfield, Breau, & Camfield, 2001; Shatla et al., 2001; Wirrell et al., 2008). Children with DRE also exhibit behavioral issues (Wirrell, et al., 2008), depression, and learning disabilities (Cushner-Weinstein et al., 2008) which result in increased parental stress reported by their mothers (Wirrell, et al., 2008). Poor quality of life for parents of children with chronic illness has been associated with increased parent-related stress (Tung et al., 2014). Overall well-being is influenced by an inter-related aspect to family caregiving between the caregiver and care recipient. Parents of individuals with epilepsy have demonstrated poor quality of life when their child's quality of life is also poor. For this reason, parental quality of life is equally important to understand (van Andel et al., 2009).

Glossary of Key Terms

Caregiver: informal and unpaid provider of care

City of Hope Quality of Life Model for Caregivers: a theoretical model that examines the psychological, social, physical, and spiritual issues and concerns facing families (Ferrell et al., 1999)

Coping: the dynamic behavioral and cognitive effort to manage demands, both internal and external, that exceed an individual's resources (Lazarus & Folkman, 1984)

Drug-resistant epilepsy (refractory epilepsy or DRE): failure of two adequate trials of appropriately chosen anti-epileptic medications used to achieve sustained seizure freedom

Epilepsy: neurological condition wherein there are two or more unprovoked seizures occurring at least twenty-four hours apart in time; one seizure with a high probability of a further seizures; or diagnosis of an epilepsy syndrome

Lazarus and Folkman's (1984) Ways of Coping Questionnaire: a measurement of the coping process when a stressful encounter occurs focusing on the adaptation to stress through behavior, cognitive, or emotional changes

Parents: primary caregivers for their child

Parental Stress: the stress related to child-rearing as well as general stressors such as financial difficulties, changes in employment, and parental relationship conflicts (Deater-Deckard & Panneton, 2017)

Parenting Stress Index (PSI) (2007): measurement to assess the degree of stress related to parental functioning, the behavioral aspects of the child, and the parent-child relationship, intended to identify issues which may lead to behavioral health issues for either the parent or the child

Quality of Life: a person's physical, psychological, spiritual and social well-being (Ferrell, 1995). Operationally defined as using constructs found in the World Health Organization Quality of Life Scale (1993), which focuses on individuals' views of their well-being, providing a new perspective on the disease

Rosenberg Self-Esteem Scale. Rosenberg's (1965): a scale that provides insight into global self-worth by measuring the positive and negative feelings about oneself

Self-Concept: the attitude (either positive or negative) one holds towards oneself as an object, the overall evaluation of an individual's worth

Social Support: a network of family, friends, and community members available when needed to give information, advice, or tangible assistance to a recipient (Gottlieb, & Bergen, 2010)

Social Support Questionnaire: questionnaire that examines the quantity and quality of support perceived and the degree of satisfaction with those who provide support for an individual (Sarason et al., 1983)

The Purpose of the Research

Caring for a child with epilepsy impacts the quality of life for the child and the family as well. For those parents caring for children with DRE, there may be additional changes in quality of life. Little is known about these parents' lived experience and the effects on their quality of life; therefore, this study proposes to examine them and gain insight into how parents describe and give meaning to their own quality of life relating to the lived experience of caring for their child with DRE. This study proposed a narrative approach

of understanding the rich accounts shared by the parents of children living with DRE. Foundational assumptions regarding the cumulative effect of stress in caring for a child with DRE including stress, coping, self-concept, and social support, which affect parents' and their child's quality of life, were all weaved into the narrative of describing this experience.

Research Questions

Describing the lived experience was constructed from the research questions below:

- What is life like for a parent, caring for and living with a child with DRE?
- How extensive has the caregiver role been?
- What types of stressors do the parents experience when caring for a child with DRE?
- What resources exist to provide a sense of support for the parent?
- How has the parents' own sense of self-concept been impacted?
- What are the ways in which parents cope with the caregiver role when caring for a child with DRE?
- In what ways has the parents' quality of life been affected in caring for a child with DRE?

At the conclusion of the interview process, participants shared their thoughts regarding information important for other parents to know as well as what health care providers should know to better care for children with DRE. Although not part of the

initial interview guide, the responses which grew out of the process enhanced the findings. With discovery, as this naturally unfolded, all participants were asked what advice they would give to parents who are beginning their journey with epilepsy.

Foundational Assumptions

Chronic stress affects an individual's overall psychological well-being; a multifaceted outcome encompassing emotional and physical aspects (Pearlin, 2010). Stressors, in general, occur as acute or sudden life events. They also may present as more chronic strains, such as, from a social role and the interpersonal interaction it creates (Pearlin, 1999). Stress is a process in which stressors, in certain situations and under certain conditions, can impact an individual's psychological well-being (Pearlin, 1999). These stressors are highly complex and variable. An important goal of studying stress is to examine the overall psychological well-being of an individual (Pearlin, 1999; Pearlin, 2010). Pearlin's Stress Process Model provides a theoretical framework to examine the process of stress and the effect of the psychological well-being of an individual (Figure 1).

The Stress Process is a conceptual model in which certain key assumptions are considered. Components of the Stress Process Model include social status, typical life events, and more distant stressors, which may contribute to more proximal stressors. First, there are many factors of an individual's social status to consider. Social status refers to the level of power, privileges, and prestige hierarchical in nature (Pearlin, 1999). Social status provides the contexts which encompass individuals' daily lives, their exposure to stressors, and the resources utilized in response to the stressors. The way stress is

manifested, both through psychological and bodily functioning, is also a factor. These are all interconnected; a change in one aspect may result in a change in another (Pearlin, 1999).

Stress and its effects are not isolated events involving a stimulus and a response. Stress is part of a system with many factors connecting over time to the larger social systems in which they are involved. For example, degrees of social support, family cohesion, and marital satisfaction all impact the level of stress in parents caring for children with epilepsy (Rodenburg, Meijer, Dekovic, & Aldenkamp, 2007). The second component is of social stress that involves typical daily events. Although stress can occur from rare and unusual instances, it is more often associated with pressures of daily living such as performing the social role of parenting, dealing with financial issues, and resolving family conflicts (Pearlin, 1999).

Lastly, the Stress Process Model emphasizes the importance of examining stressors distal to the main stress as much as those of closer proximity to better understand the origins of the stress and its outcomes. According to Pearlin (1999), stressors appear as either primary or more chronic and repeated stressors. Primary stressors are life events which can be identified by a point in time; whereas, secondary or chronic stressors develop in a more subtle way over time and are likely to be more persistent. Primary stressors are life events which have a very disruptive effect on an individual's life and well-being. These events are not scheduled and not welcomed. For example, individuals with epilepsy experience the unpredictable nature of their disease, with seizures occurring in an unpredictable manner (England et al., 2012). Breakthrough seizures are an example of a life event.

More chronic stressors are associated with social roles and the interpersonal relationships they involve. Chronic stressors consider institutional roles such as parenting, marriage, and finances. These chronic stressors create stressful environments within these roles when demands exceed the individual's capacity (Pearlin, 1999). As parents, caring for a child is expected, but chronically ill children require additional and continued care beyond the stressors of the typical parenting roles.

Moderating resources that prevent, delay, or buffer the development of the stress process and its outcomes (Pearlin, 1999), are also for consideration within the Stress Process Model. Pearlin (1999) identifies three moderators within the Stress Process Model as coping, social support, and self-concept. Behaviors which are used by an individual to manage stress and its effects are referred to as coping. Examples of coping behaviors include problem-focused styles, such as planful problem-solving, and emotion-focused styles such as avoidance (Lazarus, & Folkman, 1984). Coping may change the situation, change the intensity of the stress, or shape the meaning of the stressors.

Social support, an aspect to consider in the management of stress, is a network of family, friends, and community members available when needed to give information, advice, or tangible assistance to a recipient (Gottlieb & Bergen, 2010). Social support may impact the stressors throughout the process; the type of help provided may vary at different points and depend on the type of stress involved (Pearlin, 1999).

Self-concept is the last moderating resource identified by Pearlin. Self-concept refers to the individual's understanding and belief about himself/herself (Baumeister, 1999). With a high self-concept, one sees stressors as less threatening (Pearlin, 1999).

Pearlin (1999) argues that, if there is a lack of one moderating resource, there is likely to be a lack of others as well due to the interrelated nature of the stress process and these moderators. For this reason, moderating resources should be examined together, not separately.

Although the Stress Process Model provides a foundation of learning regarding factors influencing psychological well-being, it does not provide a comprehensive framework regarding quality of life. Ferrell, Dow, and Grant (1995) describe a model of quality of life that encompasses all aspects of care. It is imperative to examine the psychological dimension and the physical, social, and spiritual aspects of an individual's life as well. The dimensions are all interrelated and encourage a holistic approach to care since a change in one dimension may affect changes in another dimension (Ferrell, Grant, Borneman, Juarez, & ter Veer, 1999).

Like the Stress Process Model, the City of Hope Quality of Life Model for Caregivers examines the psychological issues and concerns facing families such as anxiety and depression. Initially developed as a model to describe quality of life for an individual living with cancer and created to address the needs of families caring for individuals with life threatening illnesses, it examines the physical, psychological, social, and spiritual well-being of family caregivers. It describes three domains as equally important: physical, spiritual, and social. The physical domain includes the family member's ability to function, sleep, and rest. The spiritual domain provides insight into their hope, suffering, and religiosity as a source of strength. The social dimension describes the importance of roles and relationships, as well as the financial concerns caring for a loved one (Ferrell et al., 1999) (Figure 2).

To better understand the quality of life for caregivers it is imperative to address family concerns with a holistic approach; one that encompasses every aspect of well-being. By combining the existing Stress Process Model with the additional domains identified by the City of Hope Quality of Life Model for Caregivers, one may gain additional insight and a more comprehensive understanding quality of life experienced of a caregiver (Figure 3). A narrative offers a rich description of these accounts.

The Significance of the Study

Children with continued seizures and DRE have demonstrated worse quality of life outcomes (Miller et al., 2003; Modi et al., 2009; van Andel et al., 2009). Parents also are impacted by their child's epilepsy, especially parents of children with more severe forms (Camfield et al., 2001; Shatla et al., 2011; Wirrell et al., 2008). Parents of children diagnosed with DRE were invited to participate in this study, as it was important to have a deeper understanding of their experience and what it is like to be a parent of a child with DRE.

The annual medical cost for epilepsy care, both direct and indirect, ranges between \$9.6 and \$12.5 billion (Begley, Famuteri, & Anneger, 2000; Berg, Testa, Levy, & Shinnar, 1996; Institutes of Medicine, 2012). Epilepsy care imposes burdens on the individual and the family as well. In noted contrast to the above, caregivers provide over \$257 billion worth of unpaid services each year (Myaskovsky et al., 2012). The burden of caregiving may disrupt the caregivers' lives, impacting them financially as well as on other roles and relationships (Thompson & Doll, 1982). The management of epilepsy requires careful

examination of potential effects of the disease on all aspects in the parent's life (Aggarwal, Datta, & Thakur, 2011).

Boling (2005) describes the parent's role, caring for a child with epilepsy, as one that is never 'off duty.' Caring for children with epilepsy has demonstrated increased parental stress (Cushner-Weinstein et al., 2008), more so than for other children with chronic illness such as asthma (Chiou & Hsieh, 2008). The parenting role creates specific stressors either alone or in combination for parents. For example, issues specific to the pediatric population including the limited ability to perform activities, learning problems, and/or child (Cushner-Weinstein et al., 2008) and parental depression increases parental stress (Rodenburg et al., 2007).

Parents also are impacted by their child's epilepsy, especially parents of children with more severe forms (Camfield et al., 2001; Shatla et al., 2011; Wirrell et al., 2008). In particular, high levels of stress in parents of children with epilepsy have been observed (Cushner-Weinstein et al., 2008), especially with up to 40% of children under poor seizure control and refractory to medications (Mitchell, Seri, & Cavanna, 2012), whose poor seizure control has negatively impacted the family (Bahi-Buisson, Guellec, Nabbout, Guet, Nguyen, Dulac, Chiron, 2008).

The health status of a child with epilepsy is linked to the parent's quality of life (Boling, 2005). According to Cianchetti, (2015), poor quality of life in parents has been linked to their child's illness. If the parent's well-being is affected, the ability to care for the child will suffer and the quality of life for that child may be impacted as well (Boling, 2005). This makes the assessment of parental quality of life an important component of a

comprehensive approach to patient care in epilepsy (Cianchetti et al., 2015). Understanding how parents describe and give meaning to the lived experience of caring for children with DRE is critical to finding out about their quality of life and providing needed support. It is paramount to examine the parents' experience and gain insight into this aspect of care to better understand their quality of life, factors that impact their overall well-being and provide care for children with DRE.

Chapter 2: Review of Literature

Purpose of the Literature Review in Qualitative Inquiry

The purpose of the literature review in qualitative inquiry is to uncover background information on parents' caring for children with DRE, which will relate to and may support findings from the narrative analysis that the primary investigator will use to identify the true essence of the parents' lived experience (Creswell & Poth, 2018). Just as the narrative analysis using in-depth interviews will allow for careful and methodical description of all the aspects of well-being: physical, psychological, social, and spiritual, represented as quality of life (Patton, 2015), this literature review delves into issues that impact the quality of life of parents of children with DRE. As a framework for the narrative analysis, this literature review discusses the quality of life of parents of children with chronic illness, specifically DRE, and related phenomena, that is stress as a negative factor and coping, social support, and self-concept as positive factors that impact the quality of life of parent-caregivers, especially those with children with DRE.

Background of the Phenomenon

A variety of illnesses such as: pediatric cancer (Tsai, et al, 2012), cystic fibrosis (Boling, 2005), diabetes mellitus (Bhadada, Grover, Kumar, Bhansalik, & Jaggi, 2011) asthma (Al-Akour et al., 2009), cerebral palsy (Brehoat et al., 2004; Raina et al., (2005), and autism (Dardas & Ahmad, 2014a; Dardas & Ahmad, 2014b; Dardas & Ahmad, 2014d; Raina et al., 2005) have been shown to impact parents' and their children's quality of life compared to that of the general population (Khanna et al., 2011).

Parents of children with chronic illness have noted increased stress, impacting their quality of life (Dardas, Ahmad, 2014a; Dardas & Ahmad, 2014b; Dardas & Ahmad, 2014d; Wirrell, Wood, Hamiwka, & Sherman, 2008). Although caregiving is a normal part of being a parent, this role takes on an entirely different significance as related to chronic illness, for example, when a child experiences functional limitations and possible long-term dependence (Coffey, 2006; Smith, Cheater, Becker, 2015). In a sample of autistic children, a significant negative association was noted between the level of behavioral problems and degree of functional impairment and parents' quality of life (Khanna, et al., 2011).

Parents are challenged to manage the child's chronic illness effectively while maintaining the requirements of everyday living; such as attending to other roles such as that of a wife/husband, impacting the marital relationship (Al-Akour & Khader, 2009). They face financial issues, difficulty paying medical bills, depleted savings, and credit card debt (Hughes, Giobbie-Hurder, Weaver, Kubal, & Henderson, 1999). Employed parents may miss days of work, quit, or retire early to provide childcare (Raina et al., 2005; Al-Akour & Khader, 2009). A resulting lower income is predictive of decreased functioning in their role, relationships, and their general health (Piran, Khademi, Tayari, & Mansouri, 2017).

The unpredictable nature of epilepsy has an increased psychological impact on all involved (Jacoby, Snape, & Baker, 2009). Parents of children with epilepsy often experience higher levels of psychological distress, report poorer quality of life (Lv et al., 2009), and have an increased risk of mental health issues such as depression (Shore, Austin, Huster, & Dunn, 2002). Approximately one-third of mothers of children with new-onset

epilepsy are at risk for clinical depression (Speechley et al., 2012), which seems to have a significant negative impact on their and their child's quality of life as well (Ferro, Avison, Campbell, & Speechley, 2011).

The severity of an illness impacts the overall quality of life, with worsening of disease resulting in lower quality of life (Al-Akour & Khader, 2009). Parents of children with uncontrollable epilepsy such as DRE report higher parental depression, higher levels of stress, and lower quality of life scores than parents of children with well-controlled epilepsy (Speechley et al., 2012).

Few studies exist that examine parental quality of life with even fewer inquiring into those caring for children with DRE. Lv et al. (2009) found differences in parents' quality of life; comparing parents of patients with DRE to those whose seizures that are well-controlled and to parents of healthy children. There were statistically significant differences between the parents of children with epilepsy compared to parents of healthy children as well as between caregivers of drug resistant and well-controlled epilepsy. Parents of healthy children and parents of patients with well-controlled epilepsy demonstrated higher quality of life compared to the parents of children with DRE, while parents of children with DRE showed worse mental aspects of quality of life with increased levels of depression and anxiety (Lv et al., 2009). Lv et al. (2009) did not discuss any differences with respect to mothers' and fathers' quality of life; no mention to differences or similarities between parent genders regarding the impact on their parental roles was given.

Related Phenomena

Stress.

Stress is a concern for parents of children with chronic illness. A relationship was noted between higher stress levels and lower quality of life for parents of children with cancer compared to the general public (Tsai et al., 2013). In addition, parents of children with disabilities report experiencing greater amounts of stressors than that of children with normal development (Goudie, Narcisse, Hall & Kuo, 2014). Murphy Christian, Caplin, and Young (2006) identified stress as negatively impacting parental physical and mental well-being when caring for a child with a disability. Although type of disability was not specified, constant worry about the child's future, increased stress, and unpredictability of illness were noted to negatively impact parents' well-being (Murphy et al., 2006).

Increased parental stress related to parenting children with DRE negatively impacts quality of life (Nolan, Camfield, & Camfield, 2006). Pearlin (1999) identified two types of stressors, primary and chronic, as contributing to their overall well-being. Primary stressors, that is, seizures are unpredictable events that disrupt life. As poor seizure control increases, so does stress (Cousino, & Haze, 2013; Nolan et al., 2006). Chronic stressors occur as part of being a parent of a child with DRE, for example, constant worry to safeguard the child. Parents report that the unpredictable nature of seizures, constant worry, and financial strains all increased stress and impact their quality of life (Nolan et al., 2006). The cumulative consequences result in tensions and contradictions that the parent struggles with when imagining the coherence in their life story and in achieving a unitary sense of self in the face of these life challenges as caretaker, parent, and safeguard for a child with unpredictable seizure disorder.

Social Support.

Social support has a positive impact on physical and psychological aspects of quality of life (Ji et al., 2014). It buffers the effects of stress on parental quality of life, resulting in better mental aspects of quality of life regardless of the illness trajectory (Al-Akour & Khader, 2009). The need for social support is widely appreciated across many chronic illnesses. A positive relationship has been demonstrated between social support and coping styles (Cousino & Hazen, 2013) in parents with children who have autism (Ji et al, 2014). Parents of children with phenylketonuria have better quality of life with increased social support, which impacts the stress and quality of life for these parents (Fidika, Salewski, & Goldbeck, 2013). Parents of children with congenital heart disease have identified social support as impacting the degree of stress; with both fathers and mothers reporting significantly lower perceived social support with higher parental stress (Tak & McCubbin, 2002). Parents of children with epilepsy, mothers more than fathers, have reported support as important to them in describing the need to not feel alone (McNelis, Buelow, Myers, & Johnson, 2007).

The benefits of social support on quality of life are not universal. Studies of parents with children with special needs, identified as either having a chronic disease, a disability, or an emotional problem, have not demonstrated a statistical difference in the degree of social support and the physical health aspects of quality of life compared to children developing normally (Smith & Grzywacz, 2014). However, only 25% of participants in this study had special needs.

In a study of parents with children who had newly diagnosed cancer, diabetes, or epilepsy, parents of children with diabetes and epilepsy were more likely to seek social support than parents of children with cancer. This increased support-seeking was correlated with higher parental psychological well-being (Goldbeck, 2001). The parents of newly diagnosed children with cancer had lower quality of life compared to those of children with diabetes and epilepsy (Goldbeck, 2001). In this study, however, only 17 of the 122 children had epilepsy. The lack of mention regarding the severity of illness for the groups compared was a clear limitation to the study as was the relatively small number of children living with epilepsy compared to those living with diabetes or cancer.

Researchers have examined the impact of parents' characteristics, sources of parenting stress, family functioning, and informal social support on the well-being of the parents of children with chronic illness (Raina et al., 2005). Predictors of the parents' overall well-being were: the child's behavior, care giving demands, and the functioning of the family (Raina et al., 2005). Fewer behavior issues among children were associated with higher self-perception and better management of stress by parents (Raina et al., 2005). Social support was not a predictor.

Coping.

Parents use coping strategies to decrease their stress and improve their quality of life (Dardas & Ahmad, 2014e). Problem-focused strategies such as accepting responsibility and planful problem solving were associated with lower levels of stress and adaptive behaviors (Dardas & Ahmad, 2014e) and improved quality of life, while strategies such as avoidance increased stress levels and lowered levels of quality of life (Dardas &

Ahmad, 2014c). Use of coping strategies may differ based on parent gender. In a study of Chinese parents with disabled children, mothers reported more stress levels than fathers and verbalized emotions to cope, while fathers tended to increase substance abuse as a coping mechanism more than mothers (Wang, Michaels, & Day, 2011).

Self-Concept.

According to Pearlin (1999), in addition to social support and coping, self-concept is a moderating factor key to improving quality of life. The effects of self-concept and social support have been examined in other caregiving roles. Formal caregivers such as social workers, for example, experience distress when new to their role. Self-concept and social support lower this distress and the negative aspect of stress among this group (Wu & Pooler, 2014).

Among informal caregivers such as parents of children with chronic illness, those with higher levels of self-concept and mastery over their situation experience better psychological well-being (Raina, et al, 2004). There is a paucity of literature regarding the impact of self-concept and its relationship to stress and quality of life for parents; no literature addresses parents of children with epilepsy.

Summary of the Literature Review:

A variety of chronic illnesses impact parents' quality of life as they face the challenges related to the specific illness and attempt to blend everyday parenting with the difficulties of caring for their ill child. The resulting stress impacts parents' quality of life, regardless of the child's illness; however, the degree of severity of illness relates to the worsening of stress they confront (Al-Akour & Khader, 2009). Parents of children with

DRE, with its unpredictable nature of epilepsy, often experience higher levels of psychological distress and report poorer quality of life (Lv et al., 2009). The cumulative consequences of primary stressors (seizures) and chronic stressors (unpredictable nature of seizures, constant worry, and financial strains) result in tensions and contradictions with which parents struggle (Nolan et al., 2006). Social support (Ji et al., 2014), coping (Dardas & Ahmad, 2014e), and self-concept can positively impact physical and psychological aspects of quality of life (Pearlin, 1999).

Although literature exists regarding parents' experience caring for chronically ill children, little exists about those of children with DRE. Little is known about the effects of stress, and the positive effects of social support, self-concept, and coping on quality of life in this population. Further, little is known about how these parents give meaning to everyday life while being this caretaker, and more importantly, about the turning points, the tensions, and their interpretation of their descriptions of caring for a child with DRE. Hidden in their stories are epiphanies about life and caring for their ill child and the unfolding chronology of their experience. A focus on the participants, their described issues, the chronology of their story, and reflexive thinking will become the touchstones for fully understanding the evolving story of caring for a child with DRE. Giving parents the ability to share their stories will allow for a deeper insight into the meaning and provide context, added to the previously identified issues (Riessman, 1993) surrounding the care for a child with DRE.

Chapter 3: Methods

In Support of Methods

Epilepsy is one of the most common neurological disorders impacting all age groups, especially those less than 18 years of age, affecting millions of children worldwide (England et al., 2012). The unpredictable nature of epilepsy impacts the health and well-being of those living with the disease. Seizure control is possible for many individuals, although roughly one-third of those diagnosed with epilepsy will be resistant to drug therapy. Seizure control is but one facet to consider when caring for a child with epilepsy. DRE takes a physical, financial, and emotional toll on the individual and the entire family. Previous studies have addressed the issues related to children living with epilepsy, but little is known about those children who are drug resistant. Even less is known about the parent's experience caring for a child with DRE.

Narrative analysis is an appropriate tool to understand one's own actions and feelings around various events such as caring for the child with DRE. It supports the notion that narrative is a distinct form of discourse constructed from retrospective meanings that shape and order past and current experiences. Narrative inquiry allows the construction of a meaningful whole of multiple pieces that collectively see the consequences of feelings and actions over varied periods, for example, how constrained a parent might feel caring for a child with DRE. Only when parents and researchers are aware of the interconnectedness of mixed events and feelings would we fully understand being a parent of a child with DRE, for example, learning about what cripples' parents versus what enables them is the only way to have a true sense of their life problems.

Parents' experiences are story worthy. Their voices need to be heard in order to understand their life experiences surrounding their children with DRE. Herein rests the heart of this doctoral dissertation that aims to better understand the cumulative impact of caring for children with seizures refractory to medication. Through the lens of a caretaker who may struggle with the effects of stress and their own identity, a narration arises that tells us about their notions of coherence in maintaining the roles of a caretaker and parent. This helps us understand how they resolve tensions and reconfigure their identity, parental role, and the meaning of being a parent of a child with DRE.

The purpose of this narrative study was to gain deeper insight into the life experience of parents who care for children with DRE. The Stress Process Model (Figure 1) provided a framework regarding stressors and overall mental well-being. However, the experience of parents in this population required a more comprehensive examination into all aspects of health and well-being. The Quality of Life Model for Caregivers (Figure 2) provided the additional framework to guide this study and provided a comprehensive examination of the experiences of the parents, considering the psychological well-being and the physical, social, and spiritual aspects. The merging of these theories provided the theoretic framework to elicit parent stories regarding their life history and the quality of that life caring for a child with DRE (Figure 3). Through the combination of the two theoretical frameworks, the study was constructed using the research questions listed in chapter one.

Description of the Setting(s)

Interviews were conducted in a private setting, convenient and in proximity for participants such as a meeting room in a neighborhood library. At participant request, a private setting in the practice office at 20 Prospect Avenue, Suite 801, Hackensack, New Jersey, was utilized. Each in-person interview was conducted one-on-one, as described above.

Characteristics of the Participants

A purposeful sample was utilized in order to provide information-rich cases regarding the phenomenon of interest (Creswell & Poth, 2018; Patton, 2015). Purposive sampling allows deliberate access to those participants most suited to provide the rich information needed to understand these phenomena by intentionally sampling those people who can best inform the research problem being examined (Creswell & Poth, 2018). Because the experience of parents is one that only they experience, the focus is shifted away from the interviewer and directly on the interviewee; this purposive selection of parents of children with DRE was the most suitable way to objectively study the subjective expressions of the participants who best understand life a parent of children with DRE.

The sample size was determined by the information needed (Stake, 2003; van Manen, 2014). Given the need for repeated interviews, increasing the text for each participant, smaller numbers of participants were required (Stake, 2003; van Manen, 2014). Through narrative inquiry, the story is the object of the research (Creswell & Poth, 2018) meant to provide a conduit for the participant's own story to be heard and understood. In sampling for narrative inquiry, small sample sizes of one or two were used except in the attempt to develop a collective story (Creswell, & Poth, 2018) that offers descriptions of the life world of these interviewees with respect to an awareness and interpretation of being

a parent of a child with DRE. An equal representation of five mothers and fathers participated in the study. A model of a priori thematic saturation was utilized as well as data saturation considerations (Saunders et al., 2018).

After receiving approval from the Institutional Review Board (IRB) at Rutgers, the State University of New Jersey, the following methodology was utilized. An informational flyer, that included the PI's contact information, was posted in the waiting room of a physician's office and examination rooms (Appendix B). The flyer was also distributed to parents of any patients scheduled for follow up visits who had the following ICD-10 diagnosis codes for DRE; G40.011, .019, .111, .119, .219, .311, .319, .411, .419, .A11, .A19, B11, .B19, 803, .804, .813, .814, .821, .822, .823, .824, 911, .919. The physician also gave the flyer to parents of subjects who met the inclusion criteria.

A purposeful sample of parents of children with DRE were selected from those who spoke with the physician and/or responded to the flyer (Appendix C). These parent participants used the private practice that specialized in the care of pediatric epilepsy associated with a large Level IV epilepsy center in northern New Jersey (Appendix F), which provides invasive, intracranial monitoring, and a broad range of surgical options. Participants who were 18 years of age or older, who could read and speak English, were included. Excluded from participation were parents of children with epilepsy not refractory to medication, a parent of a child not listed with the aforementioned ICD-10 diagnosis codes, or those parents who could not speak English. Individuals who were unable to understand and consent were also excluded from participation. The PI, who no longer works with pediatric patients and their families, disclosed having worked for the practice

as a nurse practitioner, who did not, however, provide direct care to the patient participants recruited for this study.

Protection of Human Subjects

Creswell and Poth (2018) recommend examining each phase of the research process in order to identify and address any ethical issues that may arise. Three principles regarding human studies guided the research study: respect for individuals, concern for their welfare, and justice (Creswell, & Poth, 2018). Respect for the participants was addressed by seeking consent and maintaining privacy. At the beginning of the interviews, verbal informed consent was obtained from potential participants after describing what the study involved (Appendix D). The study was explained to the subject by the principal investigator, the consent was read, and the subject's questions were answered. After reviewing the consent form, written consent was obtained, which confirmed acceptance for participation.

All interviews were audio recorded on a Sony ICD-PX333 digital audio recorder purchased for study. The narrative was transcribed verbatim, using no personal information that would identify the participant during the interview. Rather, participants were identified by an assigned code number to protect anonymity. The data were entered into a password protected and encrypted computer and electronically stored and accessed only by the PI. The recorded data were stored by the primary investigator in a locked cabinet to which only she has access at the primary investigator's home office. Recordings will be permanently deleted after six years or upon publication of the dissertation.

Those interested in participating directly contacted the primary investigator on her new private cellular phone device purchased for this purpose, using the number provided on recruitment flyers. The PI was the only individual to use this phone and was the only individual with the password protection code used to access any voice messages. The voice message greeting specified the PI's name with a message that that the phone number was devoted to a scientific study sponsored by Rutgers, the State University of New Jersey. The study phone number, which remained active during the study period, was deactivated upon its completion.

The welfare of the participants was addressed. They were assured that they would not experience any untoward relationship at this medical practice and were advised of their ability to withdraw from the study at any time. Should parents have experienced emotional distress during an interview, the interview would stop; none reported any distress or withdrew. Emotional support, however, would have been provided by the Epilepsy Services of New Jersey (Appendix E), a non-profit organization which provides education and support for epilepsy patients and their families.

To facilitate justice, that is, treating all potential participants fairly and equitably, the study was advertised openly. As previously stated, recruitment flyers were first posted in the physician's practice waiting room and examination rooms, describing the study details (Appendix B). Patients meeting the inclusion criteria were also provided with a flyer by the physician during their encounter. The PI either contacted potential participants, or they contacted her directly, after which, she discussed study participation with them (Appendix C). Participants did not receive compensation for participation. The study did not involve any cost to the participant.

Data Source and Collection

Sharing lived experiences in the form of a narrative or story is a way to construct meaning in those experiences (Riessman, 1993), allowing for the recounting of events important and meaningful to those interviewed, and providing a more in depth understanding into their experience (Reissman, 2008). Individual face-to-face interviews were conducted to glean a detailed account of participants' experience caring for a child with DRE, not merely short answers or responses (Riessman, 2008). Little is known of parents' perspectives; therefore, their narratives provided a window into their world. The length of time was approximately 60 minutes in order to provide ample time to share their story and discuss events of importance and meaning. The interviews were transcribed by the primary investigator or a research assistant who was added to the research staff for this sole purpose.

Descriptive demographic data were collected including age, race, religious preferences, education, and outside employment, without patient identifiers on demographic forms. Open-ended questions explored concepts and allowed participants to share their experiences. Each participant was interviewed on three occasions, beginning with general questions regarding their lives meant to establish a rapport prior to discussing more intimate questions. An interval between each interview gave the PI and the participant an opportunity to reflect on the stories shared. Feedback from participants gave essential information regarding how well the data collected represented their lived experience (Riessman, 1993).

A series of interview guides provided the structure for initiation of the conversations (Attachment A) surrounding the central questions. Sub-questions probed for

further meaning of the stories shared (Reissman, 1993). The Stress Process Model (1999) and the City of Hope Quality of Life Model for Caregivers (1999) helped identify concepts to facilitate the interview process and questioning techniques. Areas of interest included physical well-being, psychological well-being, social well-being, spiritual well-being, parental stress, self-concept, coping, and social supports. As previously stated, these sensitizing concepts facilitated discussion and provided an initial area of dialogue during the interview process. Interview one centered on getting to know the participant and provided an overview of the experience of daily living. The second interview focused on parenting a child with DRE. The last interview centered the quality of their life in all aspects relating to caring for a child with DRE.

Data Analysis

Data analysis was accomplished through a five-stage, structured process that began with the transcription of conversations, an interpretive process (Reissman, 1993, 2006) with the goal of hearing the narrators' voices (Chase, 2003). Once an abstracted story summary was created, lines of transcriptions were coded with a letter representing six aspects of the step-by-step distinct stage of transcription (Labov & Waletzky, 1997; Reissman, 1993, 2008):

- Abstract or lines of transcription addressing part of the story summary (A).
- Orientation to any person, place, time, or situation (O).
- Complicating Action or sequence of events (CA).
- Evaluation or significance of an action or attitude expressed by the narrator (E).

- Resolution or result of the action (R).
- Coda or return to the present (C).

Stage two of the multi-stage interpretive data analysis process incorporated concept mapping to synthesize information and provide a visual representation in order to identify relationships between elements of the story (Yoost & Crawford, 2017). Stage three incorporated a matrix grid that illustrated central thoughts from the concept map that identified common expressions, which were matched with corresponding statements that reflected topics common to the themes of the narrator. In stage four, the discovery of further relationships became evident as common thoughts arose and patterns established as a summary of the participant narratives was completed story by story. The fifth and last stage identified patterns from the common, linked ideas, which allowed the researcher to identify common life experiences regarding the experience of caring for a child with DRE. Ultimately, there was a case-by-case analysis and then a cross-case analysis in which the patterns that emerged were summarized with a narrative, detailing the major events noted and the evaluation or meaning attached to the actions.

Trustworthiness in Qualitative Research

This study followed the ideals of researchers such as Guba and Lincoln (1989), Reissman (1993), and further, Hall, and Stevens (1991) regarding trustworthiness in qualitative research. Guba and Lincoln (1989) introduced criteria for determining the trustworthiness of qualitative research, replacing terminology for achieving rigor, reliability, validity, and generalizability with dependability, credibility, and transferability (Morse, 2015). Riessman called trustworthiness the key factor in qualitative research, part of its validation process (Riessman, 1993) and maintained four areas to establish

trustworthiness (a) describing how the interpretations were produced; (b) making visible what we did; (c) specifying how we accomplished successive transformations; (d) making primary data available to other researchers (p. 68).

Further, Hall, and Stevens (1991) maintained that trustworthiness may be achieved by following several steps (a) deliberately reflecting during the process to make sure there is accurate interpretation of data; (b) journaling at the end of each interview; (c) review field notes and the interview content for self-reflection; and (d) providing intentional spacing between the interviews to allow for reflection for the researcher and the participants.

Credibility is achieved by making sure that the participant's experience is accurately interpreted, and that member checking may be a method to do so (Hall & Stevens, 1991). Providing an authentic representation of the stories gathered was accomplished by asking participants, in subsequent meetings, if what was taken from previous conversations accurately represented what the participant meant.

A rapport must be established by means of developing a trusting relationship. Initial contact was made through an already established connection to a physician's office. Once contact was established and an initial interview conducted, the return of participants further established evidence of a rapport built.

Coherence is important to review responses and determine that it is consistent, is logical, and makes sense. By following a systematic approach to the analysis of data, referring to the original data repeatedly, the ability to maintain a well-organized and logical flow was established and ensured that the participant's meaning was accurately interpreted.

Complexity allows for capturing the variety of experiences exhibited. It was important to ask probing questions in a respectful way, without avoiding topics of a personal nature.

Consensus may establish recurring themes and is mindful of cases that are different as well. Relevance establishes that the questions asked are centered on the concerns of the participants and improves their lives. Consensus was established through collective narratives that provided for the common patterns seen in the data.

It is necessary to establish honesty and mutuality in that the research will be ethical and not deceptive in presentation, as will the truthfulness of the responses to be provided by the participants. The ability to name concepts also added to the rigor of the study, as it generated from the participant's own words describing their experience. Finally, the relationality and collaboration of all the methods provided a comprehensive way to review the entire case.

Chapter 4: Context and Informants

Historical and Sociocultural Context of the Research

Epilepsy is the fourth most common neurological disorder, behind migraines, stroke, and Alzheimer's disease (England et al., 2012). Over 65 million people worldwide are estimated to have epilepsy, including approximately 10.5 million children; one third of whom have drug resistant epilepsy (Ji et al., 2019). Parents of children with epilepsy often experience higher levels of psychological distress and report poorer quality of life (Lv et al., 2009). Although there are reports of decreased quality of life for parents of children with DRE (Ferran, Zerwij, Wibur, & Larson, 2005), little is known about how the parents describe their lived experience.

Participant Demographic Profiles

Ten parents of children with DRE, equally represented by men and women and of various ages, races, religions, marital status, and work profile as explained below, participated in the study. All completed the three interviews.

Age

As shown in Figure 1, the age range for the study participants spanned several decades, from the youngest participant at age 27 years to the two oldest participants at age 56 years. Most participants (n=6) were between the ages of 48 and 56 years. The average age of the sample (N=10) was 45 years.

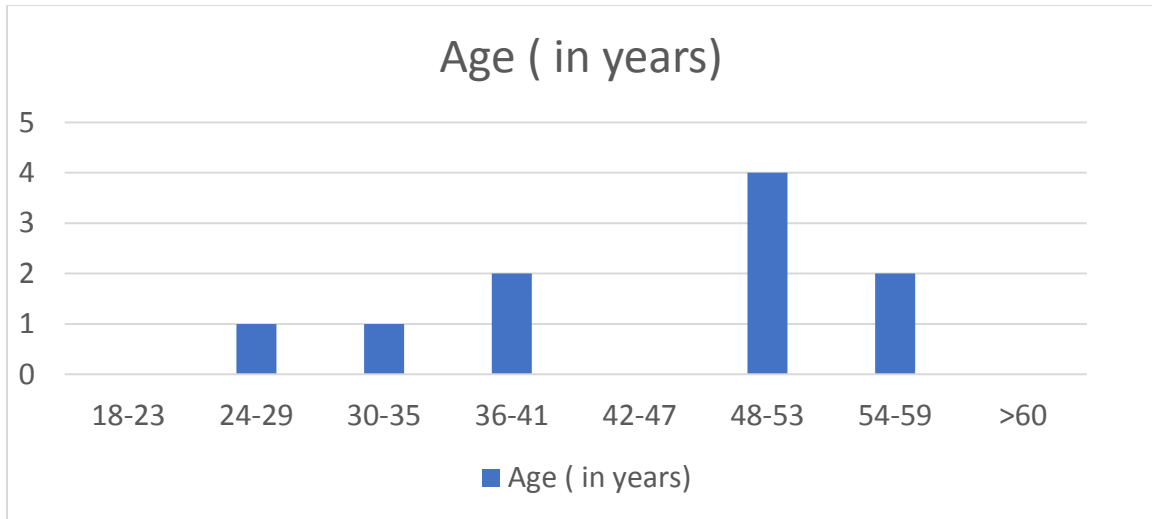


Figure 1. Age distribution

Race

The distribution of participants' race is shown in Figure 2. Most of the 10 participants self-identified as Caucasian (n=7). The other three participants self-identified as Hispanic.

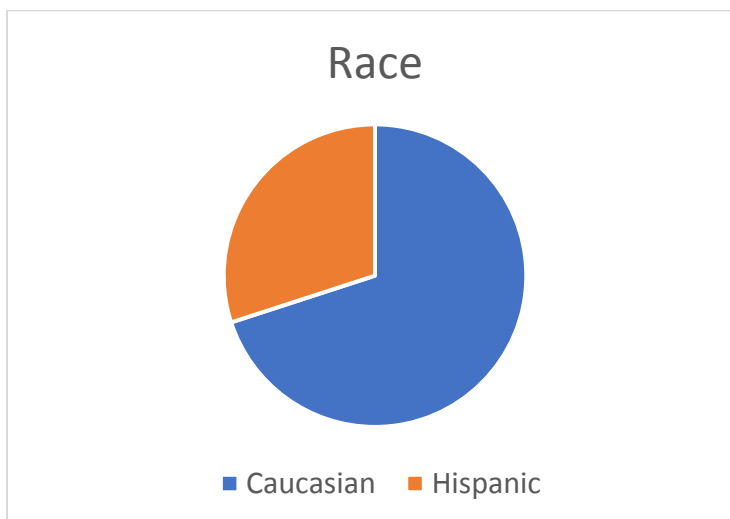


Figure 2. Self-identified race distribution

Marital status

As depicted in Figure 3, most participants (n=8) were married. The remaining two participants were single.

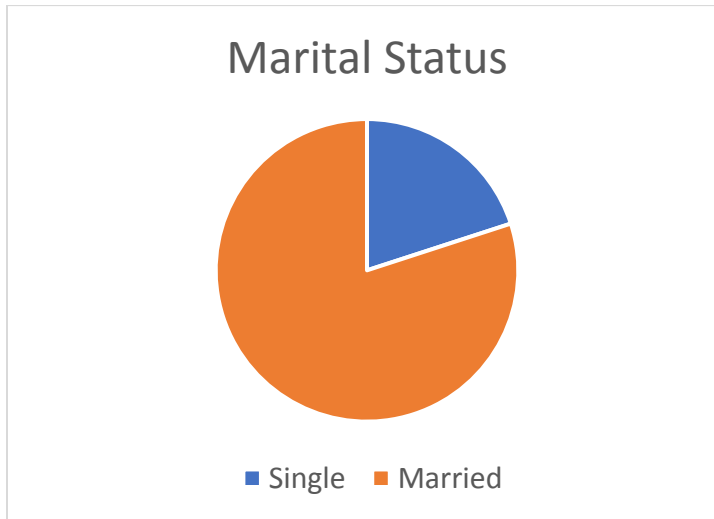


Figure 3: Marital Status

Work Outside of the Home

The distribution of participants working outside of the home is depicted in Figure 4. Most participants worked to some degree outside of the home. A total of four participants worked full-time outside of the home; three part-time, while three did not report any work outside of the home.

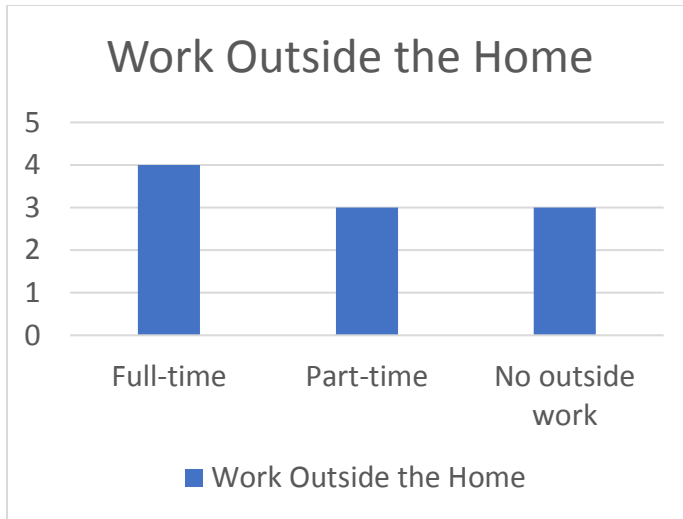


Figure 4. Work outside of the home

Religion

As shown in Figure 5, of the ten participants, eight self-identified as Christian; six Catholic, one Protestant, and one Baptist. One participant self-identified as Buddhist; one as having no religious affiliation.

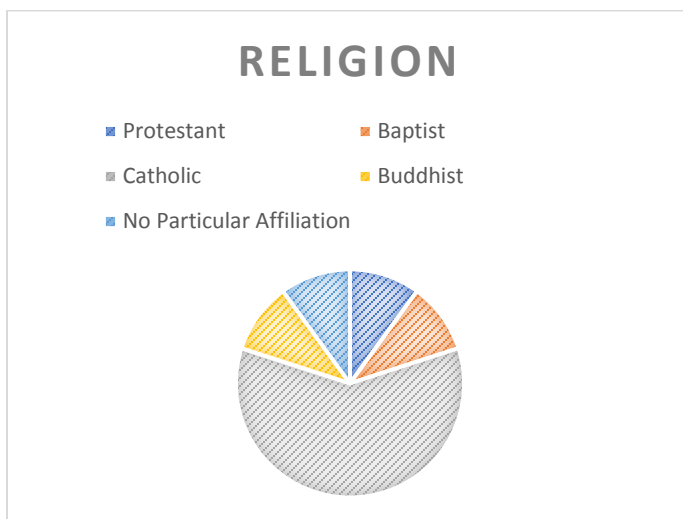


Figure 5. Religion distribution

Years since Epilepsy Diagnosis

All the participants were parents caring for a child with DRE. As demonstrated in Figure 5, the time in years of their child's living with epilepsy spanned several years. The shortest duration of time since receiving a diagnosis of epilepsy was two years; the longest time frame was 17.5 years. Most (n=9) were diagnosed between 9 and 17.5 years. The average age since epilepsy diagnosis for the sample (N=10) was 12.5 years.

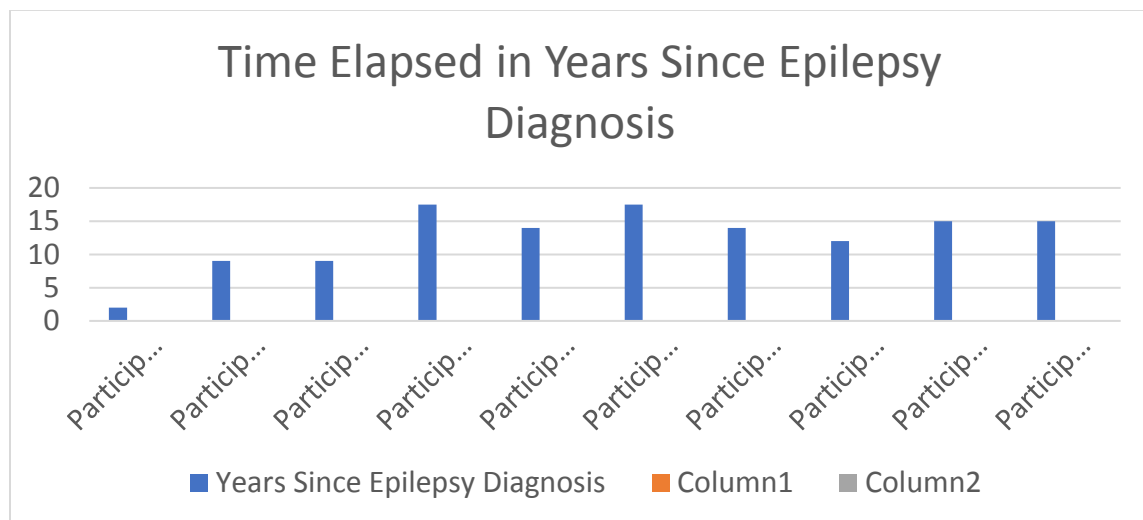


Figure 5. Time Elapsed in years since epilepsy diagnosis

Description of the Audit Trail

Each participant completed three face-to-face interviews. A narrative analysis was selected to allow for the participants to share their stories. An interview guide was used at each interview to facilitate conversation. All interviews were recorded and transcribed verbatim. No personal identifiers were used. Electronic records were kept on a password protected computer at the home office of the primary investigator (PI). Each participant was assigned a participant number. A purposeful gap in time between interviews was

established, allowing for reflection by both the interviewer and the participant. Journaling at the end of each interview and the review of field notes provided additional methods of reflection for the interviewer. The contents of the previous interview were reviewed at the start of each subsequent interview to ensure that the participant's experience was accurately interpreted.

Summary

The experience of being a parent for a child with DRE is difficult to fully understand. The narratives in the following two chapters reveal their stories and provide a deeper insight into their lives. Chapter five presents results of the within-case analysis, providing details of each participant's life history in a narrative summary. Chapter six presents results of the across-case analysis, describing commonalities in the story of parenting a child with DRE. By engaging in this narrative analysis, the expectation was to provide a deeper level of understanding to the experience of parenting this specific population of children.

Chapter 5: Description and Discussion of Narratives

As part of a narrative analysis, it is important for participants to provide their own accounts of their life experiences in their own words. Hearing their stories allows for the understanding of what has been meaningful in each of their lives while caring for a child with DRE. The interviews, which address each participants' stories, provided participants with the opportunity to explore the impact that epilepsy has played in their lives. Noteworthy are the participants' narration as well as the language they used to tell their stories. The interview summaries serve as an introduction into the lives of these individuals as parents of children with DRE.

Because the interview questions dealt with issues of a personal nature, common colloquial filler phrases such as “like”, “um”, and “you know” that indicated a pause or struggle in thought or speech are common especially for some who, for the first time, spoke aloud their experiences. However, filler phrases have been removed from the direct quotes to facilitate readability and maintain the reader’s focus on the participant’s stories.

The narrative summaries that follow represent some of the key elements of each participant’s responses and capture answers to questions that allow the reader to understand the nuances of each conversation and the nature of the three-interview series. To maintain anonymity, participants were given participant numbers.

Narrative Summaries

Participant 001

Participant 001 is a 27-year-old Hispanic female whose parents are from Ecuador. Desiring “*the American dream*” for their daughter, prior to her birth, her mother moved to the United States; her father was reunited with them “*a bit later.*” Currently, she is completing an on-line degree in computer engineering. She is the mother of three children: two boys ages five and two, and a newborn girl age one month when the interviewing process began. Her oldest son, who has DRE with absence type seizures, was diagnosed at age three and continues to have 20-30 seizures daily despite medical management. Her second child is free from any medical issues; however, her third child experienced neonatal seizures and is being treated for seizure disorder.

Participant 001 recalled the feelings she had when hearing that her oldest son had epilepsy; initially overwhelming shock, then a sense of relief to know exactly what was wrong with her child, that is, an actual diagnosis to explain her son’s symptoms. She recalls so many emotions; feeling angry and upset, expressing concern that she had done something wrong or had unknowingly transmitted the disorder to him, and sadness for what epilepsy may mean in her child’s life.

When asked what life is like as a parent for a child with DRE, participant 001 said that she “*dedicated my time to be with the kids.*” Rather than work outside the home, her daily schedule, is filled with activities caring for her children, “*full of activities from the time I wake up until I goes to sleep.*” She and her husband engage the family with schoolwork, activities of daily living: reading at the library, arts and crafts projects at Home Depot, or spending a day at the park. She credits maintaining a schedule as instrumental in managing the care of her children, especially medication administration to her son with DRE and

youngest child with neonatal seizures. Being very well organized and planning for meals, clothing, and time set aside for homework and play, prevent her from being overwhelmed.

When asked what types of stressors exist for her, the traumatic experience of the birth (still so new) and subsequent ill health of her newborn comes to mind. Having an uncomplicated pregnancy, she was alone when she went into labor. Because her husband was at work and she unable to find someone to watch the other children, there was a delay getting to the hospital. During delivery, the baby, who had heart decelerations, was thought to *"not be moving"*, so participant 001 was sent for an emergent caesarian section. The baby was not crying or breathing; her umbilical cord wrapped twice around her neck. Within minutes, she experienced multiple seizures. An anti-seizure medication was administered, but was ineffective; however, a second agent controlled the seizures. The baby also required an additional intervention for anemia and blood transfusions. She required a prolonged hospitalization, including 16 days in the Neonatal Intensive Care Unit (NICU), where she had difficulty feeding. Participant 001 remembers this as a very difficult time as she watched the numerous tests being performed, spending most of each day by her infant's side. *"I would eat there...everything. I was just there the whole day."*

On a day-to-day basis, she sees all of the things she deals with as stressors: *"I'm actually exhausted. I came to the point... I'm very exhausted."* Trying to care for her children, provide for their medical needs while completing her degree are stressful to her. She has noticed changes in her sleep as a result. Lack of sleep lead to frequent headaches. She revealed that *"I'm having these horrible headaches. And I'm trying to stay focused on my school and I can't even focus on my school, because my head hurts so much."* Part of

this stress arises from her desire to not merely receive a passing grade, but to excel and gain a deep understanding of the material, which is significantly stressful.

Another source of stress occurs in encounters with her older son's school. It is not widely known that her son has epilepsy, creating challenges. When her son had an absence type seizure, *"he said I came out of the class and then next thing I know I look behind me... I look in front of me...and my class was missing. I don't know what happened. I think he caught a seizure."* She acknowledged that since some of the staff were not aware, they may mistakenly think her son is not paying attention.

It is also challenging to maneuver life in "the world", for example, soon after learning how to ride a bike, the family took a trip to the park. Participant 001 remembers a particularly terrifying time: *"We were keeping an eye on him, watching him riding... and he caught a seizure. And then he was getting off the bike, as he was getting the seizure. And then he turns around the opposite way... and then he looks left and right, and he started running towards the cars."* As a result, she remains hyper vigilant, watching him constantly.

Staying positive is how participant 001 copes with all the stress associated with being a parent of a child with DRE. She states that she will *"just push through."* She believes that

I'm a mom. So, I have to be strong. If I'm not strong my... my kids can't be strong. I'm an example for them. So, I try to... have a happy face and you could do it and...and I even talk to myself in my head... in my car,

if I'm alone...you can do this... let's finish this. (Participant 001, interview 2, p 15)

Participant 001 describes herself as a religious person, very involved in her church, which provides her primary source of support and assists with coping. She carries a book of verses so she can read them day and night to remind her that she can make it through anything challenging.

Participant 001 does not have a large support system available. Her mother works at Costco; her father manages a Dunkin Donuts. She has a grandmother living in New Jersey and some extended family in Texas and Florida, but no close relative or friend in the area. Although at a distance, she does feel that her family provides a sense of support. Her husband has some friends associated with his job, but they all live in New York City.

Social media has also given participant 001 a broad support group. By joining a group of mothers with children diagnosed with absence epilepsy, she became aware of ways to obtain additional support for her child through the school system. She had not been aware of these through conversations with her pediatrician or other health care providers.

When asked if her views of herself have evolved or changed, participant 001 reflected and then described a sense of growth through the experience. She summarized as follows:

I thought I was very weak... very passive, which I think maybe it was true back then. People would say, no, you have to raise your kid like this. You have to do this. So, I would say I was weak and passive.

I used to go with the flow. But then, as I grow older, I learned that... I changed and I realized what was wrong with me in that sense. So, I took control and obviously I wasn't passive anymore. Like I said before, you have to be an advocate for your son. When it comes to school, I learned a lot.
(Participant 001, interview 3, p12)

She believes that she is strong and is proud of her accomplishments. Participant 001 also recognizes that she has decided to live her life with her children at the core. She provides this insight about other parents who have not had similar experiences *“They're probably going out...leaving the kids with a babysitter, and they're not spending quality time. So, I think of myself...I'm strong and family oriented.”*

Despite describing utter exhaustion at times, horrific headaches, and lack of sleep, participant 001 does not feel that the quality of her life has changed. She provided this insight. *“I don't think...it didn't change much. It's just... the focus is more on my kids... so my life revolves around them. So, I do think it didn't change as much.”*

Participant 001 was able to provide insight into some unexpected joys as just seeing her son happy. She feels that her son is doing well in school and that although he is having seizures, it is not impacting his academics. She says, *“I'm happy that he's growing...everything is normal. Everything else...he's healthy, so that's my main thing.”* She was also happy to know that cannabidiol, a chemical compound known as marijuana, was now available in New Jersey as a potential treatment for her son.

When asked what advice she would give to parents who are beginning their journey with epilepsy, participant 001 provided the following insight: *“Basically, not to give up.*

Do your research. Do what you have to do.” She also added that it is important to find additional support systems. *“I found support groups through Facebook... children with absence seizures. So, try to get involved by listening to other stories. You actually learn a lot from other moms as well.”* Participant 001 identified having a doctor who is understanding and *“actually listens to me”* as important for the healthcare community to know.

Participant 002

Participant 002 is a 32-year-old Hispanic female, born in Bolivia, who came with her parents to the United States when she was two years of age. Unmarried, her support system is further limited since her parents work and her younger brother, whom she helped raise, attends college. She works part-time at a local college as an administrative assistant, a valued employee responsible for multiple projects at the same time.

Participant 002 is a single mother of two children; an 8-year-old daughter with no medical issues and a 12-year-old son with autism and DRE consistent with Lennox-Gastaut syndrome (LGS). LGS is a syndrome characterized by cognitive dysfunction, a specific electroencephalogram pattern, and multiple seizure types including generalized tonic-clonic seizures, drop seizures, tonic seizures, hemi-clonic seizures, and absence seizures. At the age of four, he began having seizures and currently experiences two to three seizures daily, mostly tonic seizures although drop seizures are not uncommon.

When asked her feelings on hearing that her oldest son had epilepsy, participant 002 remembers that she was shocked and overwhelmed; it took almost a full year to adjust to the diagnosis. She recalled that *“It was very surprising. I didn't know what epilepsy was*

when they told me (my son) had epilepsy. It was a shock when I found out.” She recalls early on feeling incompetent any time he would have a seizure:

I felt like what can I do? How can I take that away from you? How can I make you feel better... that you don't have to go through it? And there really isn't nothing I can do that is in my power, like my manpower, that can help him. I just have to wait and see him, seeing him have an episode until he gets out of it... and that will be frustrating. Because I wish I can do something. I wish there was something that can just stop it or make it go away. And...we don't have that yet. Not even 'til now; we don't have that yet. (Participant 002, interview 2, p 11)

Participant 002 describes her life as a parent of a child with DRE, as days planned out minute-by-minute for the extensive amount of care required for her son. Her morning is very structured and regimented in order to assist him with activities of daily living, prepare him for school, facilitate medical management of DRE, and maintain his strict, limited carbohydrate diet, carefully selecting, weighing, and measuring all food for seizure control. *“It's a struggle. It's really...it's not a burden... but it's just a lot to... take.”*

After school, participant 002 takes up her afternoon schedule with picking up her children, dropping her daughter off at an after-school program, and attending her son's therapy, which is at a distance. She adheres to the clock to ascertain that she is on time to pick up her daughter at 6 p.m. Being well-organized is key; maintaining a plan and being organized are instrumental for her to avoid stress. Every event or activity must be planned out. There is no spontaneity. *“It's a little bit stressful. You need to think before you make*

a move... more or less. Any change in the schedule is a source of stress. "The schedule changes or someone cancels, and it just throws me off a little bit."

Relying on nursing has also added stress for participant 002. One example illustrates what happened when a new nurse was sent to school with her son.

One time was I didn't feel confident or comfortable when he left with the nurse. And then I got a call that he was going to the ER and I was like...what happened... what do you mean? He had fell and cut open his chin. And I was like, where was the nurse? Why do you have a nurse? And that was a stressful moment. Plus, I was at a very important meeting at work. I was presenting that day. I was doing the presentation for the company. And I just thought like... when you're put behind a wall... what do you do at this moment? I just dropped everything and said I had to go, I'm sorry. I just excused myself from the presentation and just left for the hospital. (Participant 002, interview 3, pp 5-6)

Participant 002 discussed that there are challenges associated with her son and living with DRE. She believes that she must always consider his safety and maintain a safe environment. At times, this limits activities especially if she cannot control safety risks. *"It's kind of hard to move him or make sure he is safe, out of no harm from any vehicle when he's having an episode. So, it's...those are some of the challenges we hit. I always have the second thinking many things are going to do, to make sure what if (my son) would have an episode... are we in some secure place or safe place for him that... where we can*

sit him down and lay him down if needed.” She would prefer to avoid activities all together rather than having a safety issue.

There are additional challenges when participant 002's son interacts with large groups of people, since he is extremely impulsive and does not have a sense of direction or regard for his surroundings. Now that he is older, bigger, and going through puberty, it is more difficult to prevent him from exerting excessive strength, for example, he was excited to see his grandparents, but was hugging his grandmother too much. *“He’s squeezing me too hard,”* his grandmother shouted.

One way participant 002 said she copes with stress associated with being a parent of a child with DRE is by going to the gym; running on the treadmill or swimming in the gym pool. These provide an *“energy boost.”* If she can coordinate it (which is difficult to do), she will attend a cycling or Zumba class. Although the gym has child-care options, the facility has expressed concerns regarding watching her son, which limits her options for her own participation in classes. In general, she copes with stress she experiences by remaining in the moment and not thinking too far in advance. *“I just take it day-by-day.”*

Speaking with parents with similar experience and being part of an active Christian community provide her with a sense of support and assist with coping. *“Being around church community and the people and just knowing that they’re strangers, but they welcome you with open arms, was very nice. Actually, it’s very nice to have. It’s very different support...and I think that’s what actually helped me.”*

Participant 002's mother, who introduced her to the church environment, provides a great deal of support through inspirational sayings to get through tough times, and that

helps maintain positive thoughts. She has extended family in Georgia and would like to live closer to them for support, but it would not be conducive for her son's medical care. Relocating might result in receiving fewer services or a lower level of care from specialists. It might also cause hardship for her son's father, who works long hours, to be involved in their lives on weekends, as he is now. His family is available but are not closely involved.

When asked if her views of herself have evolved or changed, participant 002 described a sense of growth through the experience, saying:

I could see now, I've learned to say, I can handle it...and be strong about it. But before, I was...I was very weak. Any little thing that would come, I would be very upset. I would get depressed and not want to talk to anybody and just close myself...just close myself. I wouldn't talk and just hold everything in. Now, I've learned...with the support groups...the parents...talking to the parents. And their stories and their experiences actually have helped. (Participant 002, interview 3, p 13)

Despite describing physical aches and pains associated from carrying her teenage son, participant 002 does not feel that her quality of her life has changed. *"I wouldn't say it hasn't changed. I think it's been more stable. Yeah, it's been stable. I wouldn't say it changed much. It's been very stable because everything is basically still where it was."* She feels a sense of strength that she tries not to think of any discomfort. *"I just try to pull through. I don't pay much attention to the aches and pains. Because sometimes I think it's just mental. Sometimes you just got... no, no go away and just try to just push through. I just try to be strong... stronger about it."*

Participant 002 was able to provide insight into some unexpected joys including seeing her son smile and enjoy activities. The following event left quite an impression on her:

He spoke! The other day we just celebrated (my son) finally said I love you. So, it melted my heart. I told him that I love you. But said he's not going to say it to...he's not saying it to me. But I'll take it...cuz he's not there. But he said it! I...cuz, it's just the bedtime routine. Good night, I love you... and God bless, you sleep tight and he looked at me and said I love you without me probing him... like say it. Yup, he was like I love you.

Oh, it was a beautiful moment! I got emotional. It was, it was. It was great because it's been a while to hear him without, like I said, without probing or without having anybody to cue him. He said it on his own and very independently. And the way his face was, you could tell he was sincere about it. So, it was a very nice moment. (Participant 002, interview 2, p 9)

At the conclusion of the interview process, participant 002 was asked what advice she would give to parents who are beginning their journey with epilepsy. She provided the following insight, focusing on the medications as part of the treatment plan.

I think knowing all your possibilities. Knowing, not just being... when it comes to medications... talking about medications, just knowing all the possibilities of medications. Knowing the... side effects it could bring on the medications is a big key. Because sometimes it may... one of the medications may solve a situation with the diagnosis he has... he was

diagnosed with. But it could be affecting him in a different area. So, you just need to know to weigh your options to see what would be the best fit.

(Participant 002, interview 3, p 15)

Participant 002 also identified the need to connect with others as helpful. *“I think knowing about the support groups...knowing that there is support.”* She really appreciated being able to ask questions of those in similar situations without feeling judged, that it was a safe group to reach out to for answers.

Regarding important issues the healthcare community should know, participant 002 identified having a doctor who would pay attention more and be more invested in your child and his care. *“How much they pay attention... a little bit more when you express your concerns. Or you say you feel like there's something's wrong, and not just getting an assumption back saying oh no...it's okay.”* She added *“that you care about the patients and you're just not going to see a patient because you're a doctor. It's not just because you got your degree. It's because you do care.”*

Participant 003

Participant 003 is a 38-year-old Caucasian female, the eldest of three girls raised by strict Italian parents. She has lived in New Jersey her entire life, recently moving into a custom-built home with a pool that provides a place for aquatic therapy for her daughter with DFE and special needs.

Currently, participant 003 does not work outside the home; however, she receives funding through a Medicaid program for \$11 per hour (35 hour-week) to care for her daughter with DRE. She describes her job as *“mom, nurse, advocate, short order*

chef...housewife, and that kind of stuff.” Participant 003 holds a Master of Science in Speech-Language Pathology and, prior to becoming a mother, worked as a speech pathologist focusing on children with special needs and early intervention, mainly at a chronic care facility. She is married to her husband of 19 years, a police officer who works full time and any overtime available to assist with finances.

Participant 003's nine-year-old daughter is an only child, her DRE the symptomatic type, secondary to hypoxic ischemic encephalopathy consistent with LGS. She was born at 33 weeks after placenta abruption. She reportedly did well immediately after birth but remained in the NICU for 19 days. Five days after discharge, she returned to the hospital for a mal-rotation of the bowel with volvulus, which required a small bowel resection followed by a prolonged admission in the Pediatric Intensive Care Unit for 50 days. Her post-operative course was complicated by septic shock and a femoral line septic infection. Currently, she has multiple medical issues such as cortical visual loss, she is non-verbal, hypotonic, non-ambulatory, and is fed by gastric tube. Until recently, the child experienced multiple seizures, as many as 30 per day. With the addition of cannabidiol to her treatment regimen, she has remained under good seizure control for the past few months.

When asked what life is like as a parent for a child with DRE, participant 003 said, “*I fully admit and agree that my life is (my daughter).*” She added that she does “*pretty much...everything. From the moment she wakes up, till the moment she goes to bed, and even after she goes to bed, I am her it girl. I’m the it girl...and I...she’s 100% dependent on me for everything.*”

Participant 003's role as caregiver for her child with DRE is extensive. She begins her day early in the morning. *"My daughter is not a good sleeper, and she's never been since day one. So, [chuckles] she usually will wake me up, but I have my alarm set for 6:30 and I... I... I... do sleep in (my daughter)'s room."* (She has slept by her daughter's side for years because she wants to be able to sooth her when she becomes restless.) She explained, *"If I waited 'til she started hollering over the monitor, it would be all over."* Mornings are very busy, with seemingly every moment planned out:

So, usually she'll start stirring after 6 a.m. I'll see...kind of leave the room... prepare her medications and her feeding. She is G-tube fed, and then I go back in and we start her bowel routine. She needs to be stimulated with a liquid glycerin suppository to move her bowels. It's just that little tiny teeny amount of liquid that gets things moving. She has severe delayed gastric emptying so...everything literally is just still until you give it that little umph, and she does...now [looking proud] use the potty three times a day. So that is part of our bowel regimen.

So, every morning, afternoon, and evening, she'll hopefully go pee and then morning and evening we'll have her evacuate and go poop. Dress her up. And we rush outside and...not outside...to the kitchen to...she has about nine or ten morning medications and then, followed by her G-tube feeding. I'll transition her to her transit chair where she would be leaving for school. And the bus comes by between 7:35 a.m. and 7:40 a.m. So, off she goes.
(Participant 003, interview 1, pp 8-9)

Maintaining a structured environment and a schedule facilitate accomplishment of all the daily tasks. She is always mindful of her daughter's response to her environment, avoiding over auditory stimulation from which she would need significant time to recover afterwards. Causes of overstimulation are unpredictable, which makes trying to prevent it very stressful.

In a sense of, if it's going to happen, what I do have control over, is controlling her environment. So, I know when (my daughter) cannot handle a restaurant, she cannot go out to eat. I know she cannot handle, just loud places, that...that inside noises, she doesn't like parties, things like that.
(Participant 003, interview 3, p 6)

Interruption of sleep causes stress, as she described: “*at times, the fact that she does not sleep through the night is stressful. I’ve become so used to it, that it's just... it's been a year so hey, that's my life now, that's her life.*” Although this constant disruption of sleep has been identified, it has become part of a typical day’s event.

Another stressor triggered the following insight:

Just seeing your child leave on the bus and hope she comes home on the bus. I guess being a wife of a police officer, and you’re trusting these bus drivers...you’re trusting the school staff, and, I think that would be for any parent, but for someone with special needs, it’s the fact that if she was put in a situation, and she cannot verbalize herself, and I know her ins and outs so well. The stress of me not being right there with her. I would say

that's a subconscious stress. Just if something happens and I'm not there.

(Participant 003, interview 3, p 4)

The unpredictable nature of epilepsy itself is challenging. *"I would say 100%, it's so challenging having a child with refractory epilepsy. That unpredictability is just the most challenging ever. Just not knowing what this day, the week, the season...whatever will bring. I feel like that's the most... that has the most impact on me I think."*

Participant 003 also finds physical care as being challenging. *"So, she's 50 pounds now and it's a 50 pound, either a 50-pound plank when she's stiff or like a 50-pound sack of potatoes where her tone... there's just no tone. Honestly, I feel like we don't...you don't really have a choice, you just have to do it."*

The way participant 003 copes with all the stress associated with being a parent of a child with DRE is by staying positive. Although she identifies with the Catholic faith, she does not turn to religion or prayer for support typically. She focuses on the holistic approach to take a break and alleviate stress using acupuncture, essential oils, guided meditation, and listening to podcasts.

Participant 003 has a small support system available. She chooses to discuss issues that arise with her husband rather than call family and friends via telephone. Other sources of support on whom she relies include: a support group of mothers of children with LGS on social media, her child's therapists whom she can contact with any questions even by text, and the nursing [staff] who are *"...almost like your second family."*

Participant 003 described her sense of growth through the experience of caring for her child with DRE. *"I do have... I've been working on doing things more for myself."*

Things that make me happy. But that doesn't really happen unless you, you really recognize that, and... and kind of call yourself out.” She's made adjustments that impacted her quality of life. *“...you have to learn to live and find happiness in your own home, 24/7. So, I do appreciate...I do feel like I'm more appreciative of things. I definitely recognize smaller things that other people probably wouldn't.”* She's found unexpected joys such as seeing how happy her daughter becomes from the simplest little things. *“Her ability to laugh and smile, at like the simplest things... a song... a noise...a phrase that mom or dad might say. Something that you and I and the typical world completely take advantage of.”*

Regarding advice and suggestions, she would give to parents who are beginning their journey with epilepsy, participant 003 said:

Well we have a few... I have a few mantras. One is, you got this. You have to believe in it. Another is one day at a time. Parents get, including myself at times, but, not anymore, you get very wrapped up in, next month, next year, what if, yada-yada-yada. All those what ifs. No...one day at a time. Focus on today, then tomorrow. [laughs] We got this. You got this. One day at a time. No one is going to come and knock on your door and provide information about your child's disorder. You need to go out and find it.(Participant 003, interview 3, p 22)

As for the healthcare community, participant 003 said she would tell them that having a doctor parents trust is important, someone with the ability to listen to their concerns. She speaks of her current provider and shares that *“he values parent report, and to me, that is the biggest support.”* This was not always the case for her and her husband.

"The neurologist we had, I forgot when it was, but before this one... complete opposite. He wanted to have an EEG routinely, every three months. And he didn't really care to listen to what we had to say." They replaced non-supportive providers.

Participant 004

Participant 004 is a 50-year-old Caucasian female, who formerly worked as a director of marketing for an investment bank until the birth of her youngest child. She and her family moved to the United States from England six years ago, seeking better medical treatment for their son. She is the mother of three children: an 18-year-old daughter, who is attending college abroad; a 16-year-old son, who is a senior in high school; and a 14-year-old boy (with DRE, consistent with LGS).

When he was five days old, participant 004's youngest son began having as many as 50 seizures daily. Currently, he has between seven to ten generalized tonic-clonic, tonic, and myoclonic seizures each day. He is blind, non-verbal, non-ambulatory, and requires being fed via gastric tube.

Participant 004 does not have family whom she chooses to see; divorced parents, an older brother, and younger sister. Estranged for years from her unsupportive mother (who has mental illness) and her sister, who are both *"unwilling or unable to look beyond their own needs"*, she expressed sorrow for the loss of a closeness that started soon after her son's birth, a time when she needed support. *"This wasn't like you're going to have a special needs kid. This was your kid might die at any minute."* She remembered a mother who sided with her sister about issues and one occasion when her sister stepped over her son to notify her husband to *"pick up that child."*

Participant 004 describes how extensive her role as a caregiver has been for her child with DRE. Although in-home nursing is in place, she is involved with much of her son's activities of daily living. Throughout the day, there are teachers and a therapist who come to the home. All these appointments require a well-organized structure to stay on schedule. The many moments of wasted time that frustrate her, such as, speaking with insurance companies, equipment vendors, and nursing agencies. She shared her frustration, recounting the process for obtaining a specialized chair:

All the same stuff that you just sent them, you have to send that all over again, and now you have to wait another, however many, 45 days or whatever it is, for them to review it all over again. And then you have to keep calling to make sure that they are actually reviewing, and so it, it sucks up an awful lot of time, if you want to try to give your son or your child as many opportunities to be involved in daily life, to... be comfortable.
(Participant 004, interview 2, p 6)

There are additional challenges in working with the home care nurses and nursing agencies. Participant 004 cannot rely on the nurses for scheduled shifts. There have been occasions when the nurse has called within minutes to hours before a scheduled shift to notify the family he/she would not be coming. The last time, she recalls thinking “*I have no idea now if I have to be up for 24 hours or if I’m going to get to be asleep tonight.*”

Participant 004 stated that the way she copes with all the stress associated with being a parent of a child with DRE is by maintaining a positive outlook. “*You can wake up and you can be freaking miserable, and then that bleeds in to your kids...and so I think*

I'd like everybody to think about me, that I'm positive and try to...just try to find a little bit of happiness every day." She also has realized that taking time away for herself is helpful in coping with stress. *"Sometimes I need a break."*

Participant 004 does not have a large support system beyond her immediate family. She has a few friends, but little opportunity to see them often. Although she is Catholic, she does not draw support from religion.

When asked if her views of herself have evolved or changed, participant 004 described a sense of growth through the experience. *"I'm definitely not the same person I was before. I think in a way though, I think a lot of new mothers go through the same thing."* She also shared insight into her view of herself compared to her husband. *"Sometimes I feel, especially now that my other two kids are getting a little bit older, and they're looking at my husband as the breadwinner...they look at me. I'm making sandwiches and doing laundry."*

Participant 004 describes utter exhaustion that impacts her quality of life. *"We're sleep deprived a lot. That changes how I live."* She describes her life as frequently being interrupted by sudden nurse staffing issues and unplanned medical crises which impact her quality of life. She is frequently worried, waiting for the next hospitalization to happen. She believes that although seizure control is unpredictable and medical issues arise, *"you have to be okay with what you have."* She provided the following outlook:

Not a lot of people would switch with me. And I'm tired, and my back hurts, but it's okay. He's here. Right? What's my option? Because... that's the other option. Right? The other option is you get to think, for

however many years that you survive him, how horrible is this, right? So, I'd really rather have this... than that. This I can at least control in some way. (Participant 004, interview 3, p 25)

In recognizing how medically fragile her son is, she acknowledged that she will most likely outlive him. *"It's hard, though. Dealing with the fact that, probably in my lifetime, I'm going to have to deal with the death of my child."* Participant 004 has made a point to have discussions with her other children regarding end of life. She has also had conversations regarding the need to have a plan in place should she die first.

Participant 004 was able to provide insight into some unexpected joys as just *"seeing how he brings out different sides of everyone else in the family."* She remembered an earlier conversation with a physician that changed her forever.

I still remember this guy. He said, do you know what? Everybody has a different story. Not everybody was put on this earth to have a good job and make a lot of money. Some people were just here to show you a different aspect of love. And that's who (your son) is. He's going to show you, he's not going to be rich, he's not going to have a job, but he's going to show you what love and life is about in a different way than your other kids. (Participant 004, interview 2, p 21)

When asked what advice she would give to parents who are beginning their journey with epilepsy, participant 004 recommended that they should *"be an advocate for their child ...if you don't, it's going to be difficult to find other people to do it for you."* It is

important to *"find the right provider, who is caring and understanding, and to be well informed."*

Make sure you understand all the types of doctors that you should think about having access to. Did I know that there was such a thing as a physiatrist? No, I did not. I found that out way too late. So, go to social services, and find out what's available. And then, sign up for everything.
(Participant 004, interview 2, p 19)

Participant 004 also emphasized the need to understand the roles of those involved with the care of their child in order to clearly delineate responsibilities. She recommended having a better understanding of the language that is used by the health care system and particularly the insurance companies. *"Understanding the nuances of things"* is helpful in services being approved. As for the healthcare community, she identified having a doctor who is understanding and provides information with the parents' input as important.

Participant 005

Participant 005 is a 56-year-old Caucasian female who has held various jobs (school assistant at her daughter's school, pharmacy technician), but does not currently work. When asked to provide general information about herself, she struggled answering, *"My life for the past 18 years has pretty much been about my kids. A defining moment is what this is...I never realized how difficult this question is."*

Participant 005 is the mother of four children: her oldest daughter, a struggling actress (age 27); two sons, one recently graduated college (age 23), the younger a cadet in the army (21); and her youngest child, a daughter (age 19) with intellectual disability and

DRE of unknown etiology, but which, according to participant 005 might be related to the newly genetic-testing revealed mutated gene on the 14th chromosome.

At 16 months, participant 005's daughter began having seizures and was diagnosed with epilepsy at that time; however, she believes that the seizures may have been present soon after birth, *"but it wasn't something we picked up on."* The fact that her daughter has several seizure types; absence type, generalized tonic clonic, myoclonic, and tonic, makes her believe that the time of onset may have been difficult to determine.

A nursing student when her daughter was four, she noticed delays in pediatric milestones beginning at six months of age. When she confronted the pediatrician, he reassured her and did not recommend intervention. She then approached a neurologist who also noticed these delays, but his exam findings were essentially normal.

The child continued to have episodes of apnea, turning blue at times of seizures, which occurred only in the home. *"I would say, the first six months, we averaged an ambulance ride and admission to the hospital every two weeks."* Because the physicians did not find evidence of seizures, the participant was told not to call the ambulance in the event of additional episodes. When her daughter was 16 months of age, she had another seizure and was transported to the hospital. When the child was about to be discharged, she had a witnessed seizure with apnea requiring cardiopulmonary resuscitation.

The Epileptologist came in and said these are really bad, we can't discharge you. Is that what you've been dealing with at home? And I was like, Yes! That was the first time that I was like...oh dear Lord...thank you! Because they actually saw what I was going through for six months.

Because nobody believed me. They thought I was actually making things up.

(Participant 005, interview 1, p 7)

Prior to this experience and diagnosis of epilepsy, participant 005 thought she must be wrong, and stopped asking for help as a result. *"I did think I was making things up. I stopped asking people for help because I was tired of trying to explain myself. So, I stopped trying to reach out to anybody. I wouldn't ask anybody for anything at all."* The witnessed seizure experience made her feel validated.

Participant 005's daughter continues to have two to three somewhat better controlled seizures daily, despite medical management. The current seizure activity is a brief myoclonic type that last only seconds, and seizures unaccompanied by apnea.

To care for her daughter, participant 005 carries out extremely structured daily activities beginning with prayer at 4 a.m. She assists her daughter with bathing, toileting, dressing, medication administration, and completing all other activities of daily living. It has been a *"difficult balance between parent and caregiver."* She continued saying:

I was just the caregiver and some days I am still the caregiver. When I'm... I'm making assessments on her, when she wakes up in the morning, and she's not right. I'm looking at her in her eyes...what her pupils are doing. How's her breathing? How... I'm doing an assessment first thing in the morning sometimes. So, it's hard for me to go back and forth between caregiver and mother. It's not easy... and it took me a very long time and after going to therapy and stuff to learn to become her mother again. That was difficult. (Participant 005, interview 2, p 3)

Upon reflection of challenges faced caring for a child with DRE, participant 005 reveals *“I think things would become so routine at this point that I don't even see the challenges anymore. I think challenges for me are whatever challenges she is going through.”* However, earlier on in the process, she remembers maintaining a normal life as a challenge *“just trying to maintain some sort of normalcy for the other three kids. They were young. They were little...their world was turned upside down. Our entire world was turned upside down, but their world was really turned upside down. So, that (was a) challenge of trying to keep things as normal for them as possible.”* There was some guilt expressed, not being more present with her other children. *“I missed out on a lot with them.”* Family plans were often cancelled at the last minute because of seizure exacerbations, sometimes requiring hospitalization. During hospital admission, it was necessary to remain in the hospital while the other children were left home with family. She also expressed regret that she was not able to spend time alone with her other three children and the difficulty finding anyone to stay and care for her daughter in order to share in activities with her other children. *“She can't stay by herself, and because of her medical fragility, there's nobody who is willing to want that responsibility.”*

Participant 005 described interactions with health care providers in the past as very stressful. She has become more assertive in order to advocate for her child's needs. *“I don't have my RN. I don't have my PhD, but damn it I do have a PhD in my child.”* She now avoids emergency departments as much as possible, at times driving over one hour to reach a medical center equipped to care for her child, passing closer hospitals which she did not feel could provide appropriate care. She recalled an interaction at a local community hospital.

We got to go sit in the emergency room... wait and argue with these people that this is what we need to do. Hopefully they're going to listen to us, but nine times out of 10 they're not going to and I'm just going to pick up my phone call and call whoever I have to call. Because it happens all the time... it happens all the time. When she was in the hospital back in 2016, when she was Heli ported....the most frustrating part to me was listening to a nurse tell me that she was having febrile seizures. She's 16 years old, 16-year-olds don't have febrile seizure [laughs]. And she stood there and started lecturing me. (Participant 005, interview 2, p 18)

Finances are an area of significant stress. *"Bills...bills are very stressful. My husband took them over five years ago...wholeheartedly took them over five years ago. I couldn't do it anymore. And I couldn't handle the paperwork for medical bills and appointments and the kids' schedule and handle all the bills at the same time."* She explained further:

(my husband and I) couldn't keep up on this. We had our electric shut-off. We had a shut off on the water bill. We had a foreclosure notice on the house. Not just because the bills were getting paid, but because we also didn't have money. So, there was the big financial burden that comes with having a child that's medically fragile. (Participant 005, interview 3, p 4)

In order to cope with the significant stress associated with the financial struggles experienced, participant 005 removed herself from the process entirely. She acknowledged

that it was one of the best decisions she has made. Participant 005 also credited her faith with a way of helping her through stressful times. *“My faith. my faith in God and the Holy Spirit moving me and moving things in my direction. I believe that wholeheartedly.”* Having a strong faith has helped shape her beliefs and perspective on life. It has also made her realize that she should attempt to help those facing similar situations.

There's things that you go through in life and they're stepping stones and building blocks to something else that you're either going to have to deal with down the road, or you're going to be able to help somebody else out with that similar situation. I've always maintained that. Because I've had parents who helped me out because of their situations. And now I know with my situation that I can just pass along the information.(Participant 005, interview 3, p 7)

At times, participant 005 identified that things may become overwhelming. In order to cope with those experiences, she shares the following:

If it gets too much, I cry. Because I realize that that's a release of energy. Because then, as long as I addressed that, and I cry... and it's okay to cry and get overwhelmed. I sometimes have to just take a step back... and just kind of put things into perspective and walk away from different things. (Participant 005, interview 3, p 13)

Participant 005 has a large supportive extended family, but they live at a distance. Family visits are not common. *“Everybody has their own things they are doing.”* Although she recalled involvement during activities with children and their parents of children as

they were growing up, she cannot recall the last time she went out socially with a friend.

“It definitely affected my social status on different levels. Not being able to socialize in different things. My social...my socialization became whatever my kids were doing.”

Participant 005 also acknowledged that, in the past, other parents of children with DRE have been very supportive. She uses social media platforms to connect to other parents. Times spent in the hospital has also provided a network of parents to reach out to with questions and concerns. Although she does not involve her extended family in issues with her child, she believes that they would be available if she contacted any of them.

When asked if her views of herself have evolved or changed since caring for a child with DRE, participant 005 described a sense of growth through the experience as well as guilt that she had been responsible for her child's condition:

It's... in the beginning more so. Because I always had a feeling of what could I have done to prevent this? Is there something that I did? Going back to my pregnancy with her and saying is there something that I did? That could have been, you know, that I could have... that I could have changed? Like did I eat something today? Was I exposed to something was it this; was it that? (Participant 005, interview 3, p 13)

She has now realized the degree to which she has grown in strength.

Now? Now I'm like... I'm a good person. I am a strong woman. To go through all of this? Damn, I'm really good at what I do. And I realize that. I don't know why... and I don't know when that kicked in... but I

realized it, that everything that we've gone through. (Participant 005, interview 3, p 14)

Although participant 005's quality of her life has remained about the same, now that the seizures are better controlled, she can leave her home more with her daughter to go shopping or attend parties with the family, which wouldn't have been possible previously.

For years we had to decline on all kinds of invitations, and this is what separated us with our families too. Because they couldn't understand... they said they understood, but families and friends and everything... declining so many invitations after while... the invitations stop. And the family invitation still came. But we were missing out on all those milestones that your families have with their children and cousins and everything else. And my kids missed out on a lot of those things. (Participant 005, interview 3, p 15)

Better seizure control brought unexpected joys. Participant 005 provided insight into some unexpected joys which came with better seizure control. *“Hmm...the first unexpected joy was watching her ride a bike... when she was a toddler. (My daughter)'s onset of her epilepsy... there was an obvious delay. But what we saw was when we gained seizure control, her balance...it was the first time I had realized that how much the seizures were really interfering with her development and her everyday everything.”*

When asked the advice she would give to parents who are beginning their journey with epilepsy, participant 005 stated, *“Don't take no for an answer. If you are not sure,*

keep asking questions until you're satisfied with that answer.” She advised being an advocate for the child and recommended keeping a journal with medical history, treatments, and medications tried, which she views as the best advice she received from another parent years ago. As for advice directed to the health care community, she recommended that they listen to the parents. *“But listen and don't try to push your knowledge and information on to them.”*

Participant 006

Participant 006 is a 56-year-old Caucasian male, married to his childhood sweetheart for 35 years. He is a father of four children; two daughters (ages 27 and 19 years) and two sons (ages 23 and 21). He has been very involved with his children, and has especially enjoyed being a Boy Scout master for his sons' troop. Although he works full time outside the home, he assists his wife with the care of his youngest daughter (age 19) who is intellectually disabled and has DRE.

When asked what life is like as a parent of a child with DRE, participant 006 remarked that his daughter, who requires constant supervision, relies on them for everything:

That's a very big topic. Basically, (my wife) and I trade off on everything. If she's not able to do something, I would... I would do it for her in care for (my daughter). That's everything from getting her up in the morning to getting her into bed at night and everything in between. Changing her diaper, she's still in diapers. Brushing out her hair... everything... medications. For the other kids? The other kids are pretty much grown up now. They are more independent....probably a lot more

independent since all the things that have gone on with (my daughter).
(Participant 006, interview 2, p 1)

Although his wife provides most of the care, he assists with the established routine beginning with daily morning care prior to going to work.

Typically, during the week, we try to stay very... very routine.
Because if she stays out late or anything like that, or past her bedtime, we
end up paying for it for a day or two afterwards. (Participant 006, interview
2, p 3)

Participant 006 said the biggest stress involves communicating with his daughter. To try to better understand her, he has initiated the use of sign language. Lack of time and funds to hire professionals to complete necessary home repairs that he can do himself is also stressful. He stated that his daughter's daily activities come first *“things that are priority... making sure she's getting her medicine... eating... her everyday stuff interferes with the bigger picture of different things the family tries to get done. So, that...that stresses me.”*

In order to cope with stressors, participant 006 described the need to prioritize, *“I have to put everything in priority order. I compartmentalize a lot.”* His thought process that has evolved over time to help cope with stress is as follows:

Different things that (my wife) and I used to worry about. You'd
come in from work and look...is the house clean... is this done? Is the
dinner on the table? It really adds up to nothing. It's like okay...dinner's
not done... the house is a wreck... dishes are piled in the sink. Did the house

burn down... no? Everybody's okay? Good. (My daughter)'s not in the hospital... okay.

That's priorities and my thought process on a lot of stuff has changed. Things that were important... really don't seem that important anymore. You look at like the frailty of life. I mean (my daughter) at any minute could go. That's it. That's our reality. So, all the other stuff... even if the house rots and I don't get the siding done... I tried. [laughs] But, it's not as important as making sure that she's taken care of... or my other kids are taken care of...or (my wife) is taken care of. (Participant 006, interview 3, pp 3)

Although participant 006 is one of six children, he does not rely on them for support, believing that they do not truly understand the daily impact of the disorder. He relies heavily on his wife for support. *"Whenever I've gotten into any kind of difficult type position, she's always been there."*

When asked if his views of himself have evolved or changed, participant 006 described his "evolution" with his ability to fix anything. He stated that if he does not know how to do something, he researches out how and then completes the task. He summarized as follows:

Actually, it is when...[laughs] before (my daughter) was born. If the kids broke something or anything like that I was always able to fix stuff. In a weird sense in a way, when I was here first looking at what's going on with (my daughter) it was more or less like... it's just... it's not working

right. It's not... it's kind of broken. But I didn't have the capability to fix it. And I struggled with that for a very long time... that there's got to be a way to fix it. I can fix everything. And anything you give me, if it's broken, I can fix it.

Now, I have something that's... what other people would consider broken... that I can't fix. So, to me that was a very hard thing to come to terms with. But, then I start to realize it's not that she's broken... it's just that she's different. And it gave me a new perspective on again what's important...and accepting people for who they are. (My daughter) with her epilepsy, and everything else; it's who she is. (Participant 006, interview 3, p 5)

When asked about his quality of life and regrets over missed opportunities, participant 006 shared this insight.

I feel like the past 18 and 20 years our quality of life is just gone out the window. We've gained a lot of it back... but it's also adjusting to (my daughter)'s needs. Like I told you earlier on we used to just get in the car and go. It's not like we can do that anymore. We, at times, I think (my wife) and I feel guilty about the other three kids possibly missing out on stuff when they were growing up. Because of different opportunities that they weren't able to do because of different things going on. (Participant 006, interview 3, p 10)

Participant 006 was able to provide insight into some unexpected joys associated with the addition of a new medication. *"His daughter's level of awareness has improved. She is more engaged in activities with them and behaves less impulsively."*

When asked the advice he would give parents beginning their journey with epilepsy, participant 006 focused on the need to be an advocate. *"If you don't think it's right...you got to speak up about it and you got to figure it out. And be relentless about it."* As for advice to the healthcare community, he identified difficulty communicating with providers, *"the non-doctor gatekeepers"* who act as a barrier to physician access. He recommended that doctors be caring and listen to the parents. *"So, it's not always bedside manner. It's a matter of attitude and doing what you need to do. The other thing is, even though it doesn't seem like it...he listens."*

Participant 007

Participant 007 is a 51-year-old male. Born in England, he moved to the United States approximately 20 years ago to marry his wife. Proud of his successes, he was the first of his three siblings to seek academia, attending a prestigious all boys' school where his grandfather once worked as a butler. He holds a doctorate in mathematics, and owns his own company focusing on foreign exchange trading.

One of four children, participant 007 describes his family as *"deeply dysfunctional"* and his parents by saying *"If you can imagine now, the two most selfish people on God's earth getting married."* He is not particularly close with his older two brothers, speaking only with his youngest brother who lives in Scotland.

Participant 007 has three children: a daughter studying in Scotland (age 18 years), a son in high school (age 16 years), and a son at home with DRE, consistent with LGS (age 14 years).

When asked what life is like as a parent for a child with DRE, participant 007 says that *“it’s like having a very large one-year-old.”* He places activities related to his son’s care into three categories (a) educational aspects, as he engages with therapists who work in the home; (b) personal care and hygiene [care of all aspects of daily living] for his son, who is blind, non-verbal and non-ambulatory. *“Diapers...(my son) cannot stand having one drop of pee in a diaper. So, that causes significant...him to be upset.”* He requires frequent repositioning and is unable to do so on his own; (c) family involvement, for example, the entire family is involved in getting his son out of bed. Participant 007 feels that it is important to have his youngest child part of the family home environment. *“Sitting down with us, just trying to get him out of that sort of medical environment and into the sort of family environment.”*

Participant 007's day begins at 7 a.m. with end-of-shift report from the in-home night nurse. *“I relieve the nurse...What night did he have? Bowel movements...void’s...seizure activity? Did he sleep? Suction...chest therapies? Have you done the food? Have you done the meds? Have you given the 7 o’clock meds? Some nurses do, some nurses don’t, so you always have to ask the question.”* Although there is somewhat of a schedule to the day, every day may be different depending on his son’s condition, which is difficult to predict. Even with an outline for all morning activities, participant 007 does not feel his family has any structure because plans may suddenly change.

The most significant challenge and the area of greatest stress, “*the thing that really, really makes (my wife) and I struggle...causes problems...is the unrelenting everyday nature of it,*” participant 007 repeated several times. There are the sudden changes in his son's medical condition, and the unrelenting everyday nature of [DRE], and the stressful, time wasting activities to which he objects that impact him:

The amount of our lives that's being wasted by dealing with the system to get the care that we need. And that's the thing that makes me hopping mad... hopping mad. I will give you a really trivial example that involve this office, for example. The fact that I have to fill out a piece of paper with his med schedule... and his name... and address... and his medical card once a year drive me around the bend. It is a dark age system, that I have to spend 15 minutes of my time... filling out this piece of paper. And you could rationally say, yeah but it's only 10 to 15 minutes...and it's only once a year. We see 10 to 15 specialists. (Participant 007, interview 1, pp 13-14)

Interactions with the health care system are also stressful; unnecessary barriers which waste more time as well. “*Calls, it will be calls to the insurance companies... we've run out of this med. Can you just run down to (the pharmacy) and get it? He takes about 20 meds, in total, of some various description. And we're always running out of those. There are no refills left. Can you contact the doctor's office? We've contacted the office, but the doctor hasn't responded. So, then you have to contact the doctor's office, deal with insurance companies. They're not there to help you; they're there to deny you. They are there to make money. They want to provide the bare minimum care.*”

The most significant stressful challenge participant 007 faces relates to the inconsistency and unreliability of nursing care. *“The nurse just doesn’t show up. The nurse calls out. A good example is last Sunday. The night nurse called out at 5 p.m. on Sunday night... I’m not feeling well. Did you not feel well for the rest of the day? So, it’s 5 p.m., now we’ve got to stay up all night. Neither of us has slept. So, now we are awake for 24 hours.”*

Participant 007 categorized the nurses as those who are looking for an easier life outside of hospital and those who *“are going to do the absolute bare minimum.”* Because he and his wife must sleep during the night in order to function as the day care providers, he needs whatever assistance he can get during the night. He shares the following stories:

The agencies have sent someone who has said...turned up and literally said to me...I’ve never worked with a kid with a seizure disorder before... never seen a seizure. So, we’ve had that. We’ve had a lady turn up and said I will try and stay awake... but I can’t guarantee it. This is a night nurse. We’ve had... we had one nurse in the last couple months turn up with her dressing-gown... wearing her dressing-gown. She came to sleep. While (my son) was crying... she was asking for the Wi-Fi password because she’s got some reading to do. So, I asked her to leave. (Participant 007, interview 2, p 6)

The worst experience from nurses resulted in his son being hospitalized for status epilepticus, unstoppable seizures.

You can't make these stories up. They're all true. And there are worse ones...trust me. So...there was one time...the result was the doctor ended up seeing (my son). The lady let (my son) seize for about 20 minutes to half an hour, we think. And we ended up here (in the hospital) for quite a while. She'd never seen a seizure. And then eventually, after 20 minutes... comes knocking on the door and says I think there's something wrong. [laughs] So....really? So, that...that...that 20 minutes, half an hour event, whatever it was...we ended up here for three to four days and then he wasn't right for a month or two months after that. So, just that lack of competency in not administration the Diastat after five minutes caused us two or three months of just...just... horrible 3 months. So, that happens. (Participant 007, interview 2, p 6)

Humor is one way that participant 007 copes with all the stress associated with being a parent of a child with DRE. Humor and staying positive help him and his wife get through difficult times. Rather than being parents who say *"this is awful, this is terrible. They're just miserable"*, they aim to be *"positive and they're going to deal with it."*

Participant 007's primary support system is his wife; finding some support from childhood and school friends in England whom he telephones and discusses issues he experiences. By choice, he has eliminated his parents from his life. *"My mother rather brilliantly said to me a few years ago...I want to say when (my son) was very young...she said that she found his condition to be too distressing...and that she didn't want to deal with it. So, regardless of whether she lives a long way away...she has never been a part of (my son)'s life."* He does not engage with other parents of children with DRE who are

pessimistic, making a conscious decision how he spends his “*emotional energy*.” “*I don’t have time for those people. It saps what little strength you’ve got.*” Bothered by those who try to engage him in any religious interactions as a method of support, he said, “*The first things you get all people telling you...God never gives you more than you can handle. God only gives special children to people who can have that child flourish. As I said, one...I’m not a religious guy [He’s atheist.] But...too...all of that is bull shit.*”

Participant 007 said that finding resources to support his son’s needs was as difficult as finding supportive people. “*It’s impossible. You just can’t navigate it. I mean you can waste days of your life trying to navigate these things...You’re always placing a hundred calls and people frankly never seem to know.*”

When asked if his views of himself have evolved or changed, participant 007 described having difficulty initially to the point of becoming depressed and suicidal. He had had a trajectory for his life; a great job, financial security, and travel, which suddenly changed with the birth of his son. After seeking treatment, he is a very different person. “*I’ve focused on the things that are really important... relationships with my family... relationships with my kids... working from home... not being on a plane all the time, trying to be a big shot. So, that’s all been great. And personally, I am far happier than I ever was prior to (my son) being around.*” He finds unexpected joys in small achievements of his son, such as, seeing him smile or laugh. Participant 007 said he has more patience now and is calmer. “*It’s actually got me in a much better place. The fact that I say that it’s not all miserable...there are some real positives.*”

Despite the chronic sleep deprivation, participant 007 said that his quality of his life has improved. *“I know who I am in the world.”* Prior to the experience of caring for a child with DRE, he focused on work. *“The only thing I ever cared about was work...everyone kind of fell in all around me, right? I always thought that I was the bread winner. Now it’s completely the other way around. So, that’s been the biggest change.”*

When asked what advice he would give to parents who are beginning their journey with epilepsy, participant 007 mentioned that it is important to be an advocate for his son. Early on, he projected an image that everything was okay, which was not the reality. However, it created a dynamic in which no one thought he needed help moving forward. *“I think the biggest thing that we miss is the support thing.”* He reflected further and provided this summary.

So, I think the first thing is...figure out the bad stuff first and get the support system you need. That would be the most important thing. Because, it’s almost impossible to do things by yourself. Similarly, is...strap on your armor. Insurance companies... do not ever take no for an answer... ever... ever... ever. Learn the system. (Participant 007, interview 2, p 10)

Regarding advice for other parents beginning their journey with epilepsy, participant 007 recommended: *“Find that doctor you trust as a doctor, but not because of his medical stuff, but personality-wise is going to be the advocate for your child.”* For the healthcare community, he identified having a doctor who listens as important. *“It’s a function of, you’re not listening, and we’ve got 15 years of knowledge...we’re not dumb people and we can help you.”* It is important that physicians realize that they do not know

more about the child than parents do. *“I don’t care how brilliant you think you are; you don’t know our son the way that we do. And you can dismiss our suggestions, but we’re not dumb people... and you should take the 5,10,15, 20 minutes to talk to us.”*

Participant 008

Participant 008 is a 39-year-old Hispanic male, the fifth child in a family of eight who are close knit, all living in New Jersey. Although they form an adequate support system, participant 008 does not contact them for assistance. *“Everyone... everyone’s busy. Everyone has their own life. So, I don’t ask. If I mention I’m doing something and someone offers it, I take him up on the offer. But other than that, I don’t try not to bother. You know, everybody else has a life.”*

Participant 008 works as a building supervisor currently responsible for overseeing 116 units, which will soon increase. His motivation is to work to provide his children with greater opportunities than he had growing up. He particularly enjoys working with his hands, spending time in his garage repairing cars when he is not at work.

Participant 008 is the father of a son (age 18 years) and a daughter (age 12 years), who describes himself as very involved in his children’s lives. At the age of two, his son was diagnosed with acute lymphoblastic leukemia, cancer of the blood and blood marrow. He was treated with chemotherapy, went into remission at approximately 6 years of age, and began having seizures soon afterward. He has DRE consistent with LGS; the seizures are generalized convulsions, head drops, and myoclonic jerks, typically in the morning. He has not had a *“big one”*, a generalized tonic-clonic seizure, in the past three months prior

to the interview process. In addition to medication management, his son follows a restricted diet for better seizure control; however, this has not improved his seizure frequency.

Participant 008 structured his day and work schedule around the needs of his children and followed a daily schedule from which he does not typically stray or rush, which seems to increase seizure activity. *“It just seems to go a lot smoother.”* In order to prevent resulting seizures, he wakes his son early to allow time for him to adjust slowly before beginning his morning activities. From 8 a.m. to noon, participant 008’s son attends a vocational program associated with his school. Afterward, he is transported with a nurse to a local hospital to work. Participant 008 stays within 10 minutes proximity in the event of a seizure at school or work. *“When he has one, we just basically stop what we’re doing to go get him and make sure everything’s okay.”*

Despite the constant monitoring he describes, participant 008 denied that he had any stress related to the care of his son. *“Stress me out? Nothing really...nothing much. I get stressed out when I see him too much on the phone...it’s a teenager thing.”* However, later in the interview, participant 008 said that he was never able to truly relax; he was always on guard. He provided the following summary:

I’m to the point where it’s like my nerves are shot. I’m not used to my son... now with the seizures being worse like anything. If I hear a bang or something... middle of night... in the room... not knowing. So, I was sleeping the one night... he’s had them. But we were up and going in and seeing him on the floor and seeing him in that condition. So, if I hear a bang...or if I call him. We’re constantly calling him... on top of him. If we

don't get a response, my first reaction is something's wrong. So, I'm running in trying to check and make sure he's okay. So, basically...that's what it turns out to be now. I'm more nervous and scared...what I can walk into.
(Participant 008, interview 1, p 12)

In further describing this fear, participant 008 stopped short of acknowledging his worst fear, finding his son dead. After a significant pause in conversation, he said, “*So, we know the outcome that could come out of it, but as far as speaking about it... that's not something we want to talk about really...losing him.*” Sharing this brings tears to his eyes.

Living with DRE is especially challenging for the parent of an 18-year-old who is striving for more independence. “*He wants to get his driver's license. He knows he's just not going to get his licenses...just from going through what he's going through is enough on its own.*” Participant 008 tries to “*figure things around it, to occupy him and take his mind off of it*” by taking him to a safe environment and riding go karts together to have a similar driving experience.

When asked how he copes with stress and challenging life experiences, participant 008 said, “*Just go about your day. Go day by day. And it crosses my mind, but if I sit there and think...what if I wake up and my son is not...I'm just going to drive myself crazy. I'd rather show him more time of having fun and enjoying yourself right now, then sitting back thinking the worst possibilities that could happen.*” After revealing such intimate thoughts, participant 008 shared that he had not talked about these feelings before; the ability to share was itself helpful. “*I appreciate the talk. I really don't talk about this, but when I do...it kind of helps. It feels like something has been lifted off of me.*”

Although many of his friends began having families at the same time, participant 008 does not have many friends now who are supportive. Their children are developmentally age appropriate while his son is not, which limits his desire to get together. *“He’s 18 years old, but he’s more age 14 or 15. So, all the kids that did grow up with him, from a smaller age, they’re going on doing 18 or 19-year-old things...dating. My son is still a little behind.”*

When asked if his views of himself or quality of life have evolved or changed, participant 008 said that he had not noticed any change in his self-concept or quality of life, except that he is unable to change careers, which he would enjoy. *“Sometimes I feel like if he... we didn't have to be on top of him 24/7 and I can go out there and find something... enjoy something... trying other things. But right now, I just had to pause, trying to figure out what we're going to do and how to go about it. It's just more convenient, being much closer... 10 minutes he's from work or when he's at school... 5 minutes away.”*

Participant 008 was able to provide insight into some unexpected joys as just seeing his son happy. He believes that *“it could be a lot worse...there are parents out there who have it 10 times worse. So, we can’t take it for granted and just understand what he has is something he has to deal with.”*

When asked what advice he would give to parents who are beginning their journey with epilepsy, participant 008 suggested gaining as much knowledge about epilepsy and doing research on treatment options since there are options other than pharmaceutical management available. He shared his frustration with providers who are eager to add or increase medications.

Sometimes when I go, I just think they're so quick to try different meds. They're always trying... well we'll do this... don't seem like it's working, but we'll keep that, and we'll do this. How much... when do you feel... at some point they keep adding and adding... enough is enough. I understand you're trying to figure a way... but all medicines have side effects. And I just feel at times they're just quick to throw you on top of another medicine. Instead of saying okay we'll take you off that one, it's not working. Well, let's keep that one and we'll add another one on top of it. And then you say I'm still seeing the seizures. Oh, we'll just add one more... lower dose of the others. It's a lot of medicine. (Participant 008, interview 2, p 7)

He recommended that printed materials with resources be available, which he believes would have been very helpful early on in their son's epilepsy care.

Participant 009

Participant 009 is a 50-year-old Caucasian male, a retired police officer who currently works part-time doing “odd jobs.” He is the father of a girl (age 13 years) and a boy (age 18 years) who has DRE, consistent with LGS secondary to meningoencephalitis at age three. Also, at age three, his son had two strokes. He has profound hearing loss, communicating via sign language, multiple daily seizures of varied type (generalized tonic-clonic, tonic, atonic and staring episodes), and requires significant medical interventions. Participant 009 describes the experience as “*a constant roller coaster. We lived in the hospital for quite some time last year, a couple of months almost, in and out. He got really*

sick and he overcame a lot. We almost lost him again last year. And we thought that this year was going to be a better year...and again, it's just not."

Participant 009 follows a daily schedule; however, he [laughs] says *"there is...there is no typical day."* There are certain tasks that must be done in a certain time frame such as administering medications; however, things may change throughout the day. *"He's been changing where the day will start out great, and then by midday...he, he tanks...He can get up great now, and if we have something planned for 2 or 3 in the afternoon, we really can't decide until 12."*

The unreliability of in-home night nursing has impacted the daily routine. At present it is constant, but there are times when there is no nursing support at night. When that occurs *"I'll stay up throughout the night just keeping an eye on him, just making sure that he's okay."* However, he and his wife do not sleep when a new nurse is assigned to care for his son. *"It's always difficult because they're not too sure of him."*

Stress occurs because not all the nurses perform to the same level. Some nurses do not administer morning medications prior to their departure, *"so we have to get up, we administer that."* To facilitate medication administration, he created a *"little med station"* outside his son's room.

Other healthcare providers have been the source of stress. Given recurrent hospitalizations, participant 009's son has missed several months of therapies and school, requiring him to *"constantly fight with the state about his therapies."* Therapists, for example, who come for schoolwork are ill prepared. *"We've recently just had a new therapist... walked in. She walked in with a bunch of high school books and plopped them*

down on the table....She was told he was an 18-year-old. Now, we understand that's basically all they tell them... he's deaf and he's an 18-year-old. That's it. That's all they know about him." In order to minimize wasted time, he and his wife now contact all therapists prior to arrival to make them aware of what they will *"be walking into."*

It is quite challenging to keep up with his son's therapies: speech, occupational therapy, and physical therapy. *"I mean we do as much as we can, but some days it's just physically, just demanding on us."* When his son is not motivated, it is challenging to assist with ambulation and perform range of motion exercises. *"There are days, honestly I just want to just curl up, and not do it. But I don't have that option."* Several other challenges were described by participant 009; the most challenging aspect, the one causing the greatest stress, is *"just the uncertainty of it all."* It is difficult to make plans, and each day is unpredictable.

He shared that there are physical challenges caring for a growing son, making the assistance with his ambulation difficult, as well as challenges carving out time for his younger daughter. He and his wife share most of his daughter's activities, rarely both together. *"When (my daughter) has stuff, (my wife) usually ends up doing the stuff. Because, if she's home and my son wants to go up a flight or down a flight, she has a hard time with him. So, I pretty much have to stay home most of the time. I miss out on a lot of (my daughter)'s stuff."*

When asked how he copes with all the stress associated with being a parent of a child with DRE, participant 009 said *"by not allowing all the little stressors get to you."* He and his wife work together to *"keep an eye on each other."* The two of them have a very

good understanding of each other's needs. *"If she's going down into that hole, I have to step it up or vice versa."* He provided the following summary:

So, it's kind of that...watching each other. Seeing where each other is at and just being there. Okay, go take a break. Go take a walk. Or whatever you need to do to get yourself back up a little bit. And then, once I start to back up...and that's usually the way it is...once I get in a good place, she'll usually crash. So, it's a constant, up and down of depression between the two of us. (Participant 009, interview 2 p 13)

Humor is another method he used as a coping mechanism, turning it into a new career opportunity. Participant 009 performs stand-up comedy, sharing stories of his life and experiences with epilepsy. *"Laughter and the fun keep me out of a dark place."*

Buddhism, which influences participant 009's approach to life, helps him to cope with stress and challenging times. *"It's just to the point where we're kind of like leaves in a stream. It's just whichever way it's going to take us, that's the way we're going to go."* Maintaining this perspective helps him not to stress or become upset over issues that arise.

Crediting his wife for giving him the most support, participant 009 also recognized other special needs parents and social media, where he provides updates on his son's condition and receives an outpouring of responses. A motorcycle group associated with the local sheriff's department has remained supportive over the years, providing an annual fundraising. Other friends have not been a constant as they have difficulty seeing his son in his current state, *"our kids used to hang out together and then, after it happened, I think it was very difficult for them. I get that, I understand that it's difficult to see that...I've had*

friends walk into the room that haven't seen (my son) in years and I see them immediately well up; they have to walk right back out of the room. They can't deal with it."

At one period, participant 009 sought professional support, a therapist to help him with unresolved issues:

I started to realize that there were so many other things in my life that I have never dealt with. That I had just brushed under the rug, because everything was about my son. I never dealt with my father's death. I never dealt with...I had someone, when I was working, I had someone point a gun at my face and pull the trigger. He was so high on phencyclidine (PCP) that he never racked one in the chamber, or I wouldn't be sitting here. But, it happened. I went back to work the next day, because we were still dealing with stuff with my son. So, that always took priority. So, I still have a lot of post...post-traumatic stress from other stuff in my life that I still haven't even dealt with yet.(Participant 009, interview 2, pp 14)

When asked if his view of himself has evolved or changed, participant 009 described a sense of growth through the experience. Although he has always had an inner strength, he feels that he will "dig down a little deeper" to make a better world for his children. "We all want our kids to do better in life, to leave their mark in the world." He believes that he can be an inspiration to other families going through similar issues. He also finds his son to be an inspiration to others. He reflected on how his view of the world has changed as a result of having his son. "My son's life touches so many people...I hate watching him go through it, but I see how he affects and touches many people's lives. And

to me...that's okay, that's okay. I'm okay with that. That he's made people's lives better from what he goes through."

Participant 009's constant stress and worry have impacted his quality of life. He sleeps an average of two hours each night, with interruptions caused by worry. He worries that the nurses will not be able to identify seizures at night. He is particularly concerned about nighttime seizures and the possibility that his son may die in his sleep, a fear reinforced by the recent epilepsy-related death of a popular young actor.

Participant 009 does experience some unexpected joys, such as, just seeing his son happy. Although rare, his son's "great days" give him joy.

We have a couple of those a year, and let me tell you, those are priceless to us. When he has a great day, if we all get to go out, and there's very little seizure activity or he's in good spirits, and he's eating, and he's silly. I can literally count those on one hand how many of those we have a year. But those are priceless to us, and those mean everything in the world to us. (Participant 009, interview 1, p 18)

When asked the advice he would give to parents beginning their journey with epilepsy, participant 009 said that he believes that laughter is key. Parents should focus on what needs to be done for their child as well as on getting adequate rest. He shared that it is important to "do your own research" and not rely on the negative comments and information on the Internet. As for what would be important for the healthcare community to know, participant 009 said that it is important to listen to the parents, and to have open conversations regarding treatment options.

Participant 010

Participant 010 is a 53-year-old Caucasian male who works full-time writing software for a hedge fund. He is the father of three children: a daughter (age 22 years), son (age 20 years), and a daughter (age 15 years). His oldest daughter, who has Kabuki syndrome, a rare multisystem disorder characterized by intellectual disability, altered facial features, and short stature, resides in a group home. His son, who has no medical issues, is away at college. His youngest child has Dravet syndrome, a genetic disorder characterized by developmental delays, a sodium channelopathy, and DRE with multiple seizure types: general tonic-clonic, absence, focal with impaired consciousness, and myoclonic seizure types.

At five months of age, participant 010's youngest daughter began having seizures and continues to have them, despite medical treatment, diet therapy, and enrollment into various clinical trials. Although seizure frequency and type may vary month-to-month, on average, his daughter has 15-20 absence type seizures monthly and a generalized tonic-clonic seizure approximately every five days. He believes a new investigational medication specifically for patients with Dravet syndrome is showing promise; reducing seizure activity and severity.

Participant 010 described their days as very structured. He and his wife alternate tasks to be completed. On days when he prepares meals, his wife watches his daughter and vice versa. At night, he or his wife stays in his daughter's room in order to monitor for seizures and to keep her safe. Although his daughter has attended school in the past, she is currently at home because of increased seizure frequency.

Although he used to enjoy playing golf, participant 010 spends his time working or with family caregiving, which leaves little time for leisure activities. *“I need to get home for either...on Fridays I go get my oldest daughter. On Tuesdays and Fridays, I get her...she comes home. Tuesdays, she eats with us then I take her back to her group home. On Friday, she’ll come home...just spend the night and go to take her out back to her group home after we eat on Saturday night.”* He and his wife take separate vacations, so one of them will be home to provide care. His trips are an annual event with 10 high school friends whom he considers *“kind of my brothers.”* He has no other immediate family and is an only child with deceased parents.

When asked what it is like to be a caregiver for a child with DRE, participant 010 provided the following summary:

It’s difficult, it’s not easy. You’re always waiting for the seizure to happen. You always have to think about her triggers. You think about things you wish you could do...which you can’t. Because, you always have to keep her in a certain situation. It’s not easy...love her to death though. I wouldn’t trade her for the world. But, it’s difficult. And it’s difficult managing...we’re a couple... so we both have different opinions on things. Sometimes I’m not sure what I think, she thinks is right and she thinks what I think is right. So, it’s managing that...different opinions are sometimes difficult to handle, but I think we do a good job. (Participant 010, interview 3, p 3)

Participant 010 described the type of things that are stressful as he cares for his daughter. He replied *“stress? Well when I see (my daughter) have an absence seizure. That causes stress. When my wife's not in a very good mood, that... I told her...I try to tell her...you have a lot of power. Depending upon your mood, this house runs a certain way. If you're in a bad mood, the whole house is in a bad situation...That's a stressful situation.”* Participant 010 further discussed why observing absence seizures is particularly stressful. He revealed that these types of seizures tend to be a precursor for generalized tonic-clonic seizures. *“We have to get ready. So, you get your anxiety, your cortisol kicks in. Okay, let's get her into a safe spot...make sure everything's good.”*

Anxiety forms the basis of many challenges specific to caring for his daughter with DRE. Will he trigger a seizure if he withholds disciplining her? He may be *“creating a little monster because she can get whatever she wants.”* As his son remarked, when home from college, *“his sister does things that he had never been able to do.”* But the seizures are so unpredictable, as he describes:

So, I call it you're driving in the snow...on a cold winter night and you get your hands wrapped around on the steering wheel... and you're just like this [motions to hand's tightly on steering wheel] waiting for something to...cuz, that's the way we live. Because you never know when the seizure might happen. So, you have to be constantly ready for some traumatic event to happen just like what happened. (Participant 010, interview 2, p 7)

Participant 010 referred to a recent seizure that resulted in a fractured leg, which required surgical intervention. Unfortunately, he was enrolling his daughter in a clinical

trial out of state at the time. *“We kind of took the bubble wrap off a little bit.”* A generalized tonic-clonic seizure occurred, his daughter fell and injured herself. He feels he is never able to relax. *“That’s one thing that’s hard about...living with a child with intractable epilepsy is you constantly are on the edge. You actually feel the cortisol.”*

Always maintaining his guard impacts participant 010. *“You have all this in your mind at all times.”* Concern for his daughter and her ongoing seizures has been more on his mind with the recent passing of the young Disney star who died of Sudden Unexplained Death in Epilepsy (SUDEP). He wishes to protect his daughter from the truth. *“It’s like, with these Dravet kids, a lot of them have passed. I know one of her very good friends died because of SUDEP...so, it’s a real-life thing. So, it’s tough.”* When asked if he just came to this realization that his daughter may die, he acknowledged that has known the possibility of death for a long time. However, he states *“ I was in denial. I’m still kind of in denial about it cuz, it’s hard to live like that.”*

As a method of coping, participant 010 said he uses humor and tries to create a fun environment for his child. He has a small support system: his wife and son, and some high school friends. As the family provider, he wished that his wife would be more supportive at times. He recognized that his wife remains home each day; however, he felt that she may resent that he is able to leave to go to work outside the home. *“I think that sometimes the spouse thinks that...well you get to get away. No, I’m going to do a job. It’s not like I’m going out to party with my friends. But, I feel horrible that you have to do this. You almost wish you could cut yourself in half, so you could be home with her plus do the work, too.”*

When asked if his views of himself have evolved or changed, participant 010 described a change in his mood. *“I used to be very even-keeled like very mellow. Nothing*

would really affect me. And I noticed that the stress levels make me more agitated quicker. So, I'm really trying to focus on that."

Participant 010 has noticed that his constant stress (and stress-related eating) has contributed to a decrease in mental clarity. He said that exercising more would improve his mental clarity and overall quality of life, and realized he needs to address his physical well-being. Improving his physical well-being would improve his emotional well-being. As part of a physical well-being process, his aim is to eat and sleep properly.

There were some unexpected joys in the life of participant 010:

Well, you know, I always look at it this way. What 15-year-old girl would allow me to hold your hand still? There's not a lot. Watch cartoons with me, do the things we do and just be goofy. A lot of 15-year-old kids hate their dads at this point. So, it's....so, I look at that like a positive.
(Participant 010, interview, 3, p 5)

When asked what advice he would give to parents who are beginning their journey with epilepsy, participant 010 provided the following insight specific to his daughter's genetic disorder. He believes that there is a wealth of information available on the Internet regarding Dravet, which parents should continually research. He recommended navigating the resources early on to explore treatment options because even with a provider whom you trust, that provider may not be aware of the most cutting-edge treatments. For advice regarding health care providers, he would hope that they become more familiar with options beyond their own local area.

Chapter 6: Discussion of Findings

The Research Questions

Chapter six provides cross-case analysis of ten narratives, based on the research questions which were formulated to uncover the lived experience of parents caring for children with DRE. From their responses to six questions, the PI learned about the following areas of participants' lives: (a) the extent of their role as caregiver; (b) the types of stress they experienced and how they coped, the sense of support they received; (c) the impact on their self-concept; (d) their overall quality of life. The accumulated case knowledge was compared and contrasted to produce new knowledge, that is, commonalities emerged, and the following five life patterns produced:

- What is best for my child
- Functioning in silos
- Living with uncertainty
- Maintaining a balance
- Finding meaning and purpose

Data from several interviews were formed into a composite narrative to tell a story that represents patterns of the parents' experiences caring for a child with DRE.

Relationship Among Narratives

What is Best for My Child

As part of the narrative pattern, all participants' life stories provided a window into decisions made that were in their child's best interest. These choices (sacrifices) had to do

with keeping to daily schedules, deciding to make home improvements, remaining in New Jersey, adjusting work schedules, giving up leisure activities, potential furthering of education, and being an advocate for their child.

Routines and Organization. All ten participants described moving through their day, following a routine that did not change day-by-day. Although schedules demonstrated all that is involved in providing care for their child, the use of schedules had different significance for each participant. Participants 001, 002, 003, 008, and 010 shared that maintaining a schedule was important in seizure prevention. Participant 006 stated that when his daughter's scheduled was altered, especially when it results in a change in her sleep schedule, she had "*lots of seizures. We do end up paying for it for at least a day or two.*" Organization was exceedingly important to 80% (8/10) of participants. Participants 001, 002, 003, 004, 005, 006, 008, and 010 acknowledged that maintaining a calendar with daily tasks visualized was key.

Because of the complex nature of epilepsy, scheduled medication administration; adequate sleep time allotted; therapy appointments; and ensuring gradual time to wake in stages were tasks requiring a specific time frame that which did not vary. Although participants 007 and 009 reported not having a typical day, citing lack of structure as problematic, they detailed a routine structure with activities from the moment they woke until they went to sleep, which did not change day-to-day. This outline was similar to the structured schedule provided by the other participants except that participant 007 and 009 emphasized difficulty determining how each day would go, basing it on the condition of their child and if seizure activity had increased.

The reasons for maintaining routine and organization were different for each participant. Preventing seizures, completing tasks and daily activities unique to the care of a child with DRE, and creating a visual representation by a calendar as a method of organizing their life were all identified. Even those participants who did not feel there was a structure to their day, provided a detailed account of activities that needed to be accomplished. The use of a routine was recognized by the participants as being what was best for the care of their child with DRE.

Sacrifices versus Alterations. Although all participants discussed sacrifices they made in the best interest of the child, none viewed their choices were sacrifices regardless of the context of what had occurred; rather, they made alterations to accommodate the needs of the child with DRE. As participant 003 said, *“It is what it is.”* A level of flexibility was necessary to live with the unpredictable nature of epilepsy. Although adjustments (alterations) occurred, none were viewed as a sacrifice.

Eighty percent (8/10) had greater family support out of state; yet, they opted to sacrifice living close to them, so they could maintain the best services for their child. Participants 002 and 003 contemplated moving out of state to be in a warmer environment and to have access to more family support; however, their deciding factors to remain included fear of inadequate health care services and not finding the same level of health care providers needed to treat epilepsy. Participants 003, 004, 007, 009, and 010 described moving within New Jersey as in the best interest of their child. Of these five participants, all but participant 009 specifically purchased a new home that was easily navigated by a child with disability and provided modifications to facilitate care. Participant 003 shared:

We lost a lot of money selling our first home because we put...we did put back pavers and redid the basement, but the market just stinks. So, but to me, there's no comparison. The whole first floor is all the huge tile and there's no transition pieces so I could just wheel her right into the garage. I could wheel her right into to a room. It's just so open and free.

(Participant 003, interview 1, p 21)

Participant 009 shared that selling their home was done primarily for financial reasons to pay for medical expenses. He and his family moved in with his mother-in-law. He remembered that *"things went downhill for us, and we had to sell our home. We were building, we had a house that we had bought. We had pretty much almost completely renovated. It was our dream house. We had a huge deck on the back. Put a pool in. Had a play area in the back...fenced it. We completely redid the whole house top to bottom....and then my son got sick and we couldn't afford to live there."*

Participants 003, 005, 006, and 010 decided to have a pool installed with their child as the motivating factor. Participant 003 felt it would assist with home aqua therapy, something which demonstrated a positive therapeutic outcome for her child. Participants 005, 006, and 010 believed it would provide a place for family gatherings, one that their other children would enjoy since leaving home for activities was difficult to plan. Participant 006 recounted the difficulty meeting the needs of his other children as follows:

We were planning to go to the beach with the kids. We're almost in the car...ready to go and my daughter ended up seizing on us, then she ended up going to the hospital. We were really torn between the three older

kids and my daughter... what to do. We actually decided to buy an above ground pool in our backyard...over getting the house sided because of the kids...So, that way, when my daughter did have problems, at least we had some things to do at home. (Participant 006, interview 1, pp 4-5)

In the best interest of their child with DRE, participants opted to forgo having additional support nearby. Participants consciously decided to remain in New Jersey in order to continue with the same level of services for their child. Home modifications and even the purchase of homes was discussed. These lifestyle changes were done with their child's best interest in mind.

Some home modifications were done also for the consideration of the participants' other children. Family plans were often changed or completely cancelled because of the care required for the child with DRE, impacting the siblings' lives. Alterations in the family's activities were particularly problematic for siblings. The participants' home modifications were completed to provide alternate activities for the siblings, so they did not feel neglected. Although from an outside lens these choices may be viewed as sacrifices, the participants regarded these choices, without hesitation, as simply what was needed to best meet the needs of their child with DRE.

Adjusted Work Schedules. All but one of the participants reported adjusting their work schedules, in varying degrees, to care for their child. Participants 001, 003, 004, and 009 decided to stop working in order to provide care. Participants 002, 005, 006, 007, and 008 adjusted work hours or location to better meet the needs of their child. Participants

002 and 005 changed their hours to part-time to be more available to provide care. Participant 007, who worked from home, stated that the flexible schedule provided the opportunity to care for his child along with his wife.

Participants 006 and 008 chose to work closer to home to be more accessible in the event of an emergency. They refused other employment opportunities due to increased distance, which would have been financially better and more rewarding. Participant 009, who received an offer from a well-known actor, comedian, and filmmaker to write films in California, declined without hesitation saying he would not leave his family for an extended period. Participant 008 had no regrets regarding his decisions:

That's pretty much what kind of holds me back a little. Sometimes I feel like if my son...if we didn't have to be on top of him 24/7, I can go out there and find something...enjoy something...trying other things. But right now, I just have to pause trying to figure out what we're going to do and how to go about it. It's just more convenient, being much closer...10 minutes he's from work or when he's at school...5 minutes away.
(Participant 008, interview 3, p 7)

Many of the participants' children required constant supervision. Participants described their work schedules and work environments adjusting to meet the of their child. Some participants made the decision to quit their jobs in order to be a full-time caregiver. These adjustments in work schedules, hours worked, and the job location were not identified as important to the participant's career or own desires. Even those participants whose children attended school made work choices in their child's best interest. This was

done to be available, close in proximity, should seizures occur, and their presence be required. All of these adjustments in work were done to best meet the needs of their child with DRE.

Forgoing Leisure Activities. All participants said that they had given up previously enjoyable leisure activities and activities related to self-care but did not consider these sacrifices. Seventy percent (7/10) of participants reported not being able to exercise. Participants 001, 002, 004, 007, 009, and 010 believed in the benefits of exercise, but were unable to make time to go to the gym. Participant 007 said, *“never have time. The number of times that we pay for things that we don’t...gym memberships are the most famous ones. I reckon it cost me...us, something like \$1200 a visit to the gym.”*

Participants 003 and 008 cannot participate in their favorite activities; participant 003 bike riding and participant 008 competing in pool tournaments, because their children require constant supervision and cannot be left alone. Participants 001 and 005 discussed the desire for further education but found it difficult to fit into their schedules. Although currently enrolled in an on-line program to complete an undergraduate degree, participant 001 acknowledged that she preferred being in the classroom environment, but since she must be home to care for her child, the on-line format was the only way to achieve her goal. Participant 005, who left school when she was expecting her first child, had the intent to return for her nursing degree. The severity of her child's seizures made this impossible.

Participants did not prioritize joining in leisure activities or consider them as important. They did not deem these activities as necessary, compared to the importance of caring for their child and their child’s needs. Although these activities may have been

beneficial to the participants, even citing the benefits of regular exercise by 70% of the participants for example, their child's needs came first and were their foremost thoughts as they function in their daily lives.

Advocacy. Sixty percent (6/10) expressed significant issues involving school; particularly their need to be an advocate for their child. Participants 001, 002, 005, 008, 009, and 010 have had difficulties working with school districts to identify services and to ensure that they are provided. Participants 009 and 010 home schooled their children. They shared the frustrations and difficulties having appropriate services continued. Participant 009 shared his struggle with the process of getting teaching and therapies at home, saying:

She walked in with a bunch of high school books and plopped them down on the table and said, we're going to get started. I laughed and said, no. She was told my son was 18, and now we understand that's basically all they tell them... he's deaf and he's 18...So, we have to reach out now and try to contact them even before they come and let them know that this is what you're going to be walking into. (Participant 009, interview 1, pp 14-15)

Some therapists, who had never dealt with a deaf student, refused the assignment.

The participants were compelled to advocate for their child's best interest. As participant 006 summarized this point well when he shared *"(my daughter) can't speak for herself, so we have to advocate for (her). There's no middle ground for that. If we know something's not right, we speak up about it."*

The Health Care System. Ninety percent (9/10) of the participants had negative interactions with the health care system. Participant 001 did not identify health care-related problems with her child who was diagnosed with epilepsy only two years ago and is currently functioning at grade level. Of the remaining participants, five were non-verbal, three had limited verbal output, and one was verbal who participates in a special day program at school. Compared to participant 001, the nine other participants' children required more services, such as, assistance with activities of daily living and ambulation for two who had difficulty walking; five were non-ambulatory. This may explain why participant 001 did not have health care issues.

Participant 007 shared that only with the assistance of a lawyer, had he been successful at obtaining benefits that exist as part of his insurance plan. He said *“I mean it is very, very clear to us that the M.O.[Modus Operandi] with insurance companies...to deny, deny, deny. And eventually as a parent you get worn out and you just give up.”* He further described that it *“does seem to be the clear M.O. of the insurance companies. So much so that on occasion we had to hire lawyers to intervene on our behalf and lo and behold...the lawyers intervene and the very next day...we get the thing that we’ve been arguing for three months.”*

What is more disturbing is the recommendation from a governmental office given to participant 003 as a method of obtaining more comprehensive services. *“When my daughter was an infant or toddler, one woman even went...even told me that I should get a divorce from my husband...on paper. So that I can apply for Medicaid under me and my daughter. Yes! So, that’s how hard it is...unless you really dig and find it, to get help.”*

Seventy percent (7/10) of participants found their way to special programs not widely advertised by doing just that, digging deeper and searching for services.

Throughout their lives caring for a child with DRE, the participants expended significant amounts of time and energy as they navigated the intricacies of the health care system. Participant 007 described the need for *'battling against all those issues that we battle with'* when referring to interactions with the health care system. As frustrating as the process has been, the participants acknowledged the need to continue because it was what was best for their child.

All participants, in some way, made adjustments to best meet the needs of their child. Varying degrees of home and lifestyle changes were described. Being a vocal child advocate proved beneficial in obtaining services. What is interesting to note is that although each participant shared stories of sacrifices to improve the life and needs of their child, none used the literal term "sacrifice." There was no sense of regret or feelings of being deprived. These sacrifices were just what merely needed to be done for their child's needs to be met.

Functioning in Silos

Each participant expressed difficulties finding resources for their child. The parents worked alone, most within the 12.5 year-span of living with epilepsy, carrying out the same activities to find resources, without the benefit of a common method for information gathering. Although most reported now having confidence in navigating resources, this was not always the case. Early on, all participants searched the Internet to find information specific to their child's diagnosis, and then to learn more about existing treatment options;

this information was not always positively received by health care providers who felt offended when presented with new options. Eighty percent (8/10) participants sought information regarding ongoing clinical trials. Participant 010 searched trials specific to his daughter's diagnosis of Dravet syndrome. Participant 010 said, *"I think we find out a lot of things the doctors don't know. Nothing against them at all. They're not focusing...obviously a neurologist isn't just doing Dravet, they're doing all other kinds of patients."*

Social Media. Social media platforms such as Facebook provided an avenue for them to share their experiences and learn about school services. Participant 001 found information about a 504 plan, an educational plan that assists students to be successful in their learning environment even if they may not qualify as *"special needs"*, which she discussed with her child's teacher. She recalled, *"I wasn't aware of it, but I actually joined a Facebook group that was called absences seizures for moms, with kinds of absence seizures. So, I was new to the group, and then I learned that parents were saying, if your kid is having trouble in school...see if you're eligible for the 504 plan, if he needs it. So, that's why I brought it up to her, and she said, okay, we can do that."* Without their own use of the Internet, they felt these options would not have been found.

Information regarding available services for children with DRE should be readily available and easily accessed. Participants did not experience this. Operating within individual silos, participants described the strategies used to find resources and services. No common website for information gathering was identified.

Health Care Benefits. Ninety percent (9/10) of participants had difficulty navigating resources regarding health care benefits. Participant 010 referred to the insurance industry as *“the dark arts”*, the attitude with which most participants agreed. *“It’s the craziest thing. You ask all of these questions and it’s like nobody can give the answer. You’re like...okay, how do we do this? And nobody really knows...but then I found the right person.”* Similarly, participant 007 added that even when speaking to the individual assigned to your child's case, it is difficult to navigate. *“You ask what services can my son get...right? And what you quickly hear is well, there’s lots of stuff...you just have to ask for what you want, and then we approve or deny it. Well, I don’t know what to ask for. So...to this day, we don’t know what we should be getting or not.”*

Particularly frustrating was the fact that information was not readily available to them. *“They do not know what they do not know.”* Fifty percent (5/10) reported randomly finding one knowledgeable person who proved vital to their investigation. Otherwise, interactions with insurance companies were a fight with the system, a battle needing to be won, and a significant time-wasting activity by 90% of participants. Participant 007 said, *“I think that we’re battling against all those issues that we battle against. You have to fight for everything.”*

Within the abyss of the complex health care system, participants struggled to find services, treatment options, and health care benefits covered. Each participant spent years trying to navigate systems and find available services. Even though the same processes were utilized, they had to navigate within their own silo.

Beyond that of their spouses, participants had a minimal degree of outside support.; 50% identified speaking with other parents of children with special needs as providing the initial direction to find available information and resources. All but participants 003 and 008 said that parents of other special needs children were a primary source of support for them. Participant 009 maintained, *“we’re closest with other families with special needs kids, but it’s hard. We don’t ask them for help, because we know what they’re going through and we know how difficult it is for them to break away and do something. When it comes time for talking, those usually are the families, though, that we talk to the most.”*

Friends You Cannot Count On. Participant 009 mentioned a sentiment common to 50% of participants that other friends are not a significant source of support, in fact, from experience, some friends drifted away because it was not easy to handle seeing a disabled child. *“It is very difficult for them [the other friends]...and I get that....I’ve had friends walk into the room that haven’t seen my son in years, and I see them immediately well up. They have to walk right back out of the room. They can’t deal with it.”* Participants 004, 007, 008, and 009 said that, at times, they have had to comfort family, friends, and even strangers who have found it difficult to be around their child. Participant 004 shared *“that’s another big-time consumer, trying to make everybody else feel okay about everything.”*

Although 80% of the male participants had a supportive group of friends, none of the female participants had regular interactions with friends. Had these participants had the time to attend gatherings, the number might have increased. For example, participants 003 and 004 acknowledged having a group of friends with whom they were not able to connect regularly because of their caregiver responsibilities. According to participant 005,

“I have Facebook friends...that's it. But to have girlfriends to go out and stuff...I used to have friends, but there again, that social aspect of what happens. It definitely affected my social status on different levels, not being able to socialize in different things.”

Not having friends to rely on for support and encouragement only deepened the sense of functioning in a silo. Participant 007 articulated this point when he shared *“your radius of living becomes smaller and smaller and smaller.”* Participant 003 also shared a similar sentiment when she shared that *“you have to learn to live and find happiness in your own home, 24/7.”*

No Support at All. For a variety of reasons, extended family was not available to provide support. Participants 001 and 002 had caring relationships with parents, but their busy work schedules precluded their parents' presence and availability to reach out by phone for emotional support. Participant 003 believed that her family would be supportive if contacted, but nobody was *“at arm's length.”* Participants 004 and 007 consciously decided not to involve their families in their lives. Participant 007 said, *“My wife and I have zero support”* from family. He further added that his family is deeply dysfunctional, and that it was too distressing for his mother to see his disabled child. So, she has not been involved. In fact, since his son's birth, *“she has never been a part of my son's life. She hasn't called...ever. No birthday card...nothing. So, even if she lived here, it wouldn't make a difference.”* Participants 005, 006, and 009 had family living out of state, but were not regularly in communication with them. Participant 008, who has a large family with whom he feels a close connection, who would be supportive; however, he does not reach out to them. He echoed the sentiment expressed by all the participants in that *“everyone is doing their own thing, everyone is busy.”*

Without an immediate support system, parents of children with DRE become more isolated in their own silo. It becomes difficult to see outside of that silo, as their world becomes smaller because they focus only on their child's needs rather than on the outside world.

Living with Uncertainty

The unpredictable nature of seizure activity caused constant changes in participants' lives, which contributed to uncertainty and the ongoing stress in their lives. Ninety percent (9/10) expressed a basic concern of injury from living with the uncertainty of potential seizure activity. Participant 010's daughter, who had recently experienced a fall associated with seizure activity, fractured her leg, which required surgical intervention. The event occurred out of state while enrolling in a clinical trial for epilepsy. He felt nervous flying her home, planning mentally for scenarios should a seizure occur mid-flight. *"If she's seizing in mid-air...are they going to make us land? You never know. I always wanted to call an airline and find out what they do. I don't want to affect anyone else."* He continued to say *"and, of course, I want my daughter to be safe, too. So, that's one thing that's hard about....living with a child with intractable epilepsy is you constantly are on edge. You actually feel the cortisol."* What he disclosed was absolute uncertainty.

Seizures That Do Not Stop. Participants 004, 005, 006, 007, and 008 experienced similar traumatic fears and uncertainty, since their children had experienced prolonged and difficult-to-stop seizures, requiring hospitalizations. The unplanned hospitalizations and the fear of their child's death were stressful. Included in his daily activities, Participant 008 described calling out his child's name for a response. His greatest concern was that of

a lack of response from his child or hearing a loud thud from his child's room, which would mean his child was seizing, or worse that he may find his child dead.

I'm to the point that my nerves are shot...If I hear a bang or something in the middle of the night...in the room...not knowing. So, I was sleeping one night, and he had them. But we were up and going in and seeing him on the floor and seeing him in that condition. So, if I hear a bang, or I call him. If I don't get a response, my first reaction is something is wrong. (Participant 008, interview 1, p 12)

Fear of death was also identified by participants 004, 006, 009, and 010 as a concern related to DRE. Forty percent (4/10) expressed significant stress related to the type of events described above. Participant 005 said, *"I know I was going through PTSD, without a doubt"*, as she recalled a difficult prolonged hospitalization. The whole family had been traumatized by seeing her daughter stop breathing while seizing. Because of this, she opted not to have nursing support at home. Adding a stranger to her other children's lives was not warranted because *"their lives were already turned upside down."* The near constant fear of their child's death created a level of uncertainty that never escaped the participants.

Plans Interrupted. Depending on seizure activity, plans were either put on hold or canceled altogether, which added a layer of stress and uncertainty to daily life. Ninety percent (9/10) of participants said they lacked the ability to follow through on plans that extended to other family members and friends. These plans may have been canceled at the last minute. Participant 005 stated that *"for years, we had to decline on all kinds of invitations, and this is what separated us with our families too, because they couldn't*

understand. They said they understood, but families and friends and everything...declining so may invitations, after a while...the invitations stop.” Participant 007 expressed that there is never a day off, each day brings much uncertainty with different issues. He shares that *“the thing that really, really makes my wife and I struggle...causes problems...is the unrelenting everyday nature of it.”*

Choosing to Be Positive. In order to cope with the stress of uncertainty, all participants acknowledged the need to live life “*day-by-day*” and “*maintain a positive attitude.*” Although they lacked the ability to plan, they created a schedule of daily activities to cope. Forty percent (4/10) used positive motivational talk to cope with the stress of uncertainty; the majority relied on humor as a strategy. Participant 009 said, “*that’s what gets us through the deepest, darkest, worst days is being able to find the humor.*” Humor provided a new career opportunity for participant 009 who regularly performs stand-up comedy in which he shares his life, living with a child with seizures. He has been the opening act for several well-known comedians, written jokes for other comedians, and has had a small role in a recent movie. Choosing to remain positive and the use of humor were methods of coping with the uncertainty of living with and caring for a child with DRE.

Faith and Religion. Although 90% of participants (9/10) identified with a specific faith, it was not a focus of most conversations. Only 40% (4/10) described being part of a religious community that provided a significant source of support when dealing with the uncertainty associated with DRE; however, for those participants, religion provided a significant source of support, specifically identifying prayer as a coping strategy. When asked how she handles more challenging times, participant 005 shared “*something always*

presents itself to me...something always does." She added where this belief came from by sharing *"My faith... My faith in God and the Holy Spirit moving me and moving things in my direction. I believe that wholeheartedly."* Most participants did not focus on religion as a method of coping with uncertainty, but for those who did, prayer was the primary strategy.

Maintaining Balance

Faced with multiple challenges, participants attempted to maintain balance in their lives. For example, they kept their child with DRE safe while maintaining the child's normalcy, this among "normal" siblings; administered medications that control seizures but come with unwarranted side effects; managed their own quality of life within their caregiver role; and dealt with providers who fell short of competency. All participants described their hyper vigilance in monitoring their child, who could not be left unattended for the shortest period of time, if at all. Participant 008 said, *"You want to give him his space, he's 18 years old. He wants to go out and enjoy it (life), but he can't. We're just hoping somewhere down the line, we could figure out either some medicine or different way of going about it that can at least get control over it."*

Sixty percent (6/10) of the participants were concerned about the therapeutic value of medications for seizure control versus their side effects. Participant 008 remarked, *"They keep...they want to keep upping the meds. But every time they up the meds...he's not...he's spaced out."*

Split Parenting. All but one participant had other children. The nine participants discussed trying to balance the needs of their child with DRE versus the needs of their other

children, highlighting the importance of giving them equal time participating in their activities. Because their child with DRE cannot be left unsupervised, one parent must decide to stay with that child, a routine identified by participants 004, 005, 006, 007, 008, 009, and 010. Participant 009 referred to this as *“split parenting.”* Because his son requires a great deal of physical care, he has typically been the parent who stays home. *“My wife usually ends up doing the stuff with my daughter. If she’s home, she has to go up a flight or down a flight, she has a hard time with him. So, I pretty much have to stay home most of the time. I miss out on a lot of stuff with my daughter.”* Participant 007 recalled a conversation with his son when he said *“Dad...you don’t understand, (talking about my other son), and I realized that immediate moment...I don’t understand because I never had a disabled brother. I’m not in your shoes. I have never been in your shoes and it’s really hard for me to...I’m projecting onto him my thoughts and feelings about my other son.”*

The siblings also recognized other differences. Seventy percent (7/10) of participants reported that their other children shared feelings of being a lower priority and of being treated differently. Participant 010 acknowledged that he is more lenient on his daughter because behavioral outbursts and stress may trigger seizures. *“So that you’re creating a little monster, because she can get whatever she wants. She knows there’s no solid line or a wall to go against. So, she can break through the wall anytime she wants. So, that’s difficult. And my son sees that. He’s like...wait a second, why did you let her do that?”*

Difficulties exist in balancing the needs of all their children. Maintaining that balance for both the child with DRE and their siblings weighed heavily on the participants’ minds. Because of the need for constant supervision and the desire to share in activities

with their other children, the participants found it necessary to function through split parenting. Participant 010 summarized this thought as he shared *“you almost wish like you could cut yourself in half, so you could be home with (your wife) plus do the work, too. So that’s the hard part.”*

Quality of Life. Participants found it difficult to balance their own quality of life with caregiving. Although most participants reported no changes in their quality of life, subsequent descriptions contradicted this claim. All participants expressed physical exhaustion, and then with decreased quality and/or quantity of sleep was a main area of concern. Participant 001 recounted her lack of sleep was a cause for significant headaches; however, she was unable to change her schedule to adjust her sleep. Seventy percent (7/10) complained of other physical ailments such as back pain, but they did not translate pain into feelings of poor quality of life. Fifty percent reported mental health issues; five having seen a therapist to assist with depression at some point.

Although they voiced a desire to be involved in activities to promote health, it was not a priority. Often, the participants exchanged time with their spouse to provide constant supervision for their child rather than take time for themselves in an activity. Participant 006 shared he cannot recall a time he had time available to do something for himself. He summarized *“that’s kind of hard because my wife actually trades off on my daughter. Somebody’s got to be with our daughter 24/7. So, if she’s not with my wife, she’s with me.”* The overall response by the participants was that *“if my child is happy, I’m happy.”* It appears that the two are related, the child’s quality of life is interrelated to the reported quality of life of the parent. Participant 003 explained, *“I fully admit and agree that my life is my daughter.”*

From the outside looking in, what was shared by participants resembles poor quality of life. Participants did not rate their quality of life as poor because their own well-being was intertwined with their child's quality of life. The participants' lives have been redefined in caring for a child with DRE and so their feelings regarding quality of life have also been redefined.

Establishing Trust. Perhaps the most difficult area to balance was establishing trust with health care providers, especially nurses. Of the 50% of participants who had nursing support, all reported difficulties with nursing care management. Participant 002, 003, 004, 007, and 009 complained about nurses not showing up for shift work, often with minimal advanced warning. Although assigned for certain dates and times, the participants revealed always having a level of concern that the nurse would simply not show or call within a few hours prior to the start of a shift. This lack of reliability led to participants' difficulty trusting the nurses and their agencies.

Other participants shared frustrations with nurses who lacked competency. Given their need for a few hours of sleep, participants had the hard choice of monitoring them [for completion of nursing tasks] or "trusting" that they will do what is expected. Some nurses assigned were not a good fit for their child. Participant 007 remembered an experience with a night nurse "*We've had a lady turn up and said I will try and stay awake, but I can't guarantee it*", referring to a night nurse scheduled to work. Another nurse arrived in her night gown, while another "*she was asking for the Wi-Fi password because she's got some reading to do.*" These nurses were asked to leave, which meant the parents had to stay awake for 20 hours straight to provide their son's care, which similarly occurs if a nurse does not report for duty.

Other nurses had never cared for someone with epilepsy or had never witnessed a seizure. Participant 007 continued *“There was one time, the result was the doctor ended up seeing my son. The lady let my son seize for about 20 minutes to half an hour we think. And we ended up here in the hospital for quite a while. She’d never seen a seizure. And then eventually, after 20 minutes...comes knocking on the door and says I think there’s something wrong. So that 20 minutes event...ended up here for three to four days and then he wasn’t right for a month or two months after that.”*

Participant 007 said, *“It’s the thing that really breaks your heart because nobody else will care for your child better than you can.”* However, minimum sleep is required to function. Finding that balance between trusting someone to provide a minimum level of care in order to provide the participant and his wife a few hours of sleep or monitoring the nurse was difficult. *“It’s a trade-off.”*

All participants also acknowledged the need to establish trust with their health care providers and the health care system. However, this was not a quick process. Participant 007 said, *“You go to see a doctor and he’s going to tell you everything that he knows and values. I don’t want to hear everything you know about epilepsy. I want to know how it impacts my child and how it’s going to impact me. So, we’ve seen a few neurologists in our time. You know, personality...style...bit of substance.”* Regarding trust with the health care system, participant 005 said that because of negative care received at local hospitals, she would drive a significant distance to bring her daughter to a specific hospital setting to receive care. *“So, that’s my safety net. That’s my safety net right there. That’s my go-to place right there because I don’t have to explain anything. I don’t have to go through things 20 million times because...the doctors know her, and I don’t have to explain anything.”*

Negative interactions with health care professionals have led participants to be guarded and unable to trust other health care providers. They were torn between what they physically needed to function and the need to have assistance with care for their child. As participant 007 shared *“that’s the biggest issue. So, that’s why you take the trade off with the nursing...because you have to go to bed.”* With great sadness in his voice he added how difficult it was to accept nurses into his home *“because you know that person walking in is not who you want looking out for your child.”*

Finding Meaning and Purpose

All participants spent time speaking about their experiences, providing an opportunity to share their individual journeys; somehow finding some meaning and purpose to parenting a child with DRE. Many shared feelings of growth and reflection regarding how they saw themselves. Through sharing their stories, the participants hoped others would learn from their experiences. There was an altruistic nature to the conversations, meant to help other parents and health care providers in the care of children with DRE. All participants shared advice they deemed valuable to other parents of children with DRE. Ninety percent (9/10) of participants viewed research as important in finding information on diagnosis, treatment options, and available resources. Participant 003 said, *“No one’s going to come knocking on your door...with a big box of goodies. You have to come...you have to go out on the phone, on the internet, anywhere you can...on Facebook.”* Use of social media and particularly Facebook was suggested as a method of support from other families, according to 50% (5/10) of the participants. Most participants recommended speaking with other parents experiencing similar situations and joining support groups as important to help with their journey.

Listeners. When discussing what was important when seeking a health care provider, finding a provider who would see their child as more than just a patient was identified by 50% (5/10) of the participants. Participant 007 summarized the feelings shared by the other participants when he shared *“find that doctor who you trust as a doctor, but not because of his medical stuff. But personality-wise, is going to be the advocate for your child.”* Equally important was the need for health care providers to actively listen to the participants. All participants identified a need to be heard and acknowledged for their own unique perspective regarding their child. Participant 005 provided this response which summarized the other participants thoughts in that *“I may not have a PhD...but I have a PhD in my child.”* Participant 006 added *“So, it’s not always bedside manner. It’s a matter of attitude and doing what you need to do. The other thing is, even though it doesn’t seem like it...he listens.”* Participants found purpose when sharing their personal perspectives regarding health care providers’ qualities.

Growth and Change. Sixty percent (6/10) of the participants recognized personal growth, a change in their own self-concept as part of their experiences. Seventy percent (7/10) of participants spoke of positive changes in how they view themselves. Female participants shared feeling good about the person they have become, feeling strong and independent. Participant 001 said, *“I thought I was very weak... very passive, which I think maybe it was true back then...So, I took control and obviously I wasn’t passive anymore.”* Initially, participant 005 was unable to share who she was as a person: *“that’s a good question...identity...my life for the past 18 years has pretty much been about my kids...defining moments is what this is...I never realized how difficult this question is.”*

However, upon further reflection, she said, *“I’m a good person. I am a strong woman. To go through all of this? Damn, I’m really good at what I do.”*

Two male participants, 007 and 009 noted a positive change in self-concept throughout the journey. Participant 007 shared that he had become a kinder and better person. He shared that he felt being *“a big shot”* was his identity in the past, making money was all that mattered, but now realized feeling differently about how he views himself sharing *“I know who I am in this world now.”* Participant 009 also felt a positive change, feeling that he sees himself as a role model for others to emulate. Only one participant shared a negative self-concept through the experience caring for a child with DRE. Participant 010 felt badly about himself, and thought his spouse contributed to this feeling as well. He added that he would leave for work and his wife would make him feel bad for leaving. He felt he was bad for leaving. He shared, *“I’m trying to do something to provide for the family...just don’t make me go into a negative.”*

All participants had significant reflection regarding the meaning epilepsy has played in their lives. This was evident in between the interviews. All participants found joy in the small things; a smile, a laugh, just seeing their child happy. Participant 002 was particularly affected by hearing her child speak for the first time and purposely saying *“I love you”* to her which she said *“meant the world”* to her. Although none of the parents expressed that they would never want to see another go through what they experienced, there was acknowledgement of how much happiness their children, as they are, bring them. Participants 006 and 009 shared that their children are gifts to others, identifying a greater purpose to their lives. Participant 009 shared this insight *“I see how he affects and touches*

many people's lives. And to me...that's okay, that's okay. I'm okay with that. That he's made people's lives better from what he goes through."

Relationship of Findings to the Extant Literature

Previous literature regarding parents' experience caring for chronically ill children exists and on some levels mirrors what was revealed through these narratives told. Participants in this study identified similar concerns to previously reported issues such as making work adjustments (Raina, et al., 2005), experiencing financial struggles (Hughes, et al., 1999), and increased psychological issues such as depression while caring for a chronically ill child (Rodenburg, 2007). Despite these issues having been identified decades ago, these problems remain. Participant 003 acknowledged her life was intertwined in the life of her child, as found by Cianchetti (2015) that parent quality of life is linked to that of their child.

Less is known about parents of children with epilepsy. However, what literature that does exist is similar to the narratives provided by the participants in this study. Pearlin (1999) identified primary and secondary stressors as key factors impacting well-being. As discussed by the participants, both the sudden onset of seizures and, particularly as described by participant 007, the unrelenting nature of the illness were factors in the quality of their lives.

Increased stress and lower quality of life have been reported in parents of children with epilepsy (Tung, et al, 2014). The stress experienced by parents of children with epilepsy was higher than that of other parents of children with other chronic illnesses (Cushner-Weinstein, 2008). Listening to the shared experiences of participants in this

study validated that the stress is even with parents whose children have DRE, as found by Nolan, et al., (2006). Speechley et al. (2012) found that the uncontrollable, drug resistant epilepsies resulted in lower reported quality of life scores, higher stress, and higher depression among parents of children with DRE.

Bahi-Buisson (2008) noted that poor seizure control impacts the child and the family and remains to this day. Throughout the interview process, the participants shared their perception of the impact epilepsy had on their other children. A paucity of literature addresses the siblings of children with epilepsy. Hames et al. (2009) and McNelis et al. (2007) identified concerns of siblings through focus groups; however, neither study sought the experience of siblings of children with DRE. Participant 007 provided insight into the need to better understand the siblings' concerns when he shared that he had never thought of the impact of his son's epilepsy on his other children. It was only when his son expressed his feelings, that he realized awareness of anyone else's perspective on illness. Other participants, such as 009, described the need to do "*split parenting*" in order to meet the needs of all children. Again, the narratives only provide the point of view of the parent attempting to shed light on another's concern. The sibling's story is still yet to be told.

Moderating factors such as social support (McNelis, 2007) and self-concept (Raina et al., 2004) were identified as influencing the impact of stress on quality of life. Although all participants shared having minimal social support, many provided narratives of growth and stronger sense of self and well-being as part of their journeys. Equally important was the attitude taken and the problem- solving ways to cope with stress. Caregiver mood has been found to be more impactful on quality of life than the seizure severity experienced (Jain, Subendran, Smith, & Widjaja, 2019). Similarly, Dardas et al. (2014e) found that

coping style, self-concept, and mastery impacted overall well-being. Participants in this study emphasized the need for a positive attitude and taking everything just “*one day at a time.*”

Although there are a small number of studies exploring parent issues in caring for children with chronic illness, and epilepsy in particular, the experience of a parent caring for a child with DRE is not well established. Parents of children with DRE experience more stress, increased isolation from others, less social support and more role restriction with sacrificing a sense of self to care for their child (Wirrell, et al., 2008) Parents of children with DRE appear to have a quality of life that is tied to the child’s quality of life, the parent’s quality of life improves as the child’s quality of life improves (van Andel et al., 2009). Because of this, it was important to gain insight into the experience of parents with DRE.

This narrative analysis provided insight into the experience of parents with DRE. Although the participants did not report poor quality of life, their descriptions did correlate with aspects of poor quality of life, demonstrating the importance of sharing their stories. Significant stress was shared by participants in keeping with increased stress noted with parents of children with DRE as was the acknowledgement of limited support systems. Sacrificing a sense of self was also shared through common narratives similar to Boling (2005) in that they were never “*off duty*” in their role as caregiver.

Contribution of Findings to Current Knowledge

As identified, little is known about how parents of children with DRE experience this disease and how it gives meaning to everyday life as a caretaker. Consistent with the

literature, these parents of children with DRE experienced significant stress associated with the unpredictable nature of seizures. Narrative analysis gave meaning to what the stress involved within the context of their lives. Further, analysis of these narratives allows one to fully understand the breath of these experiences in life caring for a child with DRE in this specific population.

Equally important was the realization that, although not actually stating a negative impact on quality of life, the stories they shared displayed physical, social, and psychological aspects of decreased well-being as caregivers. In addition, they showed the degree of sacrifice parents exhibited as a routine part of their lives without having any negative association for decisions they made. As part of a shared narrative, the parents identified trust in interactions with nurses, physicians, and expectations with health insurance companies as important to the care of their child.

Although previous quantitative methods have identified correlations among concepts such as social support on quality of life, lack of social support took on a whole new meaning as the degree of isolation and inability to rely on others was shared in the stories they told. Furthermore, previous studies have acknowledged mothers' depression related to caring for children with DRE, with no mention of the father's mental health or psychological well-being. Through the narratives provided, some fathers described bouts of depression and significant psychological distress as part of their experience caring for a child with DRE. This is precisely the benefit of narrative analysis.

The siblings' experience was identified through the narratives. Although from the parents' perspective, this gave insight into this illness in the context of the entire family.

Participants described the need to consider the other children and their own life issues, identified as difficult to balance, when prioritizing care for a child with DRE.

Parents reflected on their own growth as they examined their concept of self. Finding strength and positive self-concept were identified as well as a new sense of purpose in their lives. This also extended to finding a sense of purpose for their child's life, feeling life as a gift, and one to be shared with others. These stories provided a meaning to previously known quantitative findings. Giving parents the ability to share their stories allowed for a deeper insight into their meaning and provided context, adding to the previously identified issues (Riessman, 1993) surrounding the care for a child with DRE.

Chapter 7: Conclusion

Summary

Through use of a multi-structured analysis outlined by Riesmann (1993), ultimately ending in a case by case and then cross case analysis detailed in chapters 6 and 7, common narratives emerged and were summarized. Following this step-by-step approach allowed for the researcher to truly ‘hear’ the narrators. All their story transcriptions were broken down into individual summaries, then reviewed line by line. This provided a window into their world, enabling an understanding of who was involved and how things unfolded in the events shared. This was important in order to discover the meaning behind the story events shared as well as the resolution of the event before returning to the present and sharing additional meaningful events.

The narrative approach allowed for the participants to better understand their own feelings around various events caring for a child with DRE. The goal of narrative analysis was to discover what events and experience mean to them. Throughout the interview process, some of the participants shared that they had never taken time to reflect on the areas discussed. One participant felt a release by talking openly about his experience. Participant 008 shared that he did “*appreciate the talk. I really don’t talk about this, but when I do...it kind of helps. It feels like something has been lifted off of me.*” Sharing their narratives provided a shift in consciousness and became cathartic as many had not spent time thinking about their own experiences as caregivers. The voices of these parents need to be heard by professionals as well as other parents to better understand their life experience regarding their children with DRE. Their stories hold value. Finding commonalities from their narratives linked the narratives, which emerged from different

points of view. For this reason, narrative analysis was the best approach to discover these common life patterns. The aim of this study, and narrative analysis in particular, was to better understand the cumulative impact that caring for children with DRE had on their lives.

Five common narratives emerged as having an impact on all participants (a) what is best for my child; (b) functioning in silos; (c) living with uncertainty; (d) maintaining balance; and (e) finding meaning and purpose. Although expressed differently by each participant, they all shared sacrifices made to better care for their child regardless of being viewed as sacrifices. These adjustments encompassed home and life changes, as well as work-related adjustments to improve the care of their children. Structuring their lives, most literally through detailed calendars of events, allowed for some sense of control which made it easier to function. Decisions they made were always with the child's best interest in mind. The need to be an ardent advocate was identified as a key factor in decision making and necessary to maintain balance in what was best for their child.

Functioning in silos felt as if they were deep in an abyss which represented the struggles that participants faced independently as they navigated through life, interacting with others and the health care system in general. Through a case by case approach and then the cross-case analysis, the narratives revealed participants' struggles in both areas. Entering the abyss, each worked in isolation while trying to accomplish the same goals. All participants said that the care of their child was theirs, and theirs alone. Also evident was the lack of an organizational structure to locate information and services to assist with their struggle.

The unpredictable nature of seizures was at the center of the stress for the participants living with uncertainty. This unpredictability impacted nearly every aspect of their day and interactions with all family members and caused constant worry. Some participants even acknowledged that previous severely negative experiences with seizure events contributed to a feeling of stress well beyond the end of the event, even using the term post-traumatic stress disorder (PTSD) to describe the experiences. They shared the variety of methods they utilized to cope with stress and the unpredictable nature of DRE. Some found comfort in prayer and meditation; others through a sense of control brought on by maintaining a structured schedule. All believed that maintaining a positive attitude was key. Equally important was using humor to get through dark days.

As identified by Mishel's (1988) midrange theory of Uncertainty in Illness, there is the belief that uncertainty continues along the trajectory of illness, from diagnosis through living with chronic illness. There are ebbs and flows to the degree of uncertainty, with coping mechanism assisting with the stress associated with the uncertainty caring for a child with DRE. What these participants offered through their shared narratives was the idea that uncertainty is a constant with which they live and why Mishel's description of Uncertainty in Illness is important and remains relevant to this day. The participants described the uncertainty at times of diagnosis, treatment and worsening of seizure activity often resulting in hospitalization. The participants also acknowledged the support of their health care providers as key to assisting with decreasing the uncertainty.

As the narratives unfolded, maintaining a balance was shown to be difficult. The constant supervision their child needed to maintain safety as a priority made it difficult to provide them with opportunities to be more independent and enjoy typical childhood

activities. For those with other children, it was a struggle to find time to be *present* for them. The siblings felt they were a lower priority and treated differently than the child with DRE. The last area difficult to balance was whom to trust with the care of their child. Several events provided a glimpse into a shameful display by health care professionals. Allowing outsiders into the participants' lives was not done lightly. They struggled with meeting their own basic needs, while allowing for health care providers to share in the care of their child.

The last common narrative, finding meaning and purpose, described how the participants reflected on their own journey and feelings about themselves. Several shared feelings of being changed in a positive way by their life experience. Feeling stronger and independent were expressed. For some, it was the revelation that what had provided self-worth in the past was no longer important, such as having money as a value determinant.

Participants also found purpose at the onset of the process even when agreeing to be interviewed, expressing hope that the information gathered would be helpful. Participants shared that they had a desire to help others, not only other parents of children with DRE, but also health care providers. All shared what they valued and would have valued if provided by health care providers. Having providers who were not only knowledgeable about epilepsy but who would listen, accept their input, and maintain open lines of communication were all identified. They also shared how they ultimately discovered information needed regarding epilepsy treatment and services. Participant 003 shared *"I would hope that this study, somebody reads it...(it) can help other people or even professionals."*

Perhaps the most interesting stories shared in this narrative analysis was the participants' profound sense of growth through the experience of caring for a child with DRE. Participants reflected on finding joy in the small things in life as meaningful, such as a smile or laughter. Additionally, participants reflected on how their child not only changed them, but also became a change agent for those around them expressing satisfaction that their child's life had purpose and a positive impact on all who were in contact.

Conclusions

Narrative analysis allows for participants to tell their own story in their own words. It allows the narrator to share stories and events that are meaningful for the participants. With narrative analysis, there are no expectations at the onset. The process unfolds with similarities and differences which rendered each story into a composite of a shared story. Linking different points of view from multiple participants is why narrative analysis is the best method to gain insight into the experience of the parents of children with DRE. Each participant shared their journey openly, providing a window into their lives as they experienced caring for a child with DRE. The joys and challenges were shared. The frustrations and concerns were identified. Through the process of hearing their stories, there is now a better understanding of the experience and meaning of life as a parent of a child with DRE.

Strengths and Limitations

Although narrative analysis may be completed with only one or two narrators, more participants are necessary when looking for common narrative patterns. Although the

researcher was fortunate to have 10 participants, with equal representation of mothers and fathers who completed the entire interview process, this was still a relatively small sample size. This did not represent the experience of all parents caring for children with DRE or epilepsy in general.

All participants were at a similar stage receiving care and sought care at the same epilepsy practice, a comprehensive epilepsy service with access to resources, services, and additional treatment options. Most of the participants had been living with epilepsy for an average of 12.5 years. Experience over time has shaped the current narratives shared. There would be value in understanding parents who recently received a diagnosis of DRE for their child, or those receiving care who are at another practice. Those experiences, if shared, may yield additional or at least different life narratives. As the participants shared struggles with finding information early on, this too may be different for the newly diagnosed DRE parents. Furthermore, although the narratives shared provide insight into the lives of parents' caring for children with DRE, it is not representative of all parents' caring for children with epilepsy.

Although siblings were not included in the interview process, participants shared their perception of the impact of DRE on their lives, demonstrating the potential value of siblings' stories. Left untold in their own words, it is difficult to determine the meaning that DRE has in their lives as siblings. Further research is needed in this area.

Lastly, the interpretive nature of narrative analysis was performed through this researcher's lens. Although a step-by-step approach was followed throughout the narrative process, a narrative may have been structured differently by another researcher. There was

a continued reflexive process, but this was not the participant's definitive story. The context was important in trying to understand and address the multiple aspects that scaffold a life story of parents' caring for children with DRE.

Although there were areas of improvement identified, there were strengths to the study conducted. By using a multi-structured analysis, the narratives unfolded case by case. The participants and the researcher were given time to reflect on the information shared. The researcher reflected on field notes composited at the conclusion of each interview. A summary of the previous interview was reviewed with participants prior to subsequent sessions. This insured that an accurate depiction of their stories was made, allowing for validation and clarification of the story interpretations.

The use of multiple interviews given to share stories allowed for establishment of trust. Each interview probed deeper into their life experience. None of the participants avoided intimate feelings and stories as they became more comfortable with this interviewer. This provided a fuller understanding of what their lives were truly like.

The participants completed the interview process, despite having extremely limited time available. They found value in sharing their stories and willingly came to provide insight into their experiences. This was a profound revelation since, despite lack of sleep, significantly structured schedules, and difficulty finding providers to watch their children, they made the interview process a priority. At times, the one hour spent with this interviewer replaced their only one hour of sleep, leisure activity, or task completion.

Implications for Knowledge Generation and Practice

As health care providers, nurses are charged with providing care for the whole patient. This includes their families as well. This narrative approach allowed for a deeper understanding of the parents' lived experience while caring for a child with DRE. For nursing, this research provides information regarding parents' struggles, concerns, and areas where health care falls short of meeting needs. This provides nursing with the opportunity to improve more on the holistic approach to care for their patients with DRE as well as their parents, focusing on methods to better support them on this journey and their lived experience with DRE.

It is evident through the stories shared that parents want to be listened to, and feel their own perspectives are valued. This is an area in which nursing and other members of the health care team may improve. There is an overall sense of disorganization and lack of continuity of care with the health care system in general and particularly within the realm of insurance providers. This is also an area in need of improvement. Parents should not be expected to seek out, without guidance from health care providers, the services and support available. Yet they have each been working alone trying to uncover services in a variety of settings, facing significant barriers.

Probably most disheartening and painful to hear was the negative experiences with nursing which created mistrust of the profession. Nurses are care givers and one of the most trusted professions. It is not acceptable in any patient-nurse scenario to provide inadequate and uncaring services. The stories shared were quite eye-opening and allow for reflection on the part of nursing to decide how they are perceived and how they wish to nurture and care for those who cannot care for themselves. Having identified these shortcomings provides an opportunity for change and improvement in the care provided.

The last area for nursing to consider is the opportunity to partner with national organizations to create a comprehensive, widely identified depository of knowledge, one that is accessible to all patients and parents living with epilepsy. Caring for a child with DRE carries its own stress and challenges. This is an area nursing and the health care community would be able to champion and relieve that burden from the public.

Recommendations

Given the cohesiveness of the sample, all were provided with care within the same epilepsy practice. Additional stories should be sought, reaching parents from other epilepsy centers. What is clear is that participants have found providers in whom they have placed their trust. It would also be important to understand the experiences of other parents who have not yet found that trusted care provider. According to Engel (2016), it may take up to 20 years for patients with epilepsy to find their way to a comprehensive epilepsy center. This refers to all types of epilepsies and patients of all ages. However, it is important to consider that these participants have identified that they would not make life changes because of their desire to continue with their current health care provider. It would be important to hear the stories from those who have yet to find an epilepsy specialist, including those still receiving care from a general neurologist.

Trust, as a shared narrative, provided insight into a broader area of research to consider. All participants had already established a trusting relationship with their current home care nurses and physicians as part of the care of their child. Mishel's (1989) midrange theory on uncertainty in illness provides insight into the individual experiencing illness' unpredictability. Integral to assisting with the unpredictability is the role of a structured

provider such as a nurse or physician (Mishel, 1989). Hearing stories from other parents who do not have a structured provider would provide even more understanding of the experience parents live with the unpredictable nature of epilepsy.

Although through each story common life narratives were identified, it would be helpful to further explore the father's perspective. There were differences noted within the narratives that may have a gender component. However, with the small sample size, it is yet to be determined. Additionally, mental health issues, such as depression, psychological distress, and negative feelings of self-concept were identified by some of the fathers. Repeating the study with a larger sample of fathers may provide a deeper insight into their experiences and uncover new common narratives.

The last area of focus would be regarding the siblings of children with DRE. The parents provided some insight, at least from their perspective, of what the siblings lived experience may be; however, until the siblings share their own story in their own words, it will remain unknown.

This research provided the means for understanding the experience of parents with DRE. The importance of hearing their stories cannot be underscored enough. As providers of care for their children, the meaning of illness in the parents' lives is extremely important to understand. It is essential that there is a continued effort to broaden this perspective by including as many parents' stories and identifying additional common life narratives in order to better serve them as well as their children.

Final Reflections

This study was intended to better understand the experience of parents caring for a child with DRE. Through the analysis of the narratives provided by the participants, a deeper appreciation was realized regarding what this population faces on a daily basis. The stories shared were of an intimate nature and profound in insight, giving depth to their experiences. Through the structured interpretive process that narrative analysis provides, this researcher was able to identify common life experiences regarding the care of a child with DRE. Major events were highlighted, and the meanings were attached to actions taken. The participants shared joys and challenges and struggles and successes and reflected on their own personal journeys, some for the first time sharing intimate thoughts. Hearing the participants' stories in their own words had a profound impact on this researcher and has shaped her vision for how she would like to practice in the future. Participant 007 provided a heartfelt response as he shared the following:

Now, what's interesting is even answering this question...and I don't know you well, but I know you...I can feel...that I want to cry just answering this question. So, of all the things that have gotten me emotional...it's actually a very selfish thing of me, talking about me. That makes me upset and that is difficult as a parent. And ultimately, if you go back to your thesis, it is...the ability to deal with your emotions is ultimately...is the hardest thing. (Participant 007, interview 1, p 24)

Herein lies the power of narrative analysis. This method provided a forum for participants to share their stories which was not selfish at all, in fact it was a healthy process of self-reflection. Understanding the authentic representation of the parent's experience as

told through their own voice provides a profound and deeper understanding of their life experiences.

Appendices

Appendix A - Interview Guides

Interview Guide: Session One

Introduction: Thank you for agreeing to meet with me today. Please read this consent to participate in this study. (*pause*). Now that you have had time to review the consent, would you be willing to consent to participating in it? If you answer yes, this will serve as your consent to participate. I will be asking you some general questions to get to know you better. I appreciate your willingness to share your experience with me. I will be taking notes to remind myself of certain areas we touch upon and to review (and perhaps clarify) at a later time if needed. I do not want to miss anything that is said, so I will record this interview to ensure that I have fully understood the experiences you shared.

- Tell me a little about yourself
- Tell me about your family
- Tell me about your friends
- Walk me through your typical daily routine
- Other than being a caregiver, are there other activities you participate in

Interview Guide: Session Two

Introduction: Thank you for agreeing to meet with me today. I will be asking some questions about being a parent of a child with drug resistant epilepsy (DRE). I appreciate your willingness to share your experience. There is no right or wrong answer. It is

important that you respond with answers related to your understanding of what it is like to care for a child with epilepsy. I will be taking notes to remind myself of certain areas we touch upon and to review (and perhaps clarify) at a later time if needed. I do not want to miss anything that is said, so I will record this interview to ensure that I have fully understood the experiences you shared.

- Since we last met, have you remembered or thought about things we should discuss?
- What types of things do you do as a parent caring for your child?
- What time does your day usually start in caring for your child?
- What kind of routine or schedule do you follow?
- Is this the same every day?
- What type of events result in your schedule being changed?
- Tell me about some challenges you experience caring for your child?
- How do you manage those challenges?
- Are some challenges more difficult to manage than others?
- What do you experience when something unexpected happens in a day?

Interview Guide: Session Three

Introduction: Thank you for agreeing to meet with me today. I will be asking some questions about you. I would like to focus on your life and your experiences as a parent of a child with DRE. I appreciate your willingness to share your experience. There is no right or wrong answer. It is important that you respond with answers related to your understanding of what it is like to care for a child with epilepsy. I will be taking notes to

remind myself of certain areas we touch upon and to review (and perhaps clarify) at a later time if needed. I do not want to miss anything that is said, so I will record this interview to ensure that I have fully understood the experiences you shared.

- Since we last met, have you remembered or thought about things we should discuss?
- What is life like for a caregiver, caring for and living with a child with DRE?
- What are the unexpected joys?
- What are the unexpected challenges?
- What is stressful to you?
- Tell me about a time you felt stress?
- Describe the ways in which you dealt with the situation you just described.
- Tell me how you deal with your parenting role, in order to care for your child?
- How has your parenting role changed, if any, caring for your child?
- What provides a sense of strength and a source of support?
- Are there friends or family close by who are available to you?
- Have you found any resources helpful regarding caring for a child with epilepsy?
- If so, have they provided ways to help adapt?
- In what way, if any, has your own feeling of yourself been influenced?
- In what ways has the quality of your life been changed?

We have addressed several areas today; you have described many aspects of your life as a parent caring for a child with drug resistant epilepsy. Can you tell me about any other important aspects we did not address?

Thank you for taking the time to speak with me today. After reviewing the information discussed, I may have the need to clarify points made. Would it be all right to contact you by telephone to clarify at a later time and to speak with you after I have analyzed the information in order to review at the summary for accuracy?

Appendix B - Recruitment Flyer

The flyer is titled "Participate In Research!" in a large, brown, serif font. Below the title, there are two columns of bullet points. The left column contains two points: "The purpose of this narrative analysis is to gain a better understanding of the parents' experience caring for a child with drug-resistant epilepsy" and "There is no cost for participation". The right column contains three points: "Are you an English speaking parent who cares for a child with resistant epilepsy?", "Are you willing to share your experience?", and "If you are interested in hearing more about the study, contact:". Under the last point, there is a sub-bullet: "Kathleen Boreale, MS, APNC doctoral student at Rutgers, the State University of New Jersey at: boreale@sn.rutgers.edu. (848) 235-2780". At the bottom left, there is the Rutgers University logo, which includes the text "THE STATE UNIVERSITY OF NEW JERSEY" above the word "RUTGERS" in a large, red, serif font.

Participate In Research!

- The purpose of this narrative analysis is to gain a better understanding of the parents' experience caring for a child with drug-resistant epilepsy
- There is no cost for participation
- Are you an English speaking parent who cares for a child with resistant epilepsy?
- Are you willing to share your experience?
- If you are interested in hearing more about the study, contact:
 - Kathleen Boreale, MS, APNC doctoral student at Rutgers, the State University of New Jersey at:
boreale@sn.rutgers.edu.
(848) 235-2780

THE STATE UNIVERSITY OF NEW JERSEY
RUTGERS

Appendix C - Primary Investigator Query Script

Hello. My name is Kathleen Boreale. I am a student in the doctoral nursing program at Rutgers, the State University of New Jersey.

As indicated on the flyer you saw, I am conducting a research study with parents of children with drug resistant epilepsy. I would like to have a better understanding of your experiences caring for a child with drug resistant epilepsy.

If you are eighteen years of age or older and have a child with drug-resistant epilepsy, would you be willing to speak with me? The interviews will be approximately one hour in length and are aimed to provide insight into your experience. A total of three interviews will be conducted. The interviews are confidential. Any information collected that could be deemed personal will be associated with a code number and will not be used to identify you or your child.

We hope to use the findings of this study to better support parents and improve the quality of their lives. Would you be willing to speak with me regarding participation in this study?

If potential participant's response is yes:

What day and time are you available to be interviewed? At which location?

If potential participant's response is no:

Thank you for taking the time to speak with me. Should you change your mind, please let Dr. Ségal know and I would be happy to discuss this further with you.

Appendix D - Interview Consent Form with Audio Recording

My name is Kathleen Boreale. I am a doctoral student in the School of Nursing at Rutgers, the State University of New Jersey. I am conducting interviews for a research study for the completion of a doctoral dissertation project. The study is about the experience of being a parent of a child with drug resistant epilepsy (DRE). If you are at least 18 years old and caring for a child with DRE, you are eligible to participate in the study.

If you choose to participate in the study, you will be asked to answer some questions about your caregiver experiences and overall quality of life as a parent of a child with DRE. Some questions focus on your daily routine, feelings of being a caregiver, types of situations you perceive as stressful and how you deal with them, as well as the kinds of support you have. I will ask general questions about your age, ethnicity, employment, marital status, educational background, and the total number of years living caring for a child with epilepsy..

The interview will be audio-taped for the purpose of analyzing this data. It will be approximately one hour in length; however, you may expand on topics or talk about related ideas that may lengthen the timeframe. Answering questions is completely voluntary. If there are any questions that might make you feel uncomfortable that you would rather not answer, you may refuse to answer. We will stop the interview or move on to the next question, whichever you prefer.

Although the research records will include some personal information, it will not be associated with you; rather, it will be associated with a code number. Your responses (recordings) will be kept completely confidential with limited access to this data. I, as primary investigator, will alone have access to them, kept in a secure location in my home office.

The recording(s), which will include the interview content, will be used for analysis only by the research team. No names or any other identifier will be recorded. If you say anything that you believe at a later point may be injurious and/or damage your reputation, you may ask the interviewer to rewind the recording and record over such information OR you can ask that certain text be removed from the dataset/transcripts. Recordings of interviews and all study data will be permanently deleted after six years or upon publication of my dissertation. The recording(s) will not be used for any other reason than that/those stated in the consent form without your written permission.

In addition to me, the research team includes my academic advisor, Dr. Thomas Loveless and the Institutional Review Board at Rutgers University, which is a committee that reviews research studies in order to protect people who participate in research studies.

Dr. Thomas Loveless and I are the only parties who will be allowed to see and analyze the data, except as may be required by law by the IRB. If a report of this study is published, or the results are presented at a professional conference, only group results will be stated.

If you have any questions about the study or study procedures, you may contact me at the School of Nursing, Rutgers, The State University of New Jersey, 180 University Avenue, Ackerson Hall, Newark, New Jersey 07102 boreale@sn.rutgers.edu, 848-235-2780. You may also contact my faculty advisor Dr. Thomas Loveless, School of Nursing, Room 1122 SSB, Bergen Street, Newark, New Jersey., Newark, New Jersey or tj1116@sn.rutgers.edu, 973-972-8569.

If you have any questions about your rights as a research participant, please contact the Institutional Review Board at Rutgers, which has reviewed this study for the protection of human subjects. If you have any questions about your rights as a participant or if you feel that your rights have been violated, please contact the Internal Review Board at Institutional Review Board Rutgers University, the State University of New Jersey Liberty Plaza/ Suite 3200 335 George Street, 3rd Floor New Brunswick, NJ 08901; Phone 732-235-9806; Email: humansubjects@orsp.rutgers.edu

You will be offered a copy of this consent form to keep for your own reference. Once you have read it, with the understanding that you can withdraw at any time and for whatever reason, please let me know whether you are going to participate in today's interview.

Your verbal consent on this form grants the primary investigator permission to record you as described above during participation in the referenced study. Your verbal consent also acknowledges your agreement to participate in this research study.

Primary

Investigator

Signature

Date

Appendix E - Epilepsy Services of New Jersey Acknowledgement Letter



SHORE AREA OFFICE
35 BRAVERSON BLVD., BLDG 11
BRICK, NJ 08723

December 12, 2018

To Whom It May Concern,

The Epilepsy Services of New Jersey is supportive of Kathleen Boreale's narrative analysis study. Our staff and I are available to assist should any participants become upset. Here is a link to our website to learn more about our services: www.epilepsyservicesnj.org.

Thank you,

A handwritten signature in cursive script that reads "Andrea Racioppi".

Andrea Racioppi
Vice President, Epilepsy Services

Appendix F - Site Permission Letter

NORTHEAST REGIONAL
EPILEPSY GROUP

December 12, 2018

To Rutgers University, Office of Research Regulatory Affairs:

Kathleen Boreale, NP has permission to interview patient's families in our practice as part of her research project as part of her doctoral studies.

Nurse Practitioner Boreale will pursue an IRB approval prior to these interviews and will have the guidance of our research coordinator.

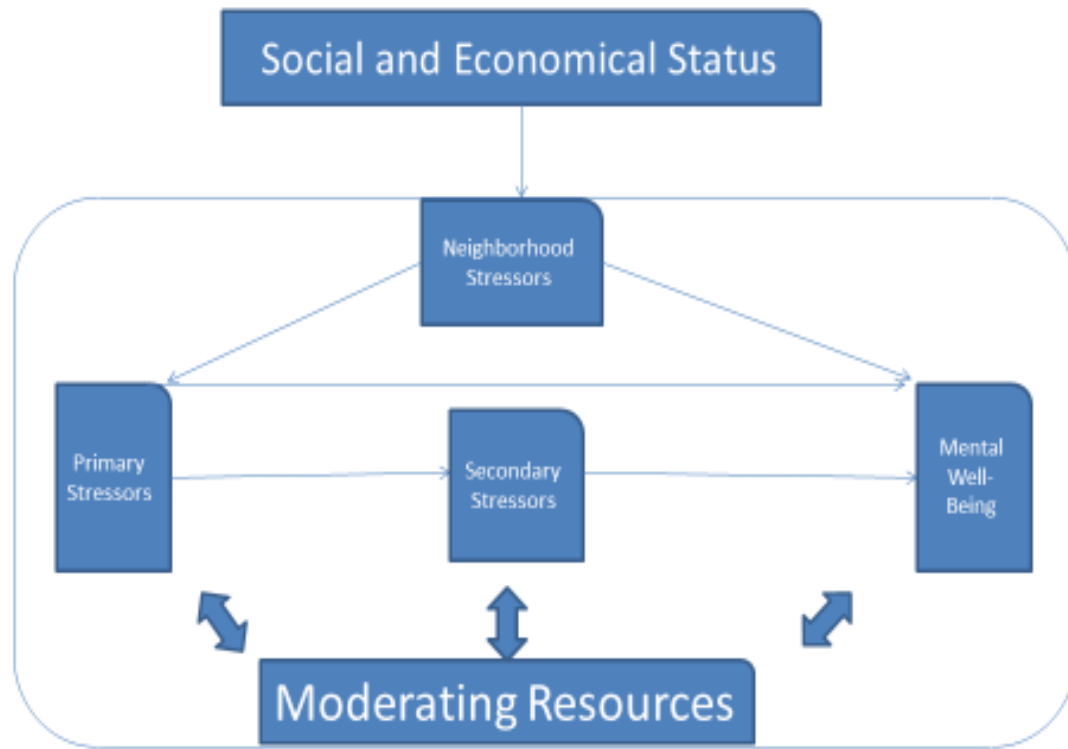
Thank you.

Sincerely,

Eric Segal, MD
Director of Pediatric Epilepsy for New Jersey
Co- Director of Pediatric Research
Northeast Regional Epilepsy Group
Hackensack, New Jersey

Figures

FIGURE 1 - Pearlin's Stress Process Model



Pearlin's Stress Process Model

FIGURE 2 - City of Hope Quality of Life Model for Caregivers

City of Hope Quality of Life Model for Caregivers

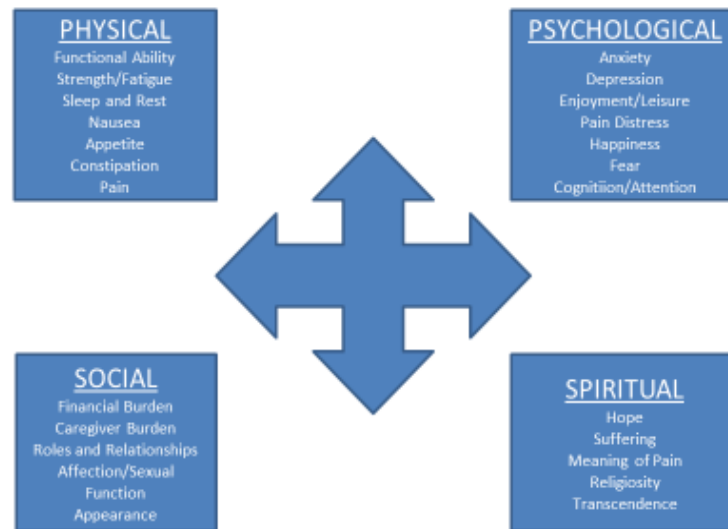
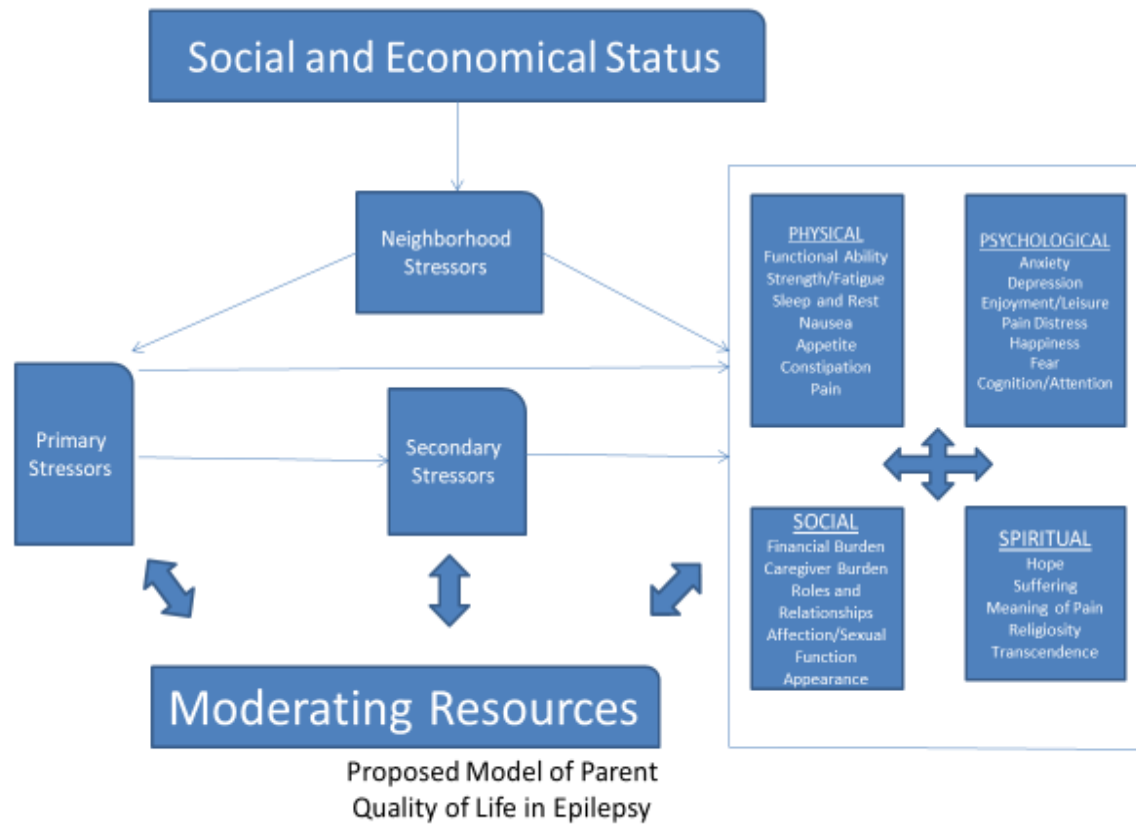


FIGURE 3 - Process Model for Parent Quality of Life in Epilepsy



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