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A Sense of Hope: Parents Treating their Epileptic Child with Cannabidiol

Jennifer Nguyen Potage
Walden University

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Walden University

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Jennifer Nguyen Potage

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Walden University
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Abstract

A Sense of Hope: Parents Treating Their Epileptic Child with Cannabidiol

by

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MA, Adams State University, 2018

MA, University of Colorado at Colorado Springs, 2014

BS, University of Colorado at Colorado Springs, 2007

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Human Services

Walden University

November 2021

Abstract

Epilepsy is the most common neurological condition in the world. Of those affected, about 30% are treatment-resistant, making it difficult for symptom relief. Children are also among those affected by epilepsy, and the unpredictable epileptic symptoms often induce stress, anxiety, confusion, depression for the parents/caretakers. Furthermore, epilepsy is a condition that can impair cognitive abilities, social interaction, and physical ailments. Antiepileptic drugs are the common medical treatment for epileptic symptoms. However, parents have often reported minimal positive change, ineffectiveness, and negative side effects that included nausea, fatigue, rash, insomnia, change in personality, cognitive impairment, and diarrhea. A review of the literature showed a gap in research regarding feelings of hope and cannabidiol treatment. The purpose of this study was to explore a sense of hopefulness as it is described by parents who are using cannabidiol to treat epileptic symptoms. Social constructivism was the conceptual framework and hope theory was applied for the theoretical framework. This study aimed to answer whether a sense of hopefulness influenced by cannabidiol treatment affected quality of life. Using a descriptive qualitative design, 11 parents were interviewed and responded to journal prompts. Data analysis resulted in six themes: frequency of seizures, experiences with antiepileptic drugs, genuine personality, independence, advocacy, and hopeful future. Results can help medical and mental health professional provide resources, support, and promote a sense of community and a better quality of life for epileptic children and their families.

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Chapter 1: Introduction to the Study

Among neurological conditions, epilepsy is the most common affecting adults and children, totaling about 3.4 million individuals in America (Zack & Kobau, 2017). Of those affected with epilepsy, about 30% are drug resistant or refractory to medical treatments (Rana & Musto, 2018). With so many experiencing epileptic symptoms, interests in cannabidiol treatment have been gaining attention (Arzimanoglou et al., 2020). Therefore, finding effective medical treatments for a child with epilepsy can be a long and discouraging experience. Also, parents have frequently reported the inefficiency of antiepileptic drugs (AEDs), and how these drugs often caused side effects, such as fatigue, nausea, vomiting, irritability, confusion, loss of appetite, sleep deprivation that negatively affected both the child and mother's quality of life (Rosenberg et al., 2015).

Epilepsy impacts well-being in many ways. Children who suffer with epileptic seizures often undergo multiple variations and trials of treatments due to the persistent symptoms that affect mental, emotional, behavioral, and physical functions and abilities (Aldenkamp et al., 2016). Children who are diagnosed with epilepsy also endure a set of limited resources, stigma, marginalization, and unique experiences in addition to the symptoms of epilepsy and treatments side effects (Rani & Thomas, 2019). Essentially, the well-being of children with epilepsy is frequently negatively impacted.

Epilepsy affects the well-being of not only the diagnosed but also the family. With the onset diagnosis, parents and other family members of children with epilepsy often experience social, emotional, mental, and physical strains that induce stress, depression, financial strain, and changes in personal roles that negatively affect how one

sees oneself, and how one also perceives that child (Duffy & Vessey, 2016). Essentially, the well-being of both the child and the parent are negatively affected (Rani & Thomas, 2019), which is why research needs to be conducted to further understand how parents experience the situation and how decisions to utilize cannabidiol treatments have influenced their own well-being and quality of life (C. Anderson et al., 2017). Because of this, the concept of hope becomes a significant contributing factor in a better quality of life both for the child with epilepsy and their parents. That is, a sense of hopefulness can influence personal motivation, goal achievement and relationships, including family dynamics (Marques et al., 2015). More simply, if the parent's experience a sense of hope, it is more likely to positively influence perception of self, child, and future.

Medical treatments such as cannabidiol for the symptoms of epilepsy became an alternative to anti-epileptic drugs (AEDs) due to negative side effects experienced by the child (Aldenkamp et al., 2016). Such side effects may include nausea, fatigue, vomiting, irritability, confusion, loss of appetite, sleep deprivation, and frequently reported as ineffective since the child continued to suffer from epileptic seizures (M. Anderson et al., 2015). With this situation suggesting hopelessness, the number of parents seeking alternative treatments began to rise, and study results have shown significant reduction in epileptic seizures with cannabidiol as the treatment (Cilio et al., 2014). Some parents who have tried cannabidiol to treat the child with epilepsy have reported limited to no psychoactive reactions in addition to minimal side effects with the use of the drug (Hadland et al., 2015). Furthermore, parents would report positive changes in their child

including the reduction in seizure frequency, better moods, attentiveness, and reduction in aggression (Thiele et al., 2018).

With reported improvements in the physical and mental improvements as result of cannabidiol as a medical treatment for epilepsy (Devinsky et al., 2015; Szaflarski & Bebin, 2014), some parents have taken the opportunity to treat their child with the drug cannabidiol, even if it is not regulated. It is this decision that can change the potential and abilities of their child, as well as the potential to remove the suffering experienced with the condition, which can influence a sense of hopefulness. Although there are laws that permit the use of this drug in different regions of the United States of America, the limited resources and the stigma attached to the utilization of the drug remains (Hadland et al., 2015; Monte et al., 2014). However, because of the potential relief cannabidiol can offer for such patients, it is important to address how the decision to treat a child with epilepsy with cannabidiol has offered a sense of hope to the child and parents of this situation; how it has influenced perspective, emotional and mental factors, and the quality of life for the child and the parents (Rosenberg et al., 2015).

With parents and children losing hope over this deteriorating condition, alternative treatments such as cannabidiol have been sought out (Rosenberg et al., 2015), and without long-term research, legislative regulations for cannabidiol treatments have been unattainable. Therefore, the purpose of this project was to provide insight into the hopefulness experienced by parents who have children with epilepsy and have chosen to seek out an alternative treatment plan that involves cannabidiol. Data from this research might provide professionals and the larger population of the sense of hopefulness

experienced by parents of an epileptic child when a treatment becomes available to those living with the condition. Essentially, those attempting to manage and cope with the situation could gain insight and choice, versus feeling hopelessness. Furthermore, this research will explore parents' experience with hopefulness through personal accounts as described by parents hoping to positively change their quality of life, thereby giving a voice and validation to those who can live the situation.

Background

Epilepsy is a chronic condition that not only brings medical risks, it also demands responsibilities that add stress and emotional distress, often paired with stigma. Study results have shown that negative labels accompany individuals with epilepsy (Herrmann et al., 2016). Children were reported to also experience negative emotions, stigma, and social barriers due to how others perceived and treated them (Eshiet & Ukpanah, 2018). The same study results showed that teachers often thought individuals with epilepsy were less intelligent and more likely to experience insanity, with some teachers being fearful of epileptic students entering their classroom (Eshiet & Ukpanah, 2018). Living with health conditions such as epilepsy often results in stigma that frequently affects social relationships, support, psychological and behavioral deficits (O'Toole et al., 2016).

Parents who have a child with epilepsy are at risk for negative psychological and behavioral responses, due to the high-pressured stigma associated with disabilities and health (Duffy & Vessey, 2016). This type of research illustrates the stigma experienced by a parent who has a child with epilepsy, and how the experience is consistent with negative connotations, which affect quality of life. Furthermore, in looking at stressors

that caregivers and parents experience when having a child with epilepsy, the chronic condition plays a large role in how the parents and caregivers perceive their family relationships and themselves, due to the stigma attached to the condition (O'Toole et al., 2016). Research in stigma indicated that having a health condition often links to deficits in availability in resources, due to resource-reducing discriminations, and social relationships, due to isolation (Aydemir et al., 2016). In addition, if the family is unable to locate what they feel are necessary resources to treat the condition, parents often feel pain and sadness for their child for having to suffer with chronic seizures (Jones & Reilly, 2016). Also, because of the chronic condition, the uncertainty of the symptoms influence how parents experience and manage stress, mood, and family functioning, which often go unresolved, due to the condition itself (Nabi et al., 2017).

Disadvantages continue as research results show how depression and anxiety are more prevalent in children who suffer with epilepsy. Because of the behavioral and psychiatric disorders, and stigma attached to those diagnosed with the condition, parents of children with epilepsy frequently report lower quality of life (Mendes et al., 2017). Finally, Jovanovic et al. (2015) also suggested that the many of the AEDs prescribed to children with epilepsy can often incur side effects that include anxiety and limited cognitive functions, which calls attention to alternative treatments, and how they can provide the benefit of a better quality of life.

Wanting a better quality of life is one of the major reasons alternative treatments have become a sought-out option for many parents who have a child with epilepsy, and cannabidiol has become a treatment option for children suffering with epilepsy (Leo et

al., 2016). Cannabidiol has become a consideration for many parents who want to treat their child with a resource outside of the traditional AEDs due to the side effects and inability to control seizures (Leo et al., 2016). However, the nature of cannabidiol, and its status as a Schedule I drug has allowed for minimal research and availability to consumers, and long-term effects are still criticized (Cilio et al., 2014). Yet, because of the harmful effects of epilepsy, many authors from previous studies have suggested further research regarding cannabidiol treatment, as it seemingly benefits the child suffering from epilepsy and their parents (Cilio et al., 2014). That is, with cannabidiol treatment, parents can regain consistency, relief, and hope for their child; their development, their potential, and their future (Rosenberg et al., 2017).

Studies have been conducted to explore the negative effects of having a child with epilepsy. Managing the symptoms of epilepsy can often be discouraging due to the nature of the condition (Nabi et al., 2017), treatment plans, and the side effects that can occur with AEDs (Aldenkamp et al., 2016). Study results also show that AEDs may contribute to impairments in health-related quality of life (Wu et al., 2014). Essentially, the quality of life for children with epilepsy and their parents have been consistently documented as poor. Among the factors that contribute to a lower quality of life include the epilepsy diagnosis, parental stress, perceived stigma, the treatment regimen, and condition management (Wu et al., 2014). In this setting, parents and their sense of hope for their child and themselves begin to deteriorate as reported by a low quality of life (Cianchetti et al., 2015; Rosenberg et al., 2017).

The literature on hope conceptualizes it as a construct that can positively influence human behavior, life satisfaction, social competence in relationships, work and academic success, and a positive outlook on the future (Marques et al., 2014). Hope is derived from several components: goals thinking, agency thinking, and pathways thinking (Chang et al., 2016). Basically, the more hope is experienced, the more likely goals will be generated and obtained through the belief that it is possible while creating more pathways to reach positive outcomes. The idea is that many parents are willing to fight and do what it takes to provide a better life for their child. Resilient, fighting parents with an epileptic child are more likely to report a higher quality of life with a sense of hope. More simply, to understand how quality of life can be influenced by hope, it is effective to address it with described experiences from the parents who chose to seek out cannabidiol treatment. This research can provide information for those in similar circumstances and help others see how the quality of life can be affected by a sense of hope that is influenced by cannabidiol treatment and living in a community that supports the treatment. A more thorough discussion of the background for this study will be found in Chapter 2.

Problem Statement

Researchers have studied epilepsy in many ways, but a review of the literature shows that there lacks research on how a sense of hope can change the perception of living with epilepsy. Epilepsy is the most common neurological condition, affecting nearly 70 million people worldwide, and often, parents have a hard time accepting the new onset diagnosis of their child (O'Toole et al., 2016). In addition, study results show

that current numbers also include an average number of 30%–40% of those affected with epilepsy to suffer from a drug resistant form of epilepsy (Laxer et al., 2016). In the United States alone, about 3.4 million individuals have been diagnosed with epilepsy (Zack & Kobau, 2017). A specific condition such as epilepsy burdens both the child affected and the parents and family members, and takes a toll on both parties mentally, emotionally, and physically, in addition to social and behavioral issues with the child (Rani & Thomas, 2019).

Records show then that cannabidiol is not always available for those wanting to use it to treat epileptic conditions. The problem is that parents begin to lose hope due to a reported poor quality of life influenced by the condition of epilepsy (Jones, 2014). According to Koo and Kang (2017), about 30% of epileptic patients continue to suffer with frequent seizures despite 20 different kinds of AEDs available. In addition, 12 AEDs were shown in a study to cause negative side effects such as rash, behavioral issues, fatigue, irritability, and nausea, with 60% of patients experiencing adverse drug reactions (M. Anderson et al., 2015). With the high rates of adverse drug reactions, parents have sought out cannabidiol to try to effectively reduce symptoms while providing a higher quality of life for their child with epilepsy (C. Anderson et al., 2017). This situation has led to an unreported number of families who seek out alternative treatments in the form of cannabidiol (C. Anderson et al., 2017; Filloux, 2015).

A number of studies were conducted to look at the stress levels among parents who have a child with epilepsy, and a consensus illustrates that most parents experience high levels of stress and anxiety because of the unpredictable nature of the condition as

well as feeling hopeless (Rosenberg et al., 2017; Wu et al., 2014). Epilepsy is not just a seizure disorder; individuals who suffer with epilepsy endure challenges and uncertainties that present themselves in education, relationships, work, and being autonomous in addition to the lack of resources that delay a healthier lifestyle (Szaflarski, 2014). As a result, many families have moved to the state of Colorado to seek out cannabidiol treatment (Detyniecki & Hirsch, 2015).

Research results now illustrate higher frequency and utilization of cannabidiol in cases of epileptic children due to the adverse effects of AEDS on the children and the unpredictable nature and uncertain epileptic symptoms, the quality of life is highly impaired. (Egunsola et al., 2018; Reichmann et al., 2019). Several factors contribute to treatment-resistant forms of epilepsy: wrong diagnosis, wrong drugs, wrong dosages, and lifestyle issues, and understanding of the AEDs (Aldenkamp et al., 2016). Because of such circumstances, there have also been reported cases of seizure aggravation (Aldenkamp et al., 2016), which not only increases physical injuries but also affects the mental and emotional stability of both the patient and family members (Devinsky et al., 2015). In addition, once treatment-resistant forms of epilepsy are diagnosed, cognitive and psychosocial developments are perceived as substantially limited, and freedom from seizures is essentially unattainable (Jones, 2014). These data demonstrate how a sense of hopelessness can be derived, making it a contributing factor for reported cases of low quality of life.

Current continual efforts to research innovated treatment plans for treatment resistant epilepsy is limited and many of the nondrug forms of treatment have shown

improvement on seizure frequency, such as surgery and ketogenic diets, but most applications of treatment are minimal when compared to the decrease in seizure frequency when treated with cannabidiol (Saade & Joshi, 2015). However, study results have also indicated that treatment plans utilizing cannabis (not in the form of cannabidiol where levels of tetrahydrocannabinol [THC] is exceedingly reduced) have shown little improvement of seizure frequency (Szaflarski & Bebin, 2014), which indicates a lack of adequate understanding of the drug's potential. Alternative routes to treat epilepsy should be recognized and further researched to provide adequate forms of treatment plans and a sense of hope both for the patient and the parents.

The problem is that there is a lack of information concerning the families who have moved to the state of Colorado to treat their epileptic child with cannabidiol, and how it affects their sense of hopefulness regarding their epileptic child and situation. Understanding this experience could provide detailed descriptions that inform professional communities and legislators who can aid or serve this population, while making the experiences of these parents valid and important.

Purpose of the Study

The purpose of this qualitative study was to explore a sense of hopefulness as described by parents who are treating their epileptic child with cannabidiol. This study was conceptualized by identifying the negative factors of epilepsy that influence the quality of life and well-being of the diagnosed child and their parents. Research questions were developed to help guide the study and gathering of data.

A qualitative research method can be used to explore a situation or group of people using unstructured interviews to understand their behavior and thought process. The purpose of this qualitative study was to explore the sense of hopefulness of several families who have moved to the state of Colorado to treat the epileptic child with cannabidiol, and how this decision to relocate affects their sense of hope. The combined research by Duffy and Vessey (2016), Jones and Reilly (2016), and Ferro and Boyle (2015) explored significant findings regarding children with epilepsy and their parents, and such studies inform the topic in the following: parental stress and quality of life reported by the parents of a child with epilepsy were explored, with reported results showing parental stress consistently higher than those without a child with epilepsy (Ferro & Boyle, 2015). Basically, according to study the results, stress is a contributing factor to low quality of life, which can lead to a sense of hopelessness.

In addition, parents also reported challenges with AEDs, which frequently produced nausea and fatigue (Jones & Reilly, 2016; Jovanovic et al., 2015). A study conducted by M. Anderson et al. (2015) further supported this argument by testing the adverse drug reaction of 13 AEDs, with 31% of the patients reporting adverse drug reactions such as somnolence, rash, and behavioral problems, which supports the idea previously mentioned that AEDs may be a contributing factor in lower quality of life in that it causes stress, which negatively influences a sense of hope.

Research Questions

This study explored the following main research questions:

1. How do parents describe a sense of hopefulness or lack thereof as it is influenced by medically treating their epileptic child with cannabidiol?
2. If there is change, how does the change in hopefulness affect their quality of life as described by the parents of these children?

Theoretical Framework

Because this project explored a vulnerable population that often reports a lower quality of life than those who do not have a child with epilepsy, I used hope theory to better understand how a reported sense of hope can influence how parents cope and manage their situation. Essentially, a sense of hope can navigate a desire to move forward, look for answers and live for more instead of opposite, which would be giving up (Rosenstreich et al., 2015). Hope theory also contributes to showing how a sense of hope encourages individuals to positively respond to challenges and obstacles they may face (Rosenstreich et al., 2015). Furthermore, I selected hope theory as a theoretical framework because it can help illustrate life satisfaction, a crucial factor in a better quality of life (Van Allen et al., 2015).

This study was based on social constructivist framework, with the premise developed by Piaget that knowledge is constructed by the experiences and mind of a learner (Bodner, 1986). Social constructivism is used to make sense of the described experiences (Amineh & Asl, 2015). With hope theory as a theoretical framework, hope as a main construct is looked at as it helps guide parental decisions. Using a social constructivist framework can help make sense of the experience with hopefulness when having a child with epilepsy (McKinley, 2015). With a social constructivist approach, the

representation of human insight (McKinley, 2015) was described by a vulnerable population that often experiences stigma yet aims for a better quality of life with a sense of hope. This study examined behaviors and concepts as patterns emerged, while promoting the value of the participants by validating the participants' experiences and illustrating the significance of their experience towards the topic (Bekenkamp et al., 2014).

Nature of the Study

This generic qualitative study utilized multiple participants who meet a specific criterion to explore and describe this specific situation. A qualitative design is intended to illustrate and inform the real-life human experiences that include human thoughts and human senses (Leung, 2015). With a qualitative design, the experience with hopefulness as described by the participants was used to provide detailed descriptions and themes within the situation (Bradshaw et al., 2017). In addition, a descriptive qualitative design provided information that helped outsiders understand the unique scenario (Bradshaw et al., 2017). That is, a descriptive qualitative design was chosen for the intention to describe the specific experience with a sense of hope and how it affects quality of life by the parents who experience it. This design allowed for the ability to acknowledge the subjective thoughts surrounding the sense of hope in general (Bradshaw et al., 2017).

The sources used for this study included responses from interviews collected from 11 participants, as it had reached the point of saturation, and personal journals written by the participants over the course of 3 weeks during the data collection process. Selection criteria for participants included having treated their epileptic child with cannabidiol for

over 3 months to explore the sense of hopefulness after treatment. The personal experiences concerning their sense of hopefulness as described by the participants and a secondary source of personal journals was incorporated into the study, in addition to audio recording of interviews that were instantly transcribed. Having the participants journal provided a sense of reality on possible emotional distress and anxiety experienced by the parents living and coping with the situation. This was completed to ensure quality and trustworthiness for the data collected during interviews (Palinkas et al., 2015). Essentially, the journaling process was integrated to provide triangulation for data analysis (Carter, Bryant-Lukosius, Dicenso, Blythe & Neville, 2014). Finally, throughout the entire process, internal biases were recognized and kept in check by using my own personal journal, to not skew data.

Criterion sampling is used to narrow the focus by only selecting participants who meet the predetermined criteria (Palinkas et al., 2015). Using a criterion sample, the participants were parents who have a child with epilepsy and have chosen to treat their child with cannabidiol for over 3 months. The sample was gathered using closed groups on Facebook via the internet that are for parents treating their epileptic child with Cannabidiol or medical marijuana. I had asked to post a bulletin that would inform members of my study, the purpose, and why I was seeking out participants each week for 3 months. After obtaining 11 participants, I conducted individual virtual interviews and asked to record the interview to transcribe the data. The data were then carefully analyzed using the Saldana's two cycle analyzing process; categories and patterns emerged, and a detailed description of the research results will be discussed in Chapters 4 and 5.

Definitions of Terms

For this study, the following terms are defined:

AEDs: Antiepileptic drugs, which are commonly used for the treatment of epilepsy and the symptoms such as seizures. AEDs are commonly prescribed for membrane stabilization, sodium channel blockers, reduced neurotransmitter release, and increased GABA-mediated inhibition (M. Anderson et al., 2015).

Behavioral: Behavioral aspects will include all actions individuals display in social and interactions as well as in isolation or in private.

Cannabidiol: Cannabidiol is a cannabinoid which has some properties of THC, including properties that can prevent seizures. Unlike THC, cannabidiol does not elicit psychoactive effects and serves for more medicinal purposes such as anti-inflammatory, neuroprotective, anxiolytic, antipsychotic, anticonvulsant, and neurological disorders. For this study, the cannabidiol usually contains a minute amount of THC (Hadland et al., 2016).

Drug-resistant epilepsy: This condition cannot be treated with AEDs, and the symptoms of epilepsy persist. Individuals with drug-resistant epilepsy are at higher risk of premature death, injury, psychosocial dysfunction, and reduced quality of life in addition to high seizure frequency (Laxer et al., 2014).

Epileptic seizure: A transient occurrence caused by abnormalities related to neuronal activity (Fisher et al., 2014).

Hope: A cognitive construct or thought process that reflects people's motivation and capacity to strive toward personally relevant goals (Huen et al., 2015).

Hopelessness: The notion that negative thoughts and attitudes regarding the future, self and possibilities are beyond a person's control and can cause depression and sorrow (Huen et al., 2015).

Hopefulness: The notion that acceptance, social interaction, and potential are positively influenced. A way of thinking that encourages forward movement or progress due to positive thoughts and expectations (Saricam, 2014).

Mental: Functions related to the mind such as cognitive ability and development.

Physiological: Functions and activities that include physical and chemical processes of an individual.

Psychological: Functions pertaining to the mind and mental phenomena and awareness such as feeling and motivation.

Seizure: A sudden surge of electrical activity in the brain that is connected to chemical and nerve changes in the brain that affects brain cell connection and balance. A seizure can temporarily disable an individual physically and mentally (Stafstrom & Carmant, 2015).

THC: Tetrahydrocannabinol, which is the major psychoactive component of marijuana (ElSohly et al., 2016).

Assumptions

This study worked on the assumption that the parents of the children with epilepsy can provide the most information regarding parental experiences, considering they are the caretakers and can report the quality of life and well-being of the child and themselves (Carlson & Miller, 2017). That is, to gain insight regarding the sense of

hopefulness experienced by parents who have/had decided to treat their child with cannabidiol, descriptions as told by parents who live the experience are optimal for accuracy. Detailed analysis could then occur regarding the issue. The assumption was that the parents involved as participants would provide honest and accurate descriptions from their own point of view (Palinkas et al., 2015). Essentially, the narratives can be used to provide an account of actual events, reactions and challenges, and personal representations of their sense of hopefulness.

As the researcher, I chose to use a descriptive qualitative design, for it was the most suitable to gather detailed data to inform this topic. This design allowed for the exploration of a sense of hope as was described by the parents (Bradshaw et al., 2017). Using interviews and journal assignments that were dedicated to exploring their sense of hope and quality of life, it was assumed that the participants were providing honest and personal response. That is, as the researcher, I assumed that personal described experiences regarding this issue would be optimum compared to other research designs. However, this assumption was reasonable, for it allowed me as the researcher to explore the case through the eyes of those involved (Palinkas et al., 2015). Rather than obtaining statistical data that illustrated opinions and beliefs, data gathered were used to describe and inform hopefulness through intimate descriptions that cannot be categorized by a simple scale of likes and dislikes.

Scope

The research problem for this study was developed by reviewing current literature to determine what research gaps existed. In exploring recent literature, a common

reference was that parents faced challenges with treating epileptic symptoms in general, as well as coping with the epileptic symptoms and the demands and burdens parents take on due to their child's condition (Carlson & Miller, 2017). After so many cases of parents not seeing the alleviation of epileptic seizures, parents then looked for alternative treatments (C. Anderson et al., 2017). Research results then showed that parents often turned to cannabidiol to medically treat their child with epilepsy (Press et al., 2015). Recent literature includes the argument that a sense of hope can change a sense of well-being and quality of life, it is important to understand how cannabidiol treatment influences a sense of hope. That is, by exploring how parents describe their sense of hope as it is influenced by cannabidiol treatment of the epilepsy symptoms, a sense of hopefulness can be provided, which can give insight to quality of life and well-being for parents with an epileptic child.

Limitations

Limitations are factors in the research that sets restrictions. Because the criteria for the sample were devised by the researcher, this may limit the population, thereby limiting representation of the population (Palinkas et al., 2015). Also, because the participants were found using an internet venue, it is likely to exclude part of this population that is less likely to use the internet to inform the situation or to find support for their situation. However, using a snowball effect, it is possible to gain participants not using the internet (Palinkas et al., 2015). Also, this study was not able to include undisclosed descriptions or factors that may have had an influence on the experience with hopefulness. However, despite the limitations, the purpose of the study was to inform

others on the sense of hopefulness experienced by parents of epileptic children who aim to provide a better quality of life for themselves and their child. This can also provide support and information to other parents who sacrifice to support and help their child.

Some biases may come from the participants themselves. The purpose of the study was to promote the voices and opinions of the parents who make sacrifices to provide a better quality of life for their family and child, and the intention was to provide descriptive accounts on what the situation looks like as well as how it has changed lives. However, because the participants are individuals who have already decided to seek out alternative medicines or treatments, it could be due to their personal beliefs on modern medicine or AEDs. Also, responses may have been influenced by the vulnerable state of the situation itself, but this was addressed by fully informing each participant of the nature of the study, the purpose of the study, and the desire to promote the value of their voice, rather than making the situation any worse (Noble & Smith, 2015).

Another source of bias would have come from me as the researcher. My aim was to empower the voices of those afflicted by the circumstances, which is already an assumption that the situation was a negative one (Roulston & Shelton, 2015). Also, because the participants are parents who are treating their child with cannabidiol for the conditions, my bias was to think that the choice was a positive in nature, in that the parents are doing what they feel is best for her child. The discussed personal biases will be addressed professionally and scholarly, to inform the qualitative study as accurately as possible without the influence of the biases (Roulston & Shelton, 2015). That is, I have only provided what was discussed and journaled by the participants and I did not use

questions during the interview process to lead or sway the participant in anyway (Roulston & Shelton, 2015). Essentially, I aimed to promote a process that allowed the participant to discuss what they feel to be accurate.

Significance

Individuals with epilepsy often must go through a process that negatively impacts both their own and their families' lives (Ferro & Boyle, 2015). Because epilepsy is an unpredictable condition that affects the diagnosed individual mentally, physically, and emotionally, it is more likely that people report a low quality of life (Rosenberg et al., 2017). The current issues around this condition include negative side effects from AEDs such as fatigue, vomiting, and a lack of decrease in seizure frequency (Jovanovic et al., 2015), as well as limited availability to cannabidiol for those seeking the alternative medical treatment (Detyniecki & Hirsch, 2015). Also, there is a lack of regulations regarding cannabidiol for its use in the medical treatment of epilepsy (Cilio et al., 2014). Those affected by epilepsy should have their experiences heard and understood to better address the needs of the situation.

As previously mentioned, having a child with epilepsy also impacts the parents (Ferro & Boyle, 2015). Because epilepsy is a condition that affects more than just the diagnosed individual, it is important to explore the situation with a fuller picture. This project aimed to gain insight into a sense of hopefulness as experienced and described by the parents treating their epileptic child with cannabidiol. This information can illustrate how a sense of hope can positively affect quality of life. Furthermore, by allocating the voice to the parents, further understanding of what these families face is brought to light.

Previous research results have demonstrated a need for new data that informs the efficacy of cannabidiol, the potential it has on the quality of life for those with the condition, possible legislative changes that accommodate the need and availability for those wishing to be treated with it, and a better understanding of how cannabidiol can help. To address these concerns, listening to parents' descriptions provided data that informed a better quality of life. This research project explored the situation as it is related to those who play an influential role in the lives of the children who suffer from epileptic seizures. Looking at their descriptions of the experience concerning the issue should shed light on political, economic legislative, social and cultural arrangements that affect the perpetuation of marginalization and personal afflictions.

With these factors in mind, research gathered through this project have provided information that described the sense of hopefulness parents experience when trying to treat their child with epilepsy. Looking at the sense of hopefulness illustrated how quality of life is affected by epilepsy and the management of it. In addition, this information should encourage positive social change by shedding light on the experiences with anxiety and stress of having a child with epilepsy, which can be influenced by the sense of hopefulness experienced by this vulnerable population as described by their own interpretations. This research should also inform professionals who work with this situation about the reality of emotional distress experienced by parents who have a child with epilepsy, and how access to cannabidiol treatments affects their quality of life. In addition, this research project should describe the potential positive impact of cannabidiol on the treatment of epilepsy by providing descriptions of the changes in the parents'

sense of hopefulness. The data collected also provided a voice for those experiencing this situation and empowered them by encouraging them to tell their stories and provided insight to others.

Summary

With a significant number of children diagnosed with epilepsy, many parents are experiencing stress, anxiety and a sense of hopelessness that comes with the unpredictable nature of the condition. Essentially, parents were consistently reporting negative consequences and experiences as a result of the epileptic symptoms. The purpose of this chapter was to introduce the study, explore the background, problem statement, and purpose of the study. After discussing the research questions that were derived to explore a sense of hopefulness and quality of life, the research design and significance was discussed. This project aimed to promote the human voice, experience, and dignity by having parents describe their actual experience with a sense of hopelessness and hopefulness and how the quality of life was affected by using Cannabidiol to treat their child's epileptic symptoms.

Chapter two will provide a synthesis of literature review and how there was a gap in the literature. Before the Literature Review, Research Strategies and the Theoretical Framework will be discussed. In the Literature Review, the topic of epilepsy, antiepileptic drugs, children with epilepsy, treating epilepsy and the alternative Cannabidiol treatment will be explored to demonstrate the problem statement and purpose of the study. In addition, because this project aims to explore a sense of hopefulness, literature on a sense of hope and hope theory will also be explored.

Chapter 2: Literature Review

As previously mentioned, families who have a child with epilepsy face many challenges including changes to the family dynamics, stress, and depression due to the symptoms of epilepsy (Fayed et al., 2015). Parents have reported experiencing a sense of hopelessness due to the ineffectiveness of AEDs, little support, and an unpredictable lifestyle also due to the symptoms of epilepsy (McMillon et al., 2014). Because of these challenges, low quality of life has frequently been reported for children with epilepsy and their parents (Fayed et al., 2015). The problem is that parents often report high levels of stress and the inability to provide a better life for their child and themselves. Given the aforementioned background on the condition of epilepsy and how it affects the parents of the child with epilepsy, parents have often reported a sense of hopelessness that seems to directly relate to quality of life (Wu et al., 2014). According to past research, hope plays a role in quality of life, in that it can provide a positive outlook on situations and encourage resiliency (Huen et al., 2015). It is important that further discussion provide insight into the quality of life and experiences through the eyes of the parents, to recognize what influences their sense of hopefulness. The purpose of this qualitative study was to explore and describe the sense of hopefulness and hopelessness experienced by parents who have a child with epilepsy and have moved to a different state to in hopes of a better life for their child and themselves.

The following comprehensive literature review will explore past studies and how the study results demonstrate the importance of recognizing and understanding how a sense of hope can improve the quality of life for parents who have a child with epilepsy.

In short, the literature review presented in this chapter will support the need for positive alternatives in the case of having a child with epilepsy. The literature review will explore the challenges of having a child with epilepsy by presenting research that describes epilepsy and the symptoms of the diagnosed condition and the efficiency of AEDs for the symptoms of epilepsy. Also, included in this literature review are the reported experiences of parents who have a child with epilepsy, their levels of stress and strain, and personal challenges. In addition, the concepts of hope, hopefulness, and hopelessness are explored to aid in determining how hope alters perspective and potential. Finally, literature identifying and describing cannabidiol and why it has been utilized to treat epileptic conditions. Essentially, the review of literature in this chapter informs and addresses the current situation of parents attempting to positively affect their quality of life for their child with epilepsy and themselves.

The first part of this chapter will provide the literature research strategy, including the databases and search engines employed, followed by an overview of hope; how it is conceptualized, defined, achieved, and experienced. The subsequent section includes the theoretical foundation and the conceptual framework applied to the study. Chapter 2 closes with a discussion of key variables, concepts and current literature research results that influence the case of having a child with epilepsy.

Literature Search Strategy

Research literature provided in this section was chosen to inform what has been explored in past research, and what needs to be done in future research. In addition, reviewed literature also included contextual information that provided insight on parental

experiences with epilepsy. Only peer-reviewed scholarly journals and books were reviewed to inform the topic of parents with an epileptic child. Research literature was gathered via the internet, scholarly books, and articles using databases provided by Walden University and Google Scholar. Using EBSCO host, ERIC, PsycARTICLE, Academic Search Premier, PsycINFO, and SocINDEX, full text, I searched for and reviewed scholarly peer-reviewed articles starting in the year of 2014, and only incorporated literature from the year 2014 to 2019, to provide only relevant information. Key words and phrases used to navigate the research literature review include *epilepsy*, *treatment resistant epilepsy*, *cannabidiol*, *anti-epileptic drugs*, *parents of children with epilepsy*, *seizures*, *quality of life*, *well-being*, *medical marijuana*, *stress*, *strain*, *depression*, *stigma*, *childhood epilepsy*, *hope theory*, and *hopeless and hopefulness*. These key words were input into databases singularly or grouped.

The goal of this literature review was an analysis and synthesis of past and current literature that influence the case under investigation; a sense of hope possibly influenced by the availability of cannabidiol experienced by parents who have a child with epilepsy. The review of literature also provides definitions of terms related to the cases, suggestions for future research, and the benefits of conducting further research on the topic. By incorporating a copious amount of information, I analyzed a variety of factors to discern categories that may or may not affect the topic. Essentially, by reviewing literature, I recognized influential factors, determined connections and associations, developed a research problem, and exposed a research gap. Basically, a review of literature presented the case as it was conceptualized with a multitude of aspects that

affect the research problem, gap, and questions. During the process of the review of literature, categories were developed, and further literature was reviewed per subcategory and analysis was applied to determine significance of inclusion of each subcategory.

What is Hope?

In order to understand how parents conceptualize their personal situation of having a child with epilepsy, hope as a concept was part of the literature review to provide a definition and description of how it influenced choice, determination, desire for change, and personal experience. Epilepsy affects physiological, mental, emotional, social, learning, and behavioral development (Jones, 2014). Epilepsy is also the most common neurological childhood condition that affects about five children per 1,000 (O'Toole et al., 2016). In additions, about 30%–40% of epileptic patients experience drug-resistant epilepsy, where AEDs fail to suppress symptoms and increased risk of death, injury, and psychosocial dysfunction become more present, negatively affecting individual quality of life (Laxer et al., 2014). Because of this, parents often report a sense a hopelessness, or losing hope in providing a better quality of life for their child and family (Wu et al., 2014). The recognition and understanding of hope were used to provide a framework and insight on a sense of hopefulness as experienced and described by the parents who relocated to seek cannabidiol treatment for their epileptic child.

Due to the unpredictable circumstances of epilepsy, children diagnosed with the condition and their parents often report emotional and mental instability that can lead to a sense of loss, confusion, and hopelessness (Mendes et al., 2017). Hope is a motivational state influenced by positive agency and cognitive thinking (Smedema et al., 2014). To

achieve or experience hope, goal-directed energy and cognitive motivation must be recognized and reinforced by identifying effective strategies that positively affects the thinking process (Smedema et al., 2014).

Because of this, Smedema et al. (2014) argued that higher levels of hope are associated to lower levels of depression. The parents of epileptic children often experience lower levels of hope due to the circumstances and challenges of the epileptic symptoms, the development of their child, and the child's quality of life as well as their own (Pompili et al., 2014). Furthermore, because the condition is unpredictable in nature, parents are faced with challenges that require urgent responses, which impair adjustment periods while unknowingly reinforcing the negative consequences (Berg et al., 2019). These unpredictable and urgent situations require necessary responses, which induces stress, depression, and anxiety (Thompson et al., 2014).

Emotionally speaking, hope can provide a sense of relief, for it allows individuals to expect or foresee and believe the potential of positive change for the future (Chang et al., 2016). In addition, hope can provide individuals a sense of personal power or control of their abilities, achievement of goals (Chang et al., 2016). Hope can also promote validation of self, internal and external support, and insight (Huen et al., 2015). Essentially, individuals can feel hopeful when they feel supported by others and secure in their position and role in life (Marques et al., 2014). Also, individuals are more likely to be resilient when faced with difficult situations and challenges (Hullmann et al., 2014). Furthermore, hope relates to a sense of satisfaction; satisfaction in oneself, one's situation, and one's ability to do, make change, or create (Coduti & Schoen, 2014).

Because of this, a sense of hopefulness of parents who have a child with drug-resistant epilepsy diminishes, for they feel that they are unable to care for their child sufficiently and properly since the chronic condition seems untreatable (Ferro et al., 2014).

Being hopeful then, as previously mentioned, is derived from positive focus and goal attainment, optimism, and positive expectancies (Smedema et al., 2014).

Hopefulness is constructed through individual circumstantial influences or contexts, so the chance of a positive future is also influenced by an individual experience and perception (Wei et al., 2016). Hopelessness on the other hand incorporates alienation, self-blame, powerlessness, and a sense of distrust (Huen et al., 2015). In addition, Coduti and Schoen (2014) suggested that individuals suffering with depression or anxiety due to chronic health issues tend to maintain negative outlooks on their situation, thereby supporting a sense of hopelessness rather than hopefulness. The circumstances derived from having a child with epilepsy seem more like to dictate a lower potential of regaining a sense of hopefulness and a higher risk of hopelessness. Therefore, the understanding of how the sense of hope is experienced is important to gain insight on the experiences of parents who have a child with epilepsy. Essentially, the experiences of the parents who have a child with epilepsy may be influenced by the chance of hopefulness; a hope for higher quality of life, ability to provide and protect their child, and hope for their child's well-being.

Theoretical Foundation

With a social constructivist approach, the constructed knowledge concerning a sense of hopefulness can be documented, which can present accurate and adequate

information regarding the issue (Amineh & Asl, 2015), In order to illustrate accurate descriptions, only the sense of hopefulness as described by parents who have a child with epilepsy and have chosen to use cannabidiol to medically treat the symptoms of epilepsy was explored. With this theoretical framework, actual participants of the studied group were the source of knowledge, making their descriptions and experience with hope valuable and validated (Austin & Sutton, 2015).

Constructivism evaluates a topic through the experiences and realities individuals describe. The self-told narratives provide insight on the sense of hope, and these narratives have been applied and endorsed by many academic and professional fields such as education, psychology, sociology, and counseling (Sheperis et al., 2016). Not only do the descriptions supply individual perception and experiences, they also provide contextual influences on how meanings were then attached to the perspectives (Bradshaw et al., 2017). Because of this, utilizing a theoretical framework that employs the human voice as the foundation for information seemed most suitable for understanding a human issue. In short, by using descriptions provided by participants who are the parents of a child with epilepsy and can report on their own sense of hope and quality of life, more accurate insight and understanding can be obtained. The parents can describe how a sense of hope has been influenced, constructed, and internalized (Sheperis et al., 2016).

Rather than quantifying behaviors, through the lens of constructivism, different views constructed by individuals and the meanings attached to them are recognized (Amineh & Asl, 2015). In addition, with constructivism as a framework, individuals are assumed to have the ability to construct knowledge and thought in their own minds

(Olusegun, 2015). This idea is crucial for this project because it proposes that parents who have a child with epilepsy the active agents in the study (Olusegun, 2015). In short, constructivism says that people make sense of their experiences and knowledge of the world and can reflect on such experiences (Olusegun, 2015). Through the lens of constructivism, individuals can make sense of past and present knowledge and create new knowledge (Olusegun, 2015).

With this constructivism as a framework, the theory of hope can be properly applied, in that it allows for the new experience and knowledge of the world that can influence a sense of hope. With the parents as the active agents, I then described a sense of hope and explored how it was constructed (Shrader, 2015). In summation, a sense of hope was further explored and described as it is constructed by parents experiencing and constructing their own knowledge about their future, potential, and ability to attain goals. I then used this information to see if parents feel that a sense of hope affects their quality of life.

With a descriptive design, the sense of hopefulness is processed through a lens that allows analysis through descriptions, statements, and quotes in relation to the conditions and context of the situation (Bradshaw et al., 2017). This process provided further understanding of having a child with epilepsy, while also illustrating the common occurrences with a sense of hope. Furthermore, rather than predicting results and presenting a hypothesis as utilized in quantitative studies, through constructivism, the focus was uncovering how people describe their sense of hopefulness and hopelessness. Essentially, with this conceptual framework, understanding and insight was achieved by

focusing on a situation within its real-life context and boundaries (Yin, 2018). That is, the attention was on personal, individual perspectives, which validates individual experiences while placing worth on the description (Bradshaw et al., 2017).

As previously mentioned, the constructed sense of hope as described by parents of an epileptic child can be explored through social constructivism because it sheds light on their culture and population (Sutton & Austin, 2015). The reasoning behind this is the thought that a problem experienced by humans should be looked through the lens of individuals who have experienced it. Because this study adhered to a process that encouraged parents who have a child with epilepsy to speak on their own behalf, the humanness of the issue was supported and the possibility to platform the issue as worthy for further research was also promoted (Bradshaw et al., 2017). In addition, experiences were acknowledged as they are described by the parents of an epileptic child, not as it is assumed or observed by others.

Thus far, the concept of hope has been presented in a way that describes how a sense of hopelessness or hopefulness can affect how parents perceive the potential quality of life for themselves and their child (Mendes et al., 2017). Because the research was intended to explore the sense of hope as described by parents who have a child with epilepsy, the condition and symptoms of epilepsy prompts further discussion.

Epilepsy

Epilepsy is the result of disturbances in the network of neurons, which then generate the chronic state of epilepsy, or dysfunctions within the neurotransmitters and intracellular processes, and reoccurring epileptic seizures are the result of abnormal

neuronal synchronization that can influence the entire brain (Fisher et al., 2014). Due to the disturbances in the brain and the reoccurring and high frequency of epileptic seizures, this condition can also reduce cognitive development, which also affects other factors, such as learning and psychosocial development (Fisher et al, 2014). Essentially, epilepsy can harm the brain and is linked to behavioral and psychiatric conditions, which impairs quality of life (Cilio et al., 2014).

Epilepsy is a complex disorder that affects about 3 million people in the United States (Pompili et al., 2014) with it most commonly affecting children and the elderly (Rosenberg et al., 2015). Due to the unpredictable symptoms and treatment of the diagnosed condition, individuals who suffer with epilepsy often experience a major decrease in their quality of life (Rosenberg et al., 2017; Pompili et al., 2014). In addition, parents of epileptic children also report mental, physical, emotional, psychological, social, and behavioral issues (Jones, 2014). Regarding quality of life, both parents of epileptic children and epileptic patients have reported depression, anxiety and isolation (Jones, 2014; Ramsey et al., 2016). Recent studies have also incorporated the use of medical marijuana, due to current AEDs failing to treat or reduce the symptoms of epilepsy (Cilio et al., 2014).

Epilepsy is the most common neurological disorder during childhood, and the onset diagnosis normally goes without remission and can follow into adulthood (Reilly et al., 2014). As previously mentioned, epilepsy is a condition that can alter physical, mental, emotional, and behavioral delays (Mula & Sander, 2016). Symptoms of epilepsy include frequent seizures, neurodevelopmental delays, and impaired quality of life. In

addition, epilepsy also increases the risk of psychological and psychiatric conditions, especially with psychosocial development (Jones, 2014). Furthermore, several studies have shown similar results in that epilepsy symptoms affect both the quality of life of the child and the family involved, while also affecting family functioning (Berg et al., 2019; Jones, 2014).

Although many studies have looked at how epilepsy has affected young children and their family, a study result also indicates that even in older children, epilepsy affects lifestyle where research results illustrated those individuals report to have experienced with stigma due to the chronic condition of epilepsy (Jones, 2014). More specifically, Jones (2014) reported that epilepsy can cause psychiatric disorders, negatively impact social development skills, academic achievement, attention deficit hyper disorder, anxiety, and overall quality of life, which is often a long-term issue.

An overall review of literature showed that epilepsy research has been conducted in the fields of medicine, psychology, counseling sociology, and behavior. Studies in the mentioned fields were explored to obtain an expansive idea of how epilepsy affects diagnosed individuals as well as the loved ones or parents of a diagnosed individual. The research design for these studies incorporated quantitative, qualitative, and mixed methods designs that look at individual perception and experience, quantifiable results that illustrate limitations in AEDs, the lifestyle and family dynamics of families who have a child with epilepsy. In addition, studies were conducted to look at cannabidiol use with epileptic seizures and a change in seizure frequency for those using cannabidiol to treat epileptic seizures. Although the studies use methods that provide important information

regarding the topic and how it affects the human population, self-reflection, perception, and the efficiency of current medical treatments, little is known about the population that has chosen to treat their epileptic child with cannabidiol, and less is known about how that choice affected their sense of hope and quality of life.

Children With Epilepsy

The condition of epilepsy affects a child in a multifaceted manner. Not only does epilepsy impair physical and mental development, but it also affects social, learning, and emotional factors as well (Cianchetti et al., 2015). In addition, having a child with epilepsy places restrictions on personal and family activities and limitations on resources and a decrease in quality of life (Jones, 2014). Furthermore, because of the occurrence of seizures, parents often must choose treatment plans that affect family functioning, costs, and study results indicate lack of coping skills with parents who have a child with epilepsy or other special needs (Wu et al., 2014). Essentially, the challenges faced with having a child with epilepsy, how it affects the child, and the relationship of the parent and epileptic child have been explored, but there was a need for research that can inform how quality of life can be changed.

As previously mentioned, epilepsy has a direct effect on children's behavior and cognition (Rosenberg et al., 2015). Not only does epilepsy affect the family and the child directly, but it also influences psychological, mental, emotional, and learning development for the diagnosed child (Laxer et al., 2014; O'Toole et al., 2016). Jones (2014) conducted a study with results showing that even though epilepsy affects the entire family throughout the entire course of the condition, the diagnosis or onset of the

disease influences higher rates of anxiety, frustration, and depression. In addition, the initial diagnosis of treatment resistant epilepsy among children is frequented with drug resistant seizures, surgery, steroids, and ketogenic diets that have proven to show low positive effects and little to no change in seizure frequency (Pickrell & Robertson, 2017).

Furthermore, increased risk to physical injuries, accidents, suicide, and unexpected deaths are also reported with the diagnosis of epilepsy (Cilio et al., 2014). Essentially, epilepsy is frequently a comorbid condition that affects the individual physiologically as well as social and psychologically (Jones, 2014).

Children suffering with epilepsy also experience stigma, behavioral and mental health problems, which influences higher rates of anxiety and depression compared to children without a chronic condition (Hermann et al., 2016; Mendes et al., 2017). For example, Jones (2014) conducted a study with epileptic children where results indicated a significantly low score of quality of life. Regarding emotional and physical health, friends and school, results showed low academic achievement and peer approval as significantly less than children without epilepsy (Fayed et al., 2015). Because of the condition, epilepsy is rarely seen as an isolated condition, due to its influences on academic achievement, socialization, and personal development (Szemere & Jokeit, 2015). Essentially, epilepsy is frequently seen with other development and cognitive issues that the child and the family must manage.

Basically, children who are diagnosed with epilepsy endure negative experiences due to stigma and condition of epilepsy that influences peer acceptance, depression and anxiety, and an overall reported lower quality of life than kids without epilepsy (Steiger

& Jokeit, 2017). In addition, because the condition of epilepsy tends to isolate both the diagnosed and the parents of the epileptic child, social interactions, family relationships are at risk (Steiger & Jokeit, 2017). Parents influence the child's quality of life due to the stress and strain that they too experience with the unpredictable nature of the condition and the limited resources available (Jones & Reilly, 2016). Because family relationships are at risk, parents of epileptic children should be explored. The next section will discuss parents of children with epilepsy.

Parents of Children with Epilepsy

Epilepsy is a condition that not only affects the child, but it also affects the family. Family dynamics and functioning are reportedly described as negatively impacted (Thompson et al., 2014), in addition to the parents emotional, mental, and physical distress (Wu et al., 2014). Additionally, parents of an epileptic child tend to perceive themselves and the child in more negative ways than parents without a child with epilepsy (Bompori et al., 2014).

The diagnosis of epilepsy is usually followed by experiences of social stigma and changes in family support and cohesion, which is an issue felt by everyone in the immediate family (Mendes et al., 2017). Parents of children with epilepsy face uncertainty, due to their child's condition (Mendes et al., 2017). Having a child with epilepsy requires specific healthcare management with many of these children having behavioral or emotional difficulties (Reilly et al., 2014). Several factors that impact the family with a new epilepsy diagnosis include worrying about the child, family

relationships, communication, community support, finances and feeling like they need additional information (Cianchetti, 2015).

In addition to developmental and cognitive delays, the new on set condition causes uncertainty for the child with epilepsy and parents (Cianchetti, 2015).

Furthermore, because of the unpredictable nature of the seizures, parents often report the inability to manage or cope with the conditions of epilepsy, which lead to negative moods, and high levels of stress (Sirari et al., 2014). In fact, one study results show that parents of an epileptic child consistently report a sense of stigma, with many attempting to conceal their child's epileptic conditions (Aydemir et al., 2016; Nabi et al., 2017).

Essentially, parents have reported high forms of anxiety and depression, which can then negatively impact the interaction between parent and child, and parent to parent (Jones & Reilly, 2016).

As previously mentioned, the condition of epilepsy also affects family dynamics, and it affects how parents feel about themselves, their child, and their parenting abilities (Sirari et al., 2014). More clearly, distress experienced by parents of an epileptic child is often due to the unpredictable nature of the symptoms, which is reported to be stressful and accompanied with anxiety (Jones & Reilly, 2016, Sirari et al., 2014). Many parents of an epileptic child aim to help their child manage their condition but are often faced with discouraging results (Jones & Reilly, 2016). That is, the child with epilepsy experiences disrupted cognitive and behavioral developments and a significant amount of medical treatment and unpredictable seizures, while the parents experience sleep deprivation and fatigue (Porter & Jacobson, 2014). Essentially, parents report feeling

hopeless, confused and incompetent in their ability to provide and support their child in an adequate manner (Caplan, 2015).

There are many disadvantages accompanied with epilepsy, and for parents, depression and anxiety are frequently a result of having a child with epilepsy due to seizure frequency and family disruption (Jones & Reilly, 2016). These emotional responses are related to the uncertainty and unpredictable wave of events that occur with having a child who suffers from this condition (Jones & Reilly, 2016). Basically, research results show that stress levels are heightened due to having a child with epilepsy, and how that then plays a role on family functioning and dynamics. In addition to the negative impact emotionally and functionally, epilepsy can also influence behavioral and psychosocial developments for the diagnosed child (Ramsey et al., 2016).

One study illustrated that when parents reported lower quality of life, the epileptic child's emotional state was also affected (Fayed et al., 2015). Another study showed that parental depression, fear, and stress directly affected social and behavioral development with the child, in addition to negatively affecting quality of life for both the child and the parent after the on-set diagnosis of epilepsy (Wu et al., 2014). Essentially, parents feel they are not able to care for their child effectively because daily activities seem like crisis situations, due to the inability to cope with the symptoms of epilepsy and the management of the family (Wu et al., 2014).

Looking further, mothers are usually the primary caregiver, and they often experience more stress and are at greater risk for clinical depression as a response to the new diagnosis, and is usually paired with anxiety (Caplan, 2015). Regarding mothers

who have a child with epilepsy, about 50% of those mothers are at risk for depression that is often paired with anxiety disorders (Jones & Reilly, 2016). The diagnosis of their child alone can affect the relationship between mother and child, mother and family and family functioning, which affects well-being and quality of life (Wu et al., 2015). For example, stress and anxiety are frequently reported to increase because mothers report becoming over-protective and over emotional with their child having epilepsy, which affect their mental health, social relationships, and consistent feelings of frustration, anger, guilt and hopelessness (Carlson & Miller, 2017). Furthermore, because this condition impacts family organization, mothers are often not confident in their role as a parent; they become disorganized, which in turn affects the condition or other behavioral or social issues concerning the child (Carlson & Miller, 2017).

Although mothers reportedly take on more stress of having a child with epilepsy, in general, the parents of an epileptic child often report feeling unsupported and isolated (Steiger & Jokeit, 2017). In addition to parents describing a need for emotional and social support, study results indicate a challenge with obtaining information regarding this issue personally (Wu et al., 2014). For instance, parents reported having difficulty navigating the healthcare system as well as understanding the psychological impact it can have on their child and family (Mula & Sander, 2016). Because of this, the child's condition and family dynamic are frequently negatively impacted, which is why early intervention strategies are important.

In summation, the chronic condition of epilepsy usually impacts the entire family. Families who have a child with epilepsy experience significantly more stress than families

who do not have a child with epilepsy (Cianchetti et al., 2015). In addition to stress and anxiety, parents report restrictions in family life, which affect communication and relationships that often influence marital satisfaction (Steiger & Jokeit, 2017). With the onset diagnosis of epilepsy, parents perceive a shortened life span and low quality of life for their child, and the demanding routine with medical checkups and limited resources affect family parent's responsibilities and functioning (Nabi et al., 2017). From this, wellness plans can be further developed and implemented, thereby addressing what parents are going through when having a child with epilepsy, and how they gain a sense of hope. In addition, the capacity for being a good parent and the ability to help their child obtain a higher quality life can be illuminated.

Treating Epilepsy

According to research, epilepsy is treated in many ways including ketogenic diets, steroids, surgeries, and AEDs (Wheless et al., 2019). However, due to the uncontrollable frequency of seizures resulted from the condition of epilepsy, the treatment of epilepsy tends to focus on seizure control (Laxer et al., 2014). As previously mentioned, this study will be used to look at a sense of hope as described by parents of children with epilepsy who have/are treating their child with cannabidiol after trying AEDs or others forms of treatment for seizure control. Because of this, AEDs will be further explored in this section to illuminate how it was experienced by those with epilepsy, and how it may have led to the utilization of cannabidiol for the treatment of epilepsy.

AEDs are intended for the use of epileptic seizure control, with the purpose of eliminating or alleviating the frequency of epileptic seizures (Rosati et al., 2015). AEDs

can do this by applying a specific dosage for those suffering with epileptic seizures with achieved success for about 70% of the population of people with epilepsy (Laxer et al., 2014). However, about 30% of those with epilepsy suffer with drug-resistant epilepsy where AEDs are essentially ineffective (Laxer et al., 2014). In addition, for those taking AEDs, adverse drug reactions are frequently reported (O'Connell, Gloss & Devinsky, 2016). Some include aplastic anemia, liver toxicity, hallucinations, depression, diarrhea, and vomiting (Rosati et al., 2015). Other reactions including drowsiness, fatigue, dizziness blurry vision and incoordination (M. Anderson et al., 2015). Because of this, new AEDs have been and are being developed to inhibit such negative side effects, but there is still a risk of adverse drug reactions (Rosati et al., 2015). With treatment fails that include AEDs, parents started exploring different options to treat their child with epilepsy, which is how cannabidiol has become a popular treatment for epileptic seizures (Jovanovic et al., 2015; O'Connell et al., 2016).

In more recent research, cannabidiol has been an alternate treatment of epilepsy for many people due to many people suffering with treatment-resistant epilepsy (Rosenberg et al., 2015). Due to previous research indicating that treatment resistant patients have a higher mortality rate, and experience more social, psychological, and cognitive impairment, with little to no alleviation from AED treatment, more and more people have explored cannabis as an alternative (Rosenberg et al., 2015). For instance, results from a study conducted by show that on parents try different types of AEDs with most of the epileptic patients experiencing drowsiness, fatigue, appetite decrease, irritability, insomnia, aggressive behavior, weight loss, anxiety, rashes, vomiting, nausea,

dizziness, and confusion (Wu et al., 2014). Although AEDs have been reported to help with better sleep and a slight decrease in seizures, results also showed that there was an increase in lethargy while convulsions often remained, and impaired intelligence (Aldenkamp et al., 2016).

AEDs can potentially alleviate symptoms of epilepsy, mainly seizures (M. Anderson et al., 2015). AEDs can lower the frequency of seizures for over half of those who have epilepsy, many patients report experiencing an adverse drug reaction (M. Anderson et al., 2015). In addition to adverse drug reactions, side effects include a lengthy list that deters parents from continuing use of AEDs (Jovanovic et al., 2015). Furthermore, many study results show that AEDs lower seizure frequency, but when compared to cannabidiol, is falling behind in efficiency (Stockings et al., 2017)

Cannabidiol or Medical Marijuana

Recent literature pointed out that individuals often reported the failures of AEDs (Jovanovic et al., 2015). Because of this, cannabidiol or medical marijuana became a popular alternative to treat epilepsy (Maa & Figi, 2014). So far, epilepsy and how it affects the diagnosed children, their parents have been highlighted in this chapter. It is important to feature cannabidiol, for it will be a crucial part to a sense of hope being constructed by the parents of an epileptic child. This section will explore cannabidiol; what it is, how the use of it for the medical treatment of epilepsy has grown, the efficiency of it, and how it affects those affected with epilepsy.

Cannabidiol (medical marijuana) or *cannabis sativa* is the non-psychoactive element extracted from tetrahydrocannabinol (THC), meaning that it is not psychotropic,

or that it does not produce a ‘high’ like feeling when taken (Devinsky et al., 2014). Cannabidiol can be administered in different ways, including smoking, vapor, and oil-based capsules (Devinsky et al., 2014). For decades, cannabidiol has been used for ailments such as fever, malaria, gout, and pain (Fasinu et al., 2016). Unlike THC, cannabidiol does not activate CB1 or CB2 receptors, making it non psychotropic but also positively affects serotonin levels in the brain (Fasinu et al., 2016). Cannabidiol is also a strong antioxidant that can affect equilibrative nucleoside transporters, enhance and activate receptors in the brain, and provide antispastic, alleviate neuroinflammation (Devinsky et al., 2014). Regarding adverse drug reactions, study results show them to be temporary or minimal (Hadland et al., 2015).

As explained in other studies, cannabidiol has many components, and can be used to treat different forms of ailments, including neurological conditions (Hadland et al., 2015). Cannabidiol is a constituent of cannabis, but yields many pharmacological actions such as antipsychotic, anti-inflammatory, and antiemetic, anti-epileptic, and continual acknowledgement of the possibilities of cannabidiol are being explored in dementia, and psychiatric disorders (Blessing et al., 2015). More specifically, when exploring cannabidiol for the treatment of epilepsy, study results showed that administration of cannabidiol on epileptic patients did not show any signs of serious side effects or signs of toxicity (Devinsky et al., 2015). In addition, cannabidiol has been shown to test negative on physiological parameters such as heart rate, blood pressure and body temperature, and is well tolerated by most people (Blessing et al., 2015).

Although cannabis was available throughout the years, it was around 1970 when Controlled Substances Act classified it as a Schedule I drug, making it illegal. Conceived as an illegal substance, research was limited, but throughout the 1970s and 1980s, several studies showed results illustrating the non-psychoactive effects of cannabidiol in addition to be an anticonvulsant (Maa & Figi, 2014). More recently, cannabidiol has been legalized and utilized for many medical and mental conditions, and studies show that it is becoming more accepted and supported by patients and medical professionals (Blessing et al., 2015).

Because cannabidiol has rapidly become legal in many parts of the country, more and more people are interested to know if the medicinal purposes would benefit their condition or ailments (Devinsky et al., 2014; Hadland et al., 2015). In fact, Fairman showed that numbers have continue to climb for registered used for THC and cannabidiol (2016). With pharmacological prescriptions failing to alleviate epileptic symptoms, and parents wanting to help their children, interest to seek out non-traditional treatments such as cannabidiol for neurological, behavioral, and developmental pediatric conditions have gained momentum (Devinsky et al., 2014).

Many studies argue that research must be conducted to further gain insight on the pros and cons of cannabinoid (M. Anderson et al., 2015; Hadland et al., 2015; Rosenberg et al., 2015). Because of a link to long-term adverse effects such as neurocognitive, psychiatric, and psychosocial outcomes with the use of AEDs, many study results argue that is critical to continue research to understand how beneficial cannabidiol is as an alternative medical treatment (M. Anderson et al., 2015). There lacks research on

cannabidiol, and because of this, there is a growing number of online social media groups to provide support for one another and the product itself; many formed by parents (Cilio et al., 2014; Detyniecki & Hirsch, 2015). This movement has elicited the involvement of researchers and physicians and other professionals to conduct long-term studies on the effects of medical treatment with cannabidiol (Detyniecki & Hirsch, 2015). This issue also illuminates how the treatment of cannabidiol can influence a sense of hopefulness, adding on pressure and purpose for this research.

Treating Epilepsy with Cannabidiol or Medical Marijuana

A growing number of physicians encountering parents who are treating their child with cannabidiol (Detyniecki & Hirsch, 2015). A study listed that when treatment-resistant epileptic participants were treated with cannabidiol, over half reported an 80% reduction in seizure frequency (Hess et al., 2016). Some reported 90% reduction of seizure frequency, and a few reporting complete freedom of seizures (Hess et al., 2016). In the same study, parents reported improved alertness, with very few negative side effects such as fatigue and drowsiness (Hess et al., 2016).

Cilio et al. (2014) conducted a similar study that looked at parents who treated their child with epilepsy using cannabidiol. The study results concluded that 80% of parents reported a reduction in their child's seizure frequency, with 11% reporting seizure free. In addition, parents reported increased alertness, better mood, and improved sleep, with minimal reports of drowsiness and fatigue (Cilio et al., 2014). Even with several epileptic diseases such as Lennox-Gastaut syndrome, where morbidity is frequented with violent spasms and head injury, a large number who have tried CBD treatment usually

report an average on 50-75% reduction of seizure frequency, and improved alertness (Thiele et al., 2018). Although adverse drug effects reported such as diarrhea and vomiting, 61% were resolved (Thiele, 2018). Essentially, noted studies demonstrate the efficiency of cannabidiol as a medical treatment of epileptic symptoms.

When cannabidiol is used for the treatment of epilepsy, there is usually only about .2% of THC, illustrating an exceptionally low concentration of THC in the drug, (ElSohly et al., 2016). Basically, when utilized as a medical treatment, cannabidiol may contain traces of THC, otherwise known as marijuana, and this is ranged from 0 to 0.8 mg/kg/day (C. Anderson et al., 2017). However, when tested, no patients reported psychoactive effects, but majority of participants reported less frequency of seizures, better sleep, and increased alertness (C. Anderson et al., 2017). Furthermore, when compared to the use of AEDs for the treatment of epilepsy, more participants reported improved quality of life when using cannabidiol versus AEDs (Rosenberg et al., 2015).

Maa and Figi (2014) explored a popular known case of Charlotte's web, a concentration of cannabidiol that was used to treat a child with epilepsy. Charlotte was diagnosed with Dravet syndrome at months of age, and at five, was told that she was reaching the end of her road (Maa & Figi, 2014). Having tried eight different types of AEDs and a ketogenic diet, her parents were desperate, for she was experiencing about 50 seizures a day, displayed cognitive and motor delays, required feeding tubes, and struggled to walk and talk (Maa & Figi, 2014). This personal case looked at Charlotte's mom and her point of view as she described how her daughter experienced seven days

without a seizure after starting cannabidiol treatment and had even begun to feed and drink by herself (Maa & Figi, 2014).

Because of the positive change resulted with the use of Charlotte's web, other parents were willing to try cannabidiol to treat their child with epilepsy, even though long-term effects have not been fully researched (Maa & Figi, 2014). This case started moves from other states around the nation (Maa & Figi, 2014). People began to move out to the state of Colorado to treat their child with cannabidiol, otherwise unavailable in their hometown at the time (Maa & Figi, 2014). After this case, a nonprofit was started by the Stanley brothers aimed to help individuals gain access to consistent, high quality, lab-tested and high cannabidiol content (Maa & Figi, 2014). In the year 2014, the Stanley brothers will have treated over 200 patients (Maa & Figi, 2014).

Treating epilepsy with cannabis started in the late 19th century but was rarely mentioned or even recognized by society. However, as seen through research, cannabidiol has demonstrated potential in treating the epileptic symptoms. Cannabidiol has been proven to be anti-epileptic and anti-convulsant (Devinsky, et al., 2014). Because of the nature of epileptic conditions, it is crucial to treat the conditions as early as possible to decrease the effects on motor impairment, cognitive and behavioral development (C. Anderson et al., 2017). Essentially, by treating the children early on, the long-term results can positively affect adulthood (Pompili, 2014). In short, by finding a treatment that provides a sense a hope, the children with epilepsy are more likely to have adult lives with less seizures, less depression and anxiety, and less developmental and cognitive delays, thereby increasing quality of life.

Summary and Conclusions

In this chapter, the concept of hope was introduced prior to the literature review to inform how a sense of hopefulness can influence the perception of quality of life.

Essentially, hope is derived of personal experiences and subjective ideas of happiness, satisfaction, and potential (Saricam, 2014). In this view, hope can affect well-being and a personal sense of success, motivation, goal attainment and even social relationships (Huen et al., 2015). This information helps explain how a sense of hope or lack thereof can affect how parents perceive their epileptic child's quality of life and their own.

Essentially, it is important to understand how a sense of hopefulness can elicit positive perception, resourceful connections, and encouragement to positively move forward.

Furthermore, a sense of hope promotes hopeful thinking, which can help maintain positive reinforcements, personal capabilities, and positive self-reflection; all qualities that effect quality of life (Cianchetti, 2015; Huen et al., 2015).

Following the discussion of the concept of hope was the conceptual framework and literature review that included extensive examination of the condition of epilepsy, children with epilepsy, parents of children of epilepsy, treating epilepsy in general, cannabidiol, and treating epilepsy with cannabidiol. Essentially, even though research has looked at quality of life as it is affected by epilepsy, and how cannabidiol has been proven to alleviate epileptic symptoms, what is not known are descriptions on hopefulness and how it can influence quality of life. The review of literature showed that minimal research exists on how treating a child with epilepsy using the medical treatment of cannabidiol affects a sense of hope for the parents and their child.

Consistent throughout the literature review was the argument that quality of life needed to be further researched to aid in the lives of those affected by epilepsy. Due to the conditions of epilepsy, families are often isolated thereby negatively affecting their social relationships, support and essentially connection to others (Szemere & Jokeit, 2015). Saricam (2014) argued that hope is the result of the subjective sense of happiness, and because happiness is largely influenced by social acceptance and interactions, it would make sense to understand how a sense of hope is obtained, maintained, and seen as a predictive factor for personal resilience. This study aimed to look at a sense of hope as it is subjectively described by parents of children with epilepsy with the possibility of providing information that can increase positive sense of well-being and quality of life.

Literature was reviewed to provide information surrounding the topic for this project, which is a sense of hope as it is described by the parents of a child with epilepsy. This chapter provided themes that arose as literature was reviewed and how was relevant a sense of hope and quality of life. Moving forward, the following chapter provides information on the research method, specifically being a qualitative design; how it was designed and how it will be performed, and the reasoning behind it. In addition, participation criteria, sampling procedure, triangulation, collection of data and the planned analysis for collected data will be discussed.

Chapter 3: Research Method

As previously mentioned, epilepsy affects about 3 million people in the United States, and children are among the most affected (Pompili, 2014). In addition, with the number of parents reporting depression, anxiety, and loss of hope for their affected child and themselves, parents have increasingly looked for solutions or answers that can help their child have a better life (Jones, 2014; Jones & Reilly, 2016). The purpose of this qualitative study was to describe a sense of hope as described by parents who chose to treat their child with epilepsy with cannabidiol. More specifically, this study explored a sense of hope as described by parents and how it affects hopefulness and the perception of quality of life. This study was based on the premise that parents of an epileptic child often endure lower quality of life because of a sense of hopelessness as a result of the onset diagnosis of epilepsy.

Many studies have looked at the experiences of parents who have a child with epilepsy in respect to how they continue to experience marginalization, guilt, shame, and limited quality of life (Jones & Reilly, 2016). More specifically in the case of epilepsy, parents of a child with epilepsy also experience more anxiety, depression, loss of hope, confusion, and stress due to the unpredictable nature and symptoms of epilepsy (Nabi et al., 2017). In addition, the condition affects the diagnosed child in several ways that negatively affect psychological, mental, physical, and social development, which adversely affects the child's quality of life (Ferro, 2014). Furthermore, study results have indicated that individuals with epilepsy also experience depression and anxiety, which has often reportedly resulted in premature death or suicide (Mula & Sander, 2016).

Although research shows exploration affecting the situation, no research has looked at how parents describe a sense of hope as it may be influenced by treating a child with epilepsy with cannabidiol. By exploring this topic as a descriptive qualitative study, I gained insights that allowed me to describe a sense of hope as experienced by parents of an epileptic child, and how the sense of hope may have influenced their quality of life. Therefore, this study should provide significant information pertaining to the topic of epilepsy, how it affects parents and children, and how a sense of hope can alter quality of life. This information should also help other parents gain insight to work with the situation of having an epileptic child, in addition to helping professionals understand what can positively and negatively affect a sense of hope when having a child with epilepsy. Finally, further insight should be provided by giving a voice to those who experience the situation.

This chapter presents the research methodology and provides explanatory reasons as to why such methods were utilized as part of the research design. The central research concept and my role as a researcher are discussed, followed by the methodology itself, including participant selection, sample size and saturation point. Also included in this chapter is instrumentation, procedures, data collection, data analysis plan, and the possible issues with trustworthiness regarding several different factors of internal and external validity, reliability, and objectivity. Finally, ethical procedures are discussed, including the institutional review board (IRB) procedure, ethical concerns, and the treatment of data.

Research Design and Rationale

The research questions for this project asked how parents describe a sense of hopefulness or lack thereof as it is influenced by medically treating their epileptic child with cannabidiol, and if there is change, how does the change in hopefulness affect their quality of life as described by the parents of these children. Perception and behaviors are often dictated by a sense of hope, for hope can provide motivation, intention, and an optimistic look on personal and ability (Van Allen et al., 2015). Essentially, with a descriptive qualitative design, this project should provide insight into the how and why for perceptions and behaviors influenced by hope. In order to gain insight on quality of life as described by parents of children with epilepsy, I chose a descriptive qualitative design to gather information directly from parents who have a child with epilepsy.

Qualitative approaches help understand the human condition (Bengtsson, 2016). Because this research aimed to explore a sense of hope and how it influences quality of life, a qualitative approach was chosen due to the lack of literature looking at in-depth responses from the parents of a child with epilepsy. A qualitative design with an emphasis on description was ideal for data collection purposes because it aims to illustrate a situation accurately as described by those who live it (Nassaji, 2015). This helped gain a deeper understanding of the parent's opinions and perspectives (Nassaji, 2015). That is, instead of providing a general idea of the issue, this research design aimed to provide a detailed description and analysis of specific sentiments expressed by those affected by the issue on hand (Sutton & Austin, 2015).

Decision making for a qualitative study included exploring all options, including quantitative approaches. Based on the research objective, quantitative studies are usually utilized for the purpose of obtaining numerical data that can explore the research questions adequately (Queiros et al., 2017). Essentially, quantitative design aims to quantify data, to investigate or research an issue by building upon existing theories through the support of numerical or statistical data (Queiros et al., 2017). Quantitative studies also aim to explore an issue, topic, or situation in relation to statistical evidence, where hypotheses are developed in order to research, test or experiment to collect data and obtain results (Queiros et al., 2017). Furthermore, because the data are measured objectively through surveys and questionnaires to associate, relate, and correlate variables, generalizations can also be explored and determined (Queiros et al., 2017). Although a quantitative design provides important data, it was inappropriate for exploring the previously stated research questions.

For this study, a qualitative approach was chosen to gather data that was directly experienced and discussed by those who experienced the situation of a sense of hope being influenced by the utilization of cannabidiol for the treatment of epilepsy for the child. Whereas a quantitative study aims to gather data with a large sample to provide generalizations (Leung, 2015), a qualitative study tends to use smaller samples, to provide more meaningful description as well as analysis regarding the results and analysis of the collected data (Bradshaw et al., 2017). That is, although a quantitative study can provide a generalization for one group and one sample using objective measurements and unbiased results, with a qualitative study the researcher acknowledges

that the human condition can be derived of opinions and perspectives. The opinions and perspectives help towards inductively developing a pattern or theme emergent of the situation or topic (Leung, 2015). Furthermore, with a qualitative design, interviews can be conducted to describe personal experiences with the situation, and essentially illustrate how individuals construct a sense of hope (Sutton & Austin, 2015). Basically, I determined essential themes using the data collected as provided by individuals who are the active agents in constructing a sense of hope from their experience (Olusegun, 2015)

Considering the research problem, purpose, and questions, a quantitative design would have provided a numerical generalization of the population, but what went on in these individuals' lives would be negated. Rather than making the numerical results a priority, individual realities were recognized as the primary source for gaining insight on a situation otherwise unknown to the public (Leung, 2015). That is, instead of making the experiences of those who live the situation secondary, their voices and their own perspective on their experiences are the central focus (Olusegun, 2015). Essentially, a qualitative design was chosen to provide insight on the issue as it relates to significant factors in human choice, perception, and influence (Leung, 2015). Furthermore, to explore emotional, relational, or cultural factors related to the reflecting on the experiences, a qualitative design will allow for this investigation while gaining insight of their personal perception as described by the participants (Bradshaw et al.,2017).

Bradshaw et al. (2017) discussed the advantages of social research that explores social capital, collective well-being, relational well-being, and psychological empowerment, and by promoting research that encourages self-determination and well-

being, people can gain understanding concerning the predicament of their own and others. By exploring current conditions of a situation, crucial information can be uncovered, to provide valuable resources that can promote positive social change (Bradshaw et al., 2017). Furthermore, because qualitative research provides insight for situations as perceived by humans, the human condition and context can be further understood by those not experiencing the same predicament (Bengtsson, 2016). With such factors, a qualitative design was chosen to provide a thorough and descriptive analysis a sense of hope and how it affects quality of life. In short, rather than quantifying the issue, the objective was to support underrepresented perspectives and experiences while offering an interpretation of the described experiences.

When making the decision on a qualitative design, several other designs were contemplated such as a narrative study or grounded theory. Although both designs could have developed significant results, a generic descriptive qualitative study was chosen due to the desire to describe how parents describe a sense of hope and how it affects quality of life, and the lack of wanting to generate a theory from the collected data. More specifically, a narrative design explores experiences, but only with a story told or portrayed by that person or a small number of people which ignores a perceived concept, and a grounded theory approach aims to develop a theory based on the collected data that uses a larger sample size while studying the process, the action of the interaction among many individuals (Rutberg & Bouikidis, 2018). Essentially, because I wanted to describe a sense of hope as described by parents of children with epilepsy, a more general qualitative design allowed me to look at personal senses through human emotions and

perspectives. Furthermore, a descriptive qualitative study allowed for data collected to further inform how a sense of hope or lack thereof affects quality of life.

Role of the Researcher

Interviews played a large role in this project, for they provided descriptions of a sense of hope from the parents of a child with epilepsy. I as the researcher held the responsibility of being a professional and academically driven interviewer who would uphold ethical standards that protected the participants being interviewed for the study (Roulston & Shelton, 2015). To complete my role responsibly and professionally as the researcher for this project, I introspectively explored my own reasons, background, and experiences, which will be discussed further in this section.

I am a native of a state that is widely known for being one of the first states to legalize cannabidiol and THC. I have watched the city grow regarding businesses and medical clinics utilizing cannabidiol medicinally. I have also had the opportunity of seeing how families have come to the state to treat epileptic symptoms with cannabidiol. As a mental health clinician in the community, I feel am an advocate for families and children, and have had the opportunity to see how a sense of hope can relieve family stress, support family dynamics, increase positive connection and behaviors. These experiences have helped me gain insight into how families can be affected by a sense of hope. In addition, as a mental health counselor who works with children and families, I have experience with conducting interviews, working with parents and children on a one-to-one basis, and as a unit while encouraging a personal sense of hope.

Given my background in counseling, I have been thoroughly trained in empathetic listening skills, interviewing, and listening without judgment. I have also been trained to be recognize my own feelings and biases while promoting those of others, so that mine do not get in the way of the therapeutic process. Essentially, I have learned the communication skills to focus on the client and not myself. This type of knowledge and ability helped me obtain descriptive information for the research, while respecting and encouraging participants to voice their experiences. Although I have my opinions and biases regarding hopefulness, I was able to ensure that my personal experiences were removed from the research, thereby making the project about the participants and not the researcher.

In order to accomplish data collecting properly and ensure that I did not use my power over the participants, I acknowledged and demonstrated active listening, understanding of different perspectives and was aware of my own biases throughout the entire project (Cruz, 2015). A reflexive approach is based on the concept of bracketing, which means that prior knowledge and impressions are suspended from the collected data, making my own beliefs less of an interference or influence (Cruz, 2015). I used the reflexivity approach as a researcher and aimed to recognize my personal responses to be conscious of my own assumptions, concerns, and feelings. This meant that I consistently reflected on my own responses to emergent data and observations, so that the participants' experience with hopefulness emerged. In addition, I paid attention to emotional responses through tone and body language to check for emotional distress during the interview process.

Using semi structured interviews, I conducted interviews with 11 participants who fit the criteria for the study, and because the researcher in this type of design is the key instrument, I also analyzed and interpreted the data (Palinkas et al., 2016). That is, by conducting the interviews and collecting the data described by the participants, I sought out patterns, categories, and significant or quality data that present patterns or themes within the data while remaining neutral to the outcome of the results (Carter et al., 2014).

Regarding the participants, I did not have any personal or professional relationships with them, for I went through a closed group through Facebook that is for parents interested in using or currently using cannabidiol or medical marijuana to treat their epileptic child. However, being a native to the state of Colorado, where marijuana is medically and recreationally legal, I do have some biases regarding the use of marijuana, and how it is perceived. More specifically, I do believe that medical marijuana, or cannabidiol, should be regulated and reissued, to be more accessible for families or individuals seeking treatment for any condition.

Additionally, the topic for this dissertation was chosen because of my professional goals. More specifically, because I am a therapist in the community working mainly with children and families, I wanted to look at a topic that affected my own community. In addition, I wanted to see how a sense of hope could change the outlook on someone's quality of life, and how it can possibly influence their potential, role with others, self-worth, and self-reflection, while also seeing how it affects family dynamics. I also have personal beliefs that I feel would aim to advocate for the parents and their child, but because I am aware of having these beliefs, I can manage it properly by acknowledging

my emotions and judgements towards the situation rather than only looking for what I feel to be a positive result. That being said, my own preconceived notion of the situation possibly providing a sense of hope can navigate an attention to detail on certain aspects of the data results. That is, following a qualitative approach, I focused on the descriptions provided by the participants and how they describe a sense of hopefulness or hopelessness.

Methodology

Qualitative studies use human experience and descriptions to provide data that can inform a topic or situation (Nassaji, 2015). As previously stated, this qualitative study focused on descriptions provided by participants who described a sense of hope as they have experienced it. Thus far, I have discussed my role as the researcher, and my preparations to secure my role professionally and ethically. The following subsections will provide a thorough description of participant selection, instrumentation, procedures, and the data analysis plan.

Participation Selection Logic

This project aimed to give a voice to the parents who have a child with epilepsy. In order to empower the voice of these parents, thorough descriptions of their sense of hope were the main collected data. The population explored were parents who have a child with epilepsy or suffer with epileptic symptoms such as seizures who have/are treating their child with medical marijuana, or cannabidiol. Due to a snowball effect, most of my participants reside in different parts of the United States of America. However, due to technology, all interviews were completed virtually with the participants

meeting the main criteria of having a child with epilepsy and have/are treating their child with cannabidiol.

It was important include participants who were parents, so that they could describe their sense of hope before, during and after treating their child with cannabidiol from the viewpoint of a caregiver. This provided insight from individuals who may have experienced strain, distress, anxiety, confusion, and stress as reported by previous studies (Berg et al., 2019). Furthermore, the treatment with cannabidiol is essential in conceptualizing how it can affect a sense of hope, for it can impact epilepsy symptoms, which affects quality of life. Although my original plan was to include living in the state of Colorado out of convenience, due to a snowball effect with participant recruitment, and the ability to complete virtual interviews, living in the state of Colorado was no longer a requirement.

Because the population was specified with certain criterion, purposeful sampling was used to deliberately locate individuals relevant to the topic, research question and purpose (Palinkas et al., 2016). Therefore, only individuals who had met those criteria were included as participants (Palinkas et al., 2016).). To do this, I contacted the group organizer of a closed group on Facebook, where women and men can discuss and support one another regarding their situation with treating their child with cannabidiol. This closed group on Facebook was disclosed to me by a friend of mine who has a son with special needs and has been in contact with other closed groups for parents who have children with epilepsy. I contacted her to discuss with her my project and began participant recruitment with a social media post weekly. Finally, I had secured contact

with other individuals who have a child with epilepsy and have or are treating their child with cannabidiol. However, with my first interview, I was able to gain access to another closed Facebook group for parents treating or interested in treating their epileptic child with cannabidiol. Due to the first participant's acknowledgement and recommendation of my project, I was able to recruit more participants from around the country who had met the criterion for the project.

In order to determine if the participants meet the criterion, I posted a weekly bulletin on their closed page regarding my project, and I also listed the criterion needs if individuals chose to be a participant. Added in the social media prompt, I also listed my Facebook page, school email or phone number for potential participants to contact me, while communicating confidentiality and ethical procedures. In the end, a snowball effect is what helped me the most in recruiting participants as the participants discussed my project with others with similar experiences (Palinkas et al., 2015).

This sampling size for this project is a decision that has also been considered. According to a qualitative design, the number of participants advised to adequately describe a situation or experience depends on the ethical role of the researcher to provide extensive detail regarding the study (Roulston & Shelton, 2015). To reach a point of saturation while also illustrating content validity, it is important to address interviews accordingly, to gather a proper amount of information that can then be analyzed (Fusch & Ness, 2015). When data has been organized and analyzed, a researcher can then sort out patterns and themes that emerge from the collected data (Creswell, 2013; Fusch & Ness, 2015). Once coding can no longer produce additional patterns, categories or themes, a

point of saturation has been attained, and because this notion depends on the research and the responses derived from participants (Fusch & Ness, 2015), an exact number of participants and interviews that it may take to reach the point of saturation is more of an estimate. With this considered, the sample size was decided at 11 due to point of saturation and the ability to answer the research questions.

Essentially, once the information obtained from the data becomes repetitive, point of saturation has been achieved. The sample size for a qualitative study can range from 1-30 individuals depending on the specific kind of qualitative approach (Fusch & Ness, 2015). Because this study is a generic qualitative design, the final number of participants ended up being 11. Eleven participants were involved to provide a more thorough analysis of a sense of hope and how it affected quality of life. Furthermore, because the point of saturation can be influenced by the heterogeneity of the population and sample size (Fusch & Ness, 2015), it is likely that the point of saturation can be achieved with a smaller sample size due to the criterion purposive sample that sets specific parameters for appropriate participants. For this project, with criterion purposive sampling, point of saturation was in fact achieved with a smaller sample size.

Instrumentation

As the primary instrument, I was the researcher who collects the data, organizes, analyze, and interprets it while remaining neutral by being aware of my own biases and maintained open-minded (Sheperis et al., 2016). After gaining some volunteers to participate in the study, I used texting, e-mail, and messenger apps to set up virtual meetings for the interview process. To collect the data, I used virtual semi structured

interviews that lasted from 35 minutes to 1 hour, with an audio recording application simultaneously operating at the same time. I also took some brief notes during the interviews to provide more accurate data recording in addition to noting a statement in case I had further questions. Virtual interviews were completed over a secure platform that ensures privacy with passwords needed to enter the chat. Links for the virtual chat room were sent to the participant's personal email, where I as the researcher asked for their identification for verification.

The interview guide (see Appendix) was based on the research problem, research questions and the literature review that helped navigate potential concerns regarding the issue. That is, in order to elicit quality information that encourage insightful descriptions, several questions were set forth on the guide to probe elaborate disclosure (Sheperis et al., 2016). The interview questions focused on the participant's sense of hope prior to cannabidiol treatment, during and possibly after cannabidiol treatment. Interview questions also focused on if and how their sense of hope affected their quality of life. I conducted interviews in a person-centered approach as described by Sandvik and McCormack (2018), where the participant's voice is valued by incorporating reflexive dialogue while facilitating mutual respect and authenticity.

Before the interview begins, I made sure that the participants had signed a consent form, indicating their decision to be a participant in the study. During the interview process, I demonstrated active listening that promotes full engagement and attention, to encourage specification when need. Also, as previously mentioned, I used a voice-recording app during the interviews, to transcribe accurately and simultaneously, and I

also informed the participant of the usage of the app, but I also completed handwritten notes throughout the interview process when necessary. Finally, in the event where I felt it may be necessary to conduct a follow-up interview with a participant, communication took place for an additional interview or clarification.

In addition to interviews, I used journals that the participants used to describe their personal journey about a sense of hopefulness or hopelessness for a two-to-four-week period where they were asked to respond to the journal prompts. These journal entries helped provide a personal detailed description of what the parent felt was important enough to write about concerning a sense of hope or clarify and/or change their responses from the interview process. That is, rather than determining what was important to the parents, this was provided by the journals. In addition, the writing in the journals helped provide information that was used for the purpose of triangulation and accuracy. Furthermore, journals were reviewed to determine if follow-up interview questions were necessary.

Procedures for Data Collection

With qualitative descriptions, only the straight description was used to inform the research question. Data collecting was completed by me as the researcher of this project. I had developed my own interview guide (see Appendix) for the semi structured interviews and conducted the interviews while recording the data using a voice recording app while manually taking notes. The duration of the data collection process began as soon as I received IRB approval and was able to set up interview times with the participants gained through the sampling process. All interviews we completed within a

three-month time span. Additionally, journal prompts were emailed to each participant, and I would reach out to each participant after 2-4 weeks. All participants were given a notice of consent agreement as well as a debriefing prior and following the interview to inform them of the ability to exit the interview when chosen, and to answer questions voluntarily, in addition to the research purpose. No follow up interviews were needed, but clarifications were completed via email by communicating the reason needed for clarification. All clarifications were completed without the need for a follow up interview. The participants were also given information that provided follow-up procedures and the option to seek professional help if needed. Professional referrals were provided even though zero participants requesting the need for it.

Data was collected virtually with several participants residing in the same state and the remainder residing from different parts of the country. All interviews were completed with a private platform that only permitted the recipient to open the virtual meeting room. As the researcher, I collected the data with interviews, and journals that the participants completed. Interviews were completed after participants volunteered for the study and dates and times were chosen, resulting in about one to two interviews a week over a three-month span. Regarding the journals, participants had a few weeks to write their thoughts about their sense of hope, which expanded the timeline, making the data more reliable. After seven completed interviews, responses were starting to sound similar, and themes began to emerge. Four additional interviews were completed to determine point of saturation and the ability to answer the research questions. Research

questions parameters were provided by guidelines set forth by Lowe et al. (2018) in that data collected is sufficient to answer the research questions.

Data Analysis Plan

Qualitative research data collecting uses a standard that requires analysis, interpretation, and coding to determine themes and patterns (Assarroudi et al., 2018). In this study, detailed descriptions of a sense of hope were used to answer how parents describe a sense of hopefulness as it is influenced by medically treating their child with cannabidiol, and if there is change, how the change in hopefulness affects quality of life.

Following Saldana's model, I coded the data in two cycles (Miles et al., 2015). Before any coding took place, near the end of every interview, I communicated my interpretation of the responses that each participant had disclosed and made sure that each participant agreed with my interpretation. During the first cycle, I used descriptive and emotion coding labels to summarize chunks of data into segments. The segments were then used during the second cycle to form themes or patterns (Miles et al., 2015). More specifically, after each interview, I took the transcribed interviews and put them onto a word document on my laptop and filed it under a secure file that requires a passcode for accessibility.

In the word document, I would highlight with different colors to code the emotions and descriptions, and then the second cycle, I went back to color code the different themes and patterns. As a caution, all files will remain locked on my laptop for 2 years after the study is completed. During this first cycle, I was able to review the interview transcripts and explore possible labels for the responses. This same process was

also applied for the journal entries completed by the participants. After a review of the first cycle labels were completed, I devised a coding system to be able to label the prominent patterns and themes that emerge. Data linking helped me connect information for the interviews and develop categories (Miles et al., 2015).

Coding was used to index and map data to give me the researcher the ability to make sense of the collected data (Elliot, 2018). Essentially, a coding system helped me determine themes and patterns because of low inference codes (Elliot, 2018). Because this study looked at how a sense of hopefulness is described, I felt that Saldana's two stage coding was the most efficient, for it allowed the breakdown of data into emotional labels, thereby creating themes and patterns (Miles et al., 2015).

Using Saldana's two stage coding technique, I used different colored highlights to label low inference codes in hopes of reducing or refining the collected data as part of the first cycle. The aim was to review the transcripts and find similar statements or descriptions that can then be grouped into themes; eventually resulting in emerging themes and patterns. Following the two-stage technique by Saldana (2015), I also applied more descriptive words to enhance the codes into negative and positive emotions that can influence hopefulness. Adding descriptive words helped me put chunks of information together to explore human reactions such as physical and mental factors. These themes helped me conceptualize a sense of hope as experienced by parents of a child with epilepsy. In addition, because I used semi structured interviews, I was able to code responses based of the questioned asked, which helped create patterns from the data.

Since I used Saldana's two stage model for coding, my initial phase was based off a coding system that looks for prompts that can answer the previously discussed research questions by first labeling the chunks in descriptive words. My first cycle of coding was based off descriptive and emotion coding, which will summarize answers provided by the interviewee and label them by a word or a short phrase that I then used to formulate categories relevant to answering the research questions (Miles et al., 2015). I used phrases or words such as positive sense of hope, hopelessness, quality of life and change in perception, personality, and genuine happiness. In addition, because this study focused on a sense of hope, some emotion coding occurred to better detail the descriptions. Furthermore, because the research questions looked at a sense of hope and how it influences quality of life, there was a likelihood that there was some simultaneous coding to better link the two notions.

Coding the journals required more emotion coding, due to most of the participants discussing their thoughts and feelings in a more personal manner. This made emotion coding a more sufficient way to look at the participants' perspectives. In addition, concept coding was also more beneficial when going through the journals, for it will allowed me to condense phrases and paragraphs to a concept I felt to be most valuable for that segment.

Because I had transcripts of the interviews, during the manual process of coding patterns and themes among participants, I carefully read through each transcript to highlight words that frequently came up and thoughts that emerged as significant. My role as the researcher was to reduce the organized data into themes by locating emerged

patterns of similar responses and identify regularities. This helped provide a sense of hope as it is experienced by the respondents.

Moving forward to secondary coding, where I transitioned codes into patterns, my plan was to decipher from positive and negative emotions using the journal entries and necessary responses that were coded as emotional. I explored what the codes had in common and interpreted how it answered the research questions. Furthermore, patterns developed as I created a bullet point reference list that helped simplify clusters while showing connections to each response (Miles et al., 2015).

In order to prevent misuse of information and collected data, any collected data including raw data, personally transcribed, and voice recordings from each of the interviews were placed in a secure file on my laptop that requires a passcode. Raw materials were placed in a sealed manila folder in a locked filing cabinet. All materials will be safely stored for two years following the completion of the study.

Issues of Trustworthiness

Establishing trustworthiness in a qualitative research design requires the demonstration of credibility, transferability, dependability, and confirmability. In addition, the research itself must adhere to ethical procedures as dictated by the IRB concerning factors such as the treatment of human participants, institutional permission, proper protocol regarding participant recruitment, data collection, confidentiality, and data storage. As such, the following section will illustrate the factors and issues of trustworthiness regarding this dissertation project.

Credibility

To provide credibility within a qualitative study, the researcher must demonstrate, “believability and assurance that the conclusions make sense” (Sheperis et al., 2016, p. 144). In doing so, triangulation, prolonged contact, member checks, peer debriefing, and saturation are factors that need to be adequately addressed. Essentially, validity needs to be illustrated throughout the process; prior to data collection, during data collection, during data analysis and during the discussion as well (Leung, 2015). In short, the design needs to validate the research purpose and the research methods needs to validate the research design (Leung, 2015). Furthermore, recognizing and practicing the concept of Epoche will promote a sense of neutrality that decreases the number of prejudices and assumptions while maintaining an open mind and attitude regarding the research topic, problem, purpose, and questions (Roulston & Shelton 2015). Essentially, by conceptualizing the notion of Epoche, I can set aside my own personal viewpoints and beliefs regarding any issues related to the topic that then promotes an ongoing analysis rather than a fixed set event that relies only on assumptions.

Triangulation is a process that involves several credible sources that can be used to crosscheck theories, methods and information pertaining to the research topic (Sheperis et al., 2016). To properly utilize triangulation, for the purpose of this study, I have incorporated referential adequacy as part of the literature review, to provide a foundation for the research problem and purpose as well as research questions. In addition, referential adequacy was employed to explore the population, to gain insight on how such individuals are defined and perceived. In addition, I applied member checking

as part of the triangulation process, which allowed me to check my interpretation of the participants' responses with their own interpretation or attached meanings (Sheperis et al., 2016). Essentially, this process helped allocate validity in the participants' experiences, realities, and descriptions (Noble & Smith, 2015). That is, the findings more accurately represent the collected data.

Prolonged engagement is another tool that I used to provide credibility, and I completed it by building trust with the participants through the sampling process. Prolonged engagement is a process where the researchers investigate with a sense of purpose while validating the participant's experiences and perspectives, and building trust all the while (Sheperis et al., 2016), and by communicating with the closed group administrators first, and then posting the research problem, purpose and the aim for social change, I established trust prior to the interviewing process, to which I then continued to build a professional and trusting relationship with the participants.

Peer debriefing is a process that is used for the purpose of recognizing researcher biases, interpretations, and assumptions (Leung, 2015; Sheperis et al., 2016). For this project, committee members were the primary source of peer debriefing, to provide and external check on the ongoing research and data collection process as well as analysis.

Lastly, I applied a point of saturation as previously mentioned, which helped navigate a research process where the data collected no longer shows new themes, patterns or emergent properties pertaining to interpretation of the described sense of hope and quality of life (Lowe et al., 2018).

Transferability

As an external validity source, transferability provides sufficient information that can produce generalizations to other contexts or settings (Sheperis et al., 2016). In order to establish transferability, thick description will be applied, to provide thorough and elaborate descriptions from the participants. Thick description is a process during the data collection step, where measures are taken to provide information that allows the reader to understand and conceptualize the setting or issue being addressed (Bradshaw, Atkinson & Doody, 2017). In short, as the researcher of this project, I explored the topic by emphasizing in-depth responses from the participants, which helped encourage further understanding of the situation thereby allowing interpretation of meanings and significance (Bradshaw, Atkinson & Doody, 2017). Furthermore, in conjunction with thick description, participant selection posited through criterion sampling enabled the generalized conjectures regarding the research conclusion.

Dependability

Another issue of trustworthiness is dependability, which is demonstrated by research results illustrating congruence across time and across researchers (Sheperis et al., 2016). With the literature review incorporating different studies with different perspectives that relate to the topic, dependability was developed first by exploring previous studies that focus on different aspects of the topic. In addition, audit trails were used to organize and maintain accurate documentation, procedures, and data collection, to sustain reliable sources of steps taken to complete the data collection and data analysis process, as well as the research project itself.

Confirmability

Confirmability dictates that the research results are indeed an outcome of the participants' responses, descriptions and meanings attached to the described lived experiences (Sheperis et al., 2016). Using reflexivity, I started by recognizing and understanding my own political, cultural, and personal perspectives of the world around me and be aware that my own experiences and realities have developed my own perspectives; perspectives that should not interfere with the investigation, data collection and data analysis (Sheperis et al., 2016). To properly demonstrate reflexivity, I assessed my current situation, opinions, and assumptions prior to investigation, to acknowledge how such factors affect my own judgement. For example, I explored personal and professional motives for the research project, stated my own biases and assumptions, and explored what I think may be the results from the data collected. In short, personal exploration took place to remove instances for the lack of confirmability, and by providing direct quotes from the participants, accurate detailed descriptions will provide the voice of the participants' (Bradshaw et al., 2017).

Ethical Procedures

The ethical procedures for this project include access to participants, IRB application, the treatment of human participants, IRB approval, participant recruitment, data collection, and treatment of data, all of which will be discussed in this section.

Access to Participants

To gain access to participants, I completed the IRB application and received approval (IRB approval #05-24-21-0371265) prior to investigation that required access to

participants. That is, no data was collected and no communication for participation took place until IRB approval was obtained.

Treatment of Human Participants

I recruited parents who live in different parts of the United States of America, with some residing in the state of Colorado, and are or have treated their epileptic child with cannabidiol. These parents either have a child who have been diagnosed with epilepsy or have a child who suffer with epileptic seizures. Because the participants can be considered a vulnerable population, participation was strictly voluntary during the data collection process and after the interview process is completed. That is, participants were given to the option to leave the interview process at any time, answer any questions they feel they wanted to disclose, and dictated the removal of their interview responses from the project itself. Basically, participants were given a letter of consent to sign that detailed the project, why it is being conducted and the factor of voluntary participation. Furthermore, prior to the interviewing, full disclosure of the dissertation project was available for potential participants, and I did use any control or coercion to obtain participation (Korstjens & Moser, 2018). In addition, all human participants were treated professionally with dignity and respect, and the parameters were taken, so that little to no harm impacted the participants (Roulston & Shelton, 2015). Also, no incentives were given to the participants for cooperation, due to the risk of skewed data based on positive reinforcements.

Treatment of Data

All forms of data were only accessible by me, the researcher, and to my committee members when being sent for revision and approval. Measures were taken to secure accessibility only through a passcode that only I was privy too, and all data written, typed and transcribed were placed in secure files stored on my laptop that require a passcode for entry. During the process of transcribing collected data, all forms of data were stored in a secure case. After the transcribing process was completed, all data remained stored in the secured case until the completion of the project for cautionary purposes. Upon completion, all raw collected data that was written was shredded and thrown away. All transcribed data that had been electronically stored will remain in the locked file for an additional 2 years for cautionary measures. After the 2 years, all data will be destroyed or deleted permanently to secure participant identities. In addition, because data collection was completed with interviews, all participant identities will be confidential, and pseudonyms were used for everyone who participated in the data collection process, and this treatment was discussed with all participants.

Summary

This chapter was introduced with the research purpose and questions of this dissertation projection, and the research design and rational section was used to discuss qualitative versus quantitative designs, as well as the qualitative options applicable to the purpose of this research. My role as a researcher was discussed, and how the researcher being myself would serve as a primary instrument for the research design, data collection and data analysis process. My own biases were discussed, and several other ethical

concerns were acknowledged and presented. The methodology section was then used to illustrate participant selection logic such as population, sampling strategy, sampling rationale and procedures for recruitment and point of saturation in relation to the topic, criterion sample and phenomenological design. The chapter then moved on to instrumentation such as interviewing process, guides, letter of consent and follow up procedures as well as the analysis plan, which included the coding process and the software used for categorization and organization. Finally, issues of trustworthiness were discussed such as credibility, transferability, dependability, confirmability, and ethical procedures that discussed ethical treatment of human subjects, IRB approval and gaining access to participants, recruitment, data collection, and the treatment of data. This chapter will be followed by the collected data results, interpretation, and analysis of the collected data.

Chapter 4: Results

The purpose of this descriptive qualitative study was to explore a sense of hopefulness or lack thereof as it is experienced and described by parents treating their epileptic child with cannabidiol. The data collected will be discussed in this chapter in addition to the setting, demographics, the data collection, and analysis process, and trustworthiness finally followed by a summary. Findings for this project can help illuminate current issues with treating children with epilepsy, parental hardships, emotional and mental strain. Findings for this project can also provide insight to promote advocacy for patients and their families.

In this project, the descriptions told to me by the participants led to several main thoughts: epilepsy itself, emotional and mental strain, and the desire to advocate for their child's quality of life. All participants were willing to share their emotional journey with finding treatment for their child, and many would openly discuss their past and present experiences with a sense of hope. Several expressed a need for more research on the topic due to recent standards and practices in the medical field in addition to the social stigma that follows their journey and families. All but one of the participants communicated a sense of hopefulness with the cannabidiol treatment. One participant did not want to use the term hope but described a need and desire to overcome, be resilient, and move forward. Because of the previously discussed definition of hope, that answer was approved by the participant to be included in a sense of hope.

The research questions used to guide this study were as follows:

1. How do parents describe a sense of hopefulness or lack thereof as it is influenced by medically treating their epileptic child with cannabidiol?
2. If there is change, how does the change in hopefulness affect their quality of life as described by the parents of these children?

Setting

Data for this project were all collected through virtual interviews and completed journals that would then be emailed back to the researcher. Even though two of the participants lived in the same town as me, both chose to do virtual interviews due to the COVID-19 pandemic. Interviews lasted 30–55 minutes, and journals were returned within a few days or weeks, depending on how the participants felt they could answer the journal prompts. Because all interviews were virtual, participants were able to choose their private setting, and I made sure that I was in a private setting where no one else was around me or could hear the conversation. Once every interview started, I introduced myself and reminded each participant that they could refuse to answer a question or end the interview at any time. At the end of every interview, I provided my interpretation of the participant's responses and would clarify data if needed. Due to the nature of epilepsy, a few participants requested an interview via email with the interview questions and I would then clarify responses, ask further questions, or provide an interpretation so that the participant could confirm my understanding of their answers.

I did not recognize any organizational conditions that would have influenced the participants. However, a situational personal condition was noticed in that all participants had attempted AEDs and reported negative experiences or side effects. Personal

influences include my own. With personal experience doing therapy, I was able to interpret the data during the interview process, which helped explore and determine the themes for the study results.

Demographics

Demographics for this study included parents of a child with epilepsy who had treated the symptoms with cannabidiol. All parents were over the age of 18 and resided in different parts of the United States. All participants happened to be female, with most of them being the mothers of the child with epilepsy. One of the participants was the grandmother of a child with epilepsy. An unusual circumstance occurred due to the first interviewed participant. Essentially, the participant had communicated positive feedback for me and provided me with her recognition and support during a social media post. After the recognition and support provided in the social media prompt from the first participant, the remainder of the participants used for this study were attained. The first participant also reached out to a cannabidiol specialist who also has a child with epilepsy, and that person vocalized support for my study. Basically, with a snowball effect (Palinkas et al., 2015), most participants were outside the originally anticipated area of data collection. All but two participants were out-of-state residents who still met the criteria.

Table 1*Demographics of Participants*

Participant	Gender	Parent status	Use of AEDs	Use of CBD
P1	F	Grandmother	No	Yes
P2	F	Mother	Yes	Yes
P3	F	Mother	Yes	Yes
P4	F	Mother	Yes	Yes
P5	F	Mother	Yes	Yes
P6	F	Mother	Yes	Yes
P7	F	Mother	Yes	Yes
P8	F	Mother	No	Yes
P9	F	Mother	Yes	Yes
P10	F	Mother	Yes	Yes
P11	F	Mother	Yes	Yes

Note. AEDs = Antiepileptic drugs for treating epilepsy; CBD = Cannabidiol for treating epilepsy.

Data Collection

With the approval of the administrators of closed groups on Facebook, I was able to join groups that specifically met the criterion sampling for this project. More specifically, I was able to join closed groups for parents treating or were interested in treating their epileptic child with cannabidiol. In total, the data collection for this descriptive qualitative study involved eleven participants. Interviews were arranged through the Facebook messenger app, email, and text messaging. All interviews were conducted virtually due to location and the COVID-19 pandemic. Virtual interviews were arranged, consent forms were sent out via email, consent was received, and the interview

was then completed via Google Meet. Participants were recruited for 3 months. As stated in Chapter 3, the point of saturation was met when I no longer saw new or different patterns or responses. Lastly, compensation of a \$5 gift card was given to every participant.

Every interview started with an introduction, appreciation statement, and review of the consent form. The semi structured interview questions were used and depending on the participant's response, additional questions were added to clarify or confirm a participant's experience with a sense of hope or quality of life. Interviews lasted 30–55 minutes in addition to journal prompts that were answered several days or weeks after the interview to provide accuracy and more detailed descriptions. Throughout the 3 months, social media prompts were posted weekly, and participants were recruited each time. The first week, only one participant volunteered. After each social media post in the closed Facebook group, a participant or two were recruited. No interviews were video recorded, but all data were voice recorded using a transcribing application called Voice Notepad Dictation/io/Speech. All transcribed data and journal responses were stored in a password-locked file that only I can open.

Variations From Proposal

The final study had several variations from the original plan. My initial goal for the same size was about 15 participants. After conducting the interviews and collecting the data of 11 participants, and not seeing different information or patterns emerge, I determined that the smaller sample size was sufficient. As previously discussed, due to the unexpected snowball effect, most of the participants lived outside the state of

Colorado. Although living in the state of Colorado was a convenience factor for the sample, all other criteria were met by all participants in that they were all parents, apart from one grandparent of a child with epilepsy, and have or were at the time treating the symptoms with cannabidiol. Also, as described in Chapter 3, a few of the interviews were completed via e-mail. Two of the interviews took place via email due to the stressful circumstances that the participant was experiencing with the symptoms of epilepsy. The process for this was that questions would get asked via email; the participant would respond, and then I would clarify questions or build off the responses if necessary. As a result, it was an interview without seeing the participant and getting responses when convenient for the participant.

Data Analysis

The data analysis for this project required the completion of interviews and collection of journal responses that often took several weeks to gather due to participants answering the questions at a convenient time for them. Although every participant had their own unique story, many of the participants shared similar challenges with treating epilepsy and having the same concerns for their child's quality of life. After participants confirmed the accuracy of my interpretations, and journal responses were received, I started my two-stage coding process by reviewing the transcripts multiple times. During that process, I looked for similar statements or descriptions and grouped the codes into themes as suggested by Miles et al. (2015). I highlighted specific responses that aligned with a sense of hopefulness and quality of life. I then went through and highlighted specific words that frequently appeared and correlated them to either a sense of

hopefulness or quality of life. I did this by placing all the transcribed interviews into separate Word documents and completed a search action for specific words, such as “independence.” This color-coding process also helped me discover the emerging themes and patterns that were frequently discussed by each participant. In addition, I would place the coded transcribed interviews side by side to help determine what patterns could emerge by similar statements. This process also helped me clarify that the point of data saturation had been met since I no longer visually saw a new pattern (Palinkas et al., 2015).

Data analysis was organized using a Word document. After the two-stage coding process was complete, emerging themes were placed under every participant’s initials to ensure that themes were evident throughout all participant responses. This process helped me arrange the common themes and patterns so that I could outline the results, which will be discussed later in this chapter. In addition, by organizing the data this way, I was able to confirm that the research questions had been answered.

The first research question asked, “how do parents describe a sense of hopefulness or lack thereof as it is influenced by medically treating their epileptic child with cannabidiol?” All participants described a sense of hopefulness or ability to positively move forward, with no participants stating a lack of hopefulness. Although a few participants described mental and emotional strain, hopefulness was still communicated due to positive outcomes of using cannabidiol versus AEDs. Furthermore, all participants communicated cannabidiol treatment influencing different aspects of living with epilepsy, such as seizure frequency, side effects, efficiency, which all affect

hopefulness and quality of life. There were no participants who described cannabidiol as not influencing their sense of hopefulness.

The second research question asked, “if there is change, how does this change in hopefulness affect their quality of life as described by the parents of these children?” Because all participants communicated and expressed a change in hopefulness, this question was answered by the participants describing the quality of life and how they wanted to preserve that for their child and family. For example, an interview question was, “has using/used Cannabidiol to treat the symptoms of epileptic seizures influenced the quality of life for you and your family?” Another question asked was, “what factors in using cannabidiol have affected the quality of life in your household?” Every participant discussed different ways as to how a sense of hopefulness changed the quality of life for the child. Several participants described a temporary sense of hopefulness due to the unpredictable nature of epilepsy but describing that temporary sense of hope as a better quality of life due to a break in pain and suffering.

Evidence of Trustworthiness

Qualitative studies require several crucial factors that provide trustworthiness. These factors include credibility, transferability, dependability, and confirmability. All factors were established and maintained throughout the entire duration of this project. Furthermore, ethical procedures mandated by the IRB also remained intact. I made sure to follow the guidelines set by the IRB during the recruitment of participants, interview process, data collection, confidentiality, and data storage.

Credibility

Credibility was achieved in several ways. Firstly, I made sure to set aside my personal viewpoints regarding the issue on hand and maintained neutrality. Doing this helped validate the research design, purpose, and methods. Secondly, to provide accuracy, I made sure to use an already tested voice application on my laptop to record the audio from the interviews. This eliminated any forms of inaccurate data and helped me implement member checking. To complete triangulation, member checking was also completed during every interview, since I would interpret the descriptions and ask the participant to confirm or clarify my interpretation. This also validated the research method, design, and purpose, for it helped me only focus on the participant's experiences and descriptions. Credibility was also achieved through prolonged engagement. Essentially, by discussing my project with the administrators of the closed Facebook groups and getting support from the leaders of the group on my social media posts, I was able to build trust with potential participants. Finally, to make sure the point of saturation had been met, I reviewed the transcribed interviews after every interview and started the coding process, thereby giving me an advantage of recognizing when a point of saturation had been met. In addition, I sought advisement from my committee members to ensure the point of saturation. My committee members also participated in peer debriefing to provide external checks for the data collection and data analysis process.

Transferability

Transferability was attained by making sure the information gathered was a thick description of a sense of hopefulness and how it affected the quality of life. Essentially,

the data collection process aimed to gather enough data from each participant, which could answer the research questions thoroughly. Furthermore, by using a criterion sample, a generalized conjecture could be formed. Specifically, participants were recruited because they had met the criteria, and all participants were willing to disclose their personal experience with treating epileptic symptoms with cannabidiol and past experiences that felt more hopeless. This resulted in a successful form of thick descriptions that answered the research questions.

Dependability

Trustworthiness is also achieved by dependability, as it illustrates congruency across past and present research (Sheperis et al., 2016). Besides the extensive literature review completed before data collection, I made sure to complete audit trails during the data collection process. In addition, I made sure to complete the data collection process the same way with every participant to provide accuracy. All interviews consisted of the same semi structured questions unless a participant emphasized a specific topic, to which I would ask the participant to expand or clarify their description.

Confirmability

Confirmability postulates that participant responses are the basis of research conclusions (Sheperis et al., 2016). I utilized reflexivity throughout the project by noting my personal biases and perspectives and only using the collected data to develop themes and patterns (Sheperis et al., 2016). Essentially, only the voice and descriptions of the participants were used. The idea behind these actions was to preserve the integrity and accuracy of the collected data, the human voice, and the genuine descriptions.

Results

Every participant in this study disclosed sensitive situations, experiences, and emotions. What I felt to be notable during the data collection process was the vulnerability demonstrated by many of the participants. All the participants were willing to talk about past and present hardships, struggles, and thoughts. All participants seemed to speak candidly about their decision to use cannabidiol, experience with epilepsy, and perception of the child's quality of life. All participants also stated the parental decision to do what they felt benefited their child the most. This said I felt that the results from the data collection process are accurate and genuine. This section will discuss the themes that emerged and descriptions that supported those themes. The discussed themes also help answer the two research questions: how do parents describe a sense of hopefulness or lack thereof as it is influenced by medically treating their epileptic child with cannabidiol, and if there is change, how does the change in hopefulness affect their quality of life as described by the parents of these children?

Because the research questions asked about a sense of hopefulness and how that sense of hopefulness influenced quality of life, at the beginning of every interview, every participant was asked to describe hope and quality of life. The following is a synthesis of the answers to support how the surmised themes answer the research questions.

Hope: Hope is the strength to never give up, hope can be a higher power, hope is knowing that things can/will get better. Hope is being able to look forward to the future positively, and just having a content sense of well-being and having faith.

Quality of life: Being able to live your life and feel good about it, having good health, and good people around you. Quality of life is being able to experience happiness, love, joy, genuine connections, independence, being able to be your whole person, and feeling secure. Quality of life is something you should prioritize.

Theme 1: Experiences With AEDs

This first theme was common among many of the participants when discussing their decision to treat epileptic symptoms with cannabidiol. Most of the participants communicated a challenge when treating their child with AEDs. Experience with AEDs and personal research as described by the participants all lead to a decision for alternative treatments, a time that most participants communicated as experiencing a sense of hope. Essentially, participants stated seeing their child experience major side effects such as chronic fatigue, cognitive delays, personality changes, a surge in emotional dysregulation such as anger, and inefficiency to reduce seizures. One participant, P2, described her experience with using AEDs for her child's epilepsy:

We were literally at the end of our rope, it was awful, he was having 88 seizures a day, he was not happy, I was not happy, it was awful, just awful. So we tried the traditional route where they gave us medication that only seemed to make it worse and new problems popped up, so it was very hopeless, and really it came down to Googling alternatives for epilepsy...after the first dose of cannabidiol, he went to took a nap and after 3 hours, he woke up a different kid... he only had a couple of seizures a day, but he can run around and not be a zombie, not sleeping all the time, and not having anger issues from all of his prescriptions.

Another participant, P5, described a similar experience stating that

I felt very hopeless on AEDs ... my son was having sleepless nights and he didn't have an appetite, he was in a fog all day long, and when you see your child like that, how they are kind of hopeless, and you think why am I in this terrible cycle?

All participants were asked at the beginning of every interview to describe a sense of hope and quality of life in general. When deciding to treat their child's epileptic symptoms with cannabidiol, it was a common theme that the possibility of providing their child with a better quality of life was the reason for utilizing it as a treatment. Essentially, all participants either experienced negative side effects or researched the negative side effects of AEDs and felt that using cannabidiol would positively affect the quality of life. P4 described how the quality of life was positively affected by cannabidiol treatment by stating the following:

The sky's the limit you know. There was a time when I thought, she's never going to be able to drive, how is she ever going to, what is her quality of life, is she going to be an adult, and what, live with us forever because she's a fall risk, and how I see her living whatever life she wants, she's so beautiful, so she gets to be her genuine self.

P8 said,

Side effects from AEDs were awful, no sleep, hair fall, lethargic, mood swings. Hope was given to AEDs, it's only when the meds failed that using cannabidiol gave me hope again. We feel that using cannabidiol does no or little harm compared to AEDs. Sleep is much better, able to go for long walks, happier

environment, get involved in normal activities without parents restricting the child. We are not harming but enhancing our quality of life.

Theme 2: Frequency of Seizures

As noted in the literature review, parents consistently reported that the unpredictable nature of epilepsy was a source of distress and emotional turmoil due to the frequency of seizures and the inability to predict when they would come and how much it would affect their child (Jones & Reilly, 2016; Szemere & Jokeit, 2015). Within this second theme, all participants discussed how they noticed a reduction in seizure frequency when treating with cannabidiol. This was a major component in how they described a sense of hopefulness, for it had provided the ability to do things a family, relieve stress, and engage in activities that were once inconceivable or even impossible. In addition, most of the participants described how the seizure reduction also contributed to a better quality of life. Many of the participants related the seizure reduction to the ability to feel a sense of stability, peace, and hope. The following participant quotes are descriptions that support this theme:

- After the first dose, my mom noticed, his sister noticed, his dad noticed, everybody noticed it ... to be happy and run around and ride a bike with two or three seizures a day. (P2)
- We're definitely seeing a reduction in seizures for sure and it has opened up her ability to be able to try new foods, she can have a birthday cake at the birthday party now instead of having to skip out on that since it is a trigger. She's going to start preschool this year and I have a lot more hope, I'm

hopeful that she'll have a good school experience. She has a falling type of seizure that just comes out of nowhere, and we were worried about her falling, so we don't have those worries anymore, she can climb, she can run, she can play. (P6)

- Her seizures went from 100 plus a day down to a minimal 10-20 quick fast ones. It has given me hope. I just want her to be comfortable. Given she is having less seizures, it has helped quality of life at home. I can take her out in public without worrying about seizures. There is pain control, decreased number of seizures, decreased duration of the length of seizures—all these combined increases hope. (P3)
- I can now rescue seizures immediately by rubbing CBD on his gums. In the past, seizures would continue on to the point where my son would be hospitalized and I had to call 911, almost weekly sometimes. I also don't have to use valium as a rescue as often and then live with the side effects of bad behavior, constipation for days to weeks afterward...we are able to enjoy life more in general. (P7)

Theme 2: Independence

Most of the participants described a sense of independence experienced by their child with epilepsy and discussed how that sense of independence would not have happened with traditional AED treatment. These participants would describe how their epileptic child would behave and interact before and after cannabidiol treatment. Many participants also communicated how they saw a change in independence presently, and

how they felt the independence would affect their future as well. Essentially, independence for their epileptic child was an additional factor in providing a sense of hope and better quality of life not only presently but also for the child and family's future. One participant (P9) specifically expanded on her experience with observing independence and how it affected her child and the family:

I saw a lot of improvement and not just the seizures, she was able to communicate with her IPAD, she would hit her buttons better...it gave her a voice, she's brilliant, she got all A's last semesters. She told me she said she's not dying. Her goal is to go to Ireland and type without my help and support.

This participant described her experience as challenging and filled with hardships. She described seeing her daughter not communicating to being able to interact and communicate with her sibling. Fundamentally, her child having a voice was a demonstration of independence for she was communicating her needs.

Another participant (P3) also stated:

My son, I don't know if he'll ever be able to toilet himself, but we're all different when comes to quality of life. So, quality of life to me for him would be given independence to change his own diaper or something like that, where he can be as independent as possible and happy being that independent to his maximum potential, so basically just being what he wants to be in his own terms, whatever that means to him. I was always really scared to make that jump, but there comes a point when you feel hopeless...we have seen years of improvement. Six months ago, we were talking about getting a wheelchair-accessible van, getting him fitted

for a wheelchair, which we did do, and it has been sitting in the garage since it was delivered, which is like a blessing to me.

Similarly, other participants brought up independence and described how using cannabidiol helped the family interactions as well.

Quality of life is being pain-free and being able to access things that you need to live life independently, as independently as you can, having resources and not going through pain. I think pain is the biggest thing for me in regard to the quality of life. Quality of life will be better; she'll be able to like participate. It has helped with things like cognition, alertness, she's playful. We were hopeless and we felt helpless, you get stressed out and frustrated, there was definitely some strain and stress between the family. Like my boyfriend's pretty good at being patient but with everything we've gone through, my patience is so short now. I'm like why are you doing this? I know it's involuntary but it's so stressful to me that I just get mad and now it's easier to be like ok, I can do something (P4).

P6 similarly stated:

She's living, she's a lot more normal kid you know. Before we got control of the seizures, we kind of just wanted her to be in a bubble, just trying to protect anyway we could. We had to bring all of her food with us wherever we went, so just a day trip somewhere I had to portion and weigh, and you know what, we couldn't eat out because the diet was strict for seizure control. You never want to be that parent that's overbearing. You're willing to kind of let go because you trust that the cannabidiol will help.

Other participants described independence through behaviors and the need or decrease in supervising their child.

I had to keep an eye on her at all times. If it wasn't me, it was my husband, or my mom, or anyone else around who could help make sure to catch her or be there if she seized up. That was a constant constant thing. After using CBD, she was able to play on her own, she could sit on her own, she could do something, I could go to the bathroom and not worry that something was about to happen. I saw her do things on her own... looking me in the eyes, holding herself up, picking up toys, and moving them around, that's what you want for your child (P4).

Theme 4: Advocacy

Throughout the data collection process, many of the participants described their responsibility and desire to advocate for their child. Parents would communicate how it was their parental duty to provide a better quality of life for their child. As previously discussed in the literature review of Chapter 3, cannabidiol is not a formal medical treatment. Because of this, parents often are encouraged to use traditional treatments for epilepsy such as AEDs. Theme one explored the experiences with AEDs and the different results achieved by using cannabidiol. This theme emerged as parents continued to discuss their desire to provide a better quality of life despite challenges with treatment and epilepsy symptoms. The following are excerpts from interview and journal responses that support this theme.

- We tried to do the traditional route where they gave us medication, only it seemed to make it worse, and start new problems, so it was hopeless, and

it really came down to Googling like alternatives, and it was really like, we got nothing to lose, we lose just by trying. My doctor wanted to add more prescriptions, and I flat out said no. After six months of alternative treatments with cannabidiol, he was seizure-free, and the doctor, I think he finally called me and said to me you've done really well for him. You have one job as a parent, and that's what your job is. You exhaust your options, I'm not against any treatment, you just do what you have to do. I was scared at first, but I was really hopeful after we tried (P2).

- I didn't know what else to do. When I first tried to talk to doctors about CBD oil (cannabidiol), like my grandma takes it for arthritis, everybody just looked to me like why would you do that to your child, like I was telling him to smoke weed or something, it was so like it hurts your feelings as a parent you know it was just like, I'm not trying to harm my child, I'm trying to help him. On the pharmaceuticals, he was experiencing all the side effects, he was having sleepless nights, he didn't have an appetite, he was in a fog all day long. The goal was increasing quality of life, all I wanted was for him to be able to use his brain and become a little person (P3).
- Our daughter was under 2 years old when she was diagnosed, she was so small. I started reading about the medications involved and available for epilepsy and their side effects. I was very hesitant to jump on that train right away, and so I decided that we wanted to exhaust every holistic

option that we could before going to medication and CBD was sort of at the top of the list just because we know it had helped other people to treat symptoms of epileptic seizures. She's a tiny brand-new body to this world, in order to ensure a better quality of life, you overcome those obstacles and we will do anything for her (P6).

Theme 5: Genuine Personality

Genuine personality evolved as participants started describing a better quality of life. Also, for most participants, seeing their child come out of a fog and becoming more cognizant gave them a sense of hopefulness that treatment was working, that there was a chance to connect with their child on a different level. It allowed the child with epilepsy to show their emotions and the parents the ability to engage and react to the emotions and behaviors, not just a medicated induced impression of their child. One participant (P9) went into detail about seeing her child do the things that she wanted to do:

CBD has so much hope for us, for her account, she is the most fantastic artist, and has drawn since she was six, I mean, she's like nothing else, she writes her own music to play the cello, ukulele, and guitar, and she sings, and she writes stories. This way gives her the opportunity in spite of the bumps in the road, she still gets to be her, totally unaltered form of her.

Another participant (P6) described one of her reasons to explore alternative treatments for epilepsy, due to research and prior knowledge.

One of the biggest things that I looked at were the AEDs and the side effects, and to see your child become so angry and kind of lose their personality...the Keppra

(AED) was enough to just make her very angry and agitated, but I can't do that to a tiny developing brain.

Essentially, when confirming my interpretation, this participant agreed that one of her fears of using AEDs was losing her child's personality, and not giving her child the opportunity to be herself. In addition, because of her child's age, she wanted to find a treatment that she felt would be less dangerous.

Genuine personality was critical for most of the participants in this study. Many of the participants had experienced AED side effects and described how that experience made them feel helpless and that quality of life was low for the child and the family. One participant (P11) described this experience in the following.

It was that constant fog that really got to me. It seemed like she was there but not there. What do you do with that? I mean my child didn't interact, her eyes were glossed over, she didn't react too much, and it felt like the life was taken out of her. Her diarrhea got bad to the point where she was getting severe rashes, I didn't like it, not for her, not for me, not for anyone. Who would want that? After the CBD, we started seeing her react to us. Her brain was working. She was showing me how she felt about something. I could see her get happy, sad, or upset and it's silly, but that's her, that's her personality.

This last excerpt also demonstrates how using cannabidiol had influenced a sense of hopefulness and better quality of life that resulted from their child showing their genuine personality.

Now she gets to be herself, and I've never seen that. The seizures themselves are cut in half, she can have a life, and be able to go outside. Now she wants to type, have relationships. I can see that she has this need to have friends, she's not isolated from her peers, she gets to be her genuine self. She has a year younger sister, and they don't get along very well. But that's just it, she's not just having a seizure, she is able to say, "you're being dramatic". She is more open and communicated with her sister and she will voice if she wants to be left alone, watch a movie. She is standing up for herself, she has boundaries. You know what bothers her now, like when you have to ask permission to touch her. She didn't have that voice before. We get lots of eye-rolling and more facial communication, I can see her emotions and expressions. I have a real smile with eyes that light up (P9).

Theme 6: Hopeful Future

A hopeful future is crucial for a sense of hopefulness and a positive quality of life. As mentioned throughout this project, hope theory contributes to how individuals respond to challenges and obstacles they may face. A sense of hopefulness can affect life satisfaction and a sense of relief. Hopefulness can reduce feelings of depression, stress, and anxiety in addition to affecting a sense of control and positive change for the future. Most of the participants described how their sense of hopefulness had affected how their perception of their child's future and their family's future. One participant (P3) stated:

He's so much more social and so much more engaged with his environment, it's like he's out of the fog, so he's more willing to interact, and I think that is what is

a huge thing that opens the door for the kids to communicate with one another even if they have no words, classmates, and things that's just I think, he will thrive in his own way. I don't think he's going to be like the little four-year-old down the street, but I'm excited to see, I don't know what he's going to choose, but I definitely set the bar much higher now than I ever did in his life.

Others also described how their family could continue to live a more positive life.

Side effects from AEDs were awful, no sleep, hair fall, lethargic, mood swings. Using CBD resulted in no side effects. We as a family can lead a normal life, happy without fear of injury (P8).

I'm very hopeful now for his future, my sense of hope has been much stronger than in past years, and the quality of life for myself and my family has been so much better. We actually leave our house and do more things now that others take for granted. I thought my life would never change, nor would my son's, and would never be able to develop. I now have a sense of hope that that may change.

I see my son thriving and learning and becoming a typical kid (P7).

Another participant (P10) discussed her personal experience and how using cannabidiol has given her hope for the future.

My little brother's epileptic, and I'm epileptic, so I feel like me as a parent of a child who has epilepsy, I think I'm more understanding, like what it actually feels like to go through a seizure and what it feels like in the hours of seizure and there were many years where like I couldn't drive. We went from 20 [seizures] a day to less than one a month. We could leave the house. I have hope that she doesn't

have to experience all the things that I had to experience, and I hope that she does get to experience what I couldn't. I hope that she gets to drive, and I hope that she has the independence to take a shower by herself and the dignity that comes with being able to take care of yourself without being so reliant on people. So essentially getting to be herself, getting to be independent.

Summary

The purpose of this chapter was to discuss the setting, demographics, the data collection process, evidence of trustworthiness, data analysis, and the results. Chapter 4 illustrated the six themes that emerged after completing data analysis. All six themes helped provide an answer to the main research questions: how do parents describe a sense of hopefulness or lack thereof as it is influenced by medically treating their epileptic child with cannabidiol, and if there is change, how does the change in hopefulness affect their quality of life as described by the parents of these children?

The research questions were answered by the themes that had emerged. The themes discussed in the results section of this chapter demonstrate how parents of an epileptic child experienced similar journeys with wanting to provide a better quality of life for their child. Throughout the interview and journal responses, all the participants described a sense of hopefulness after cannabidiol treatment. The parents discussed the different ways that cannabidiol influenced seizure and pain control, their child's personality, independence, positive interactions, the contrast of using AEDs versus cannabidiol, and their motivation of advocating for a better quality of life for the epileptic child. Despite the challenges of epileptic symptoms and finding the right treatment, most

parents described how a sense of hopefulness was derived by seeing major changes not only with the symptoms of epilepsy, but also with their child's behaviors, abilities, and potential. Furthermore, the results also indicate that quality of life overall was positively influenced with cannabidiol treatment, as illustrated by the ability to do things together as a family, alleviating the stress of seizure frequencies, and seeing their child not only survive, but laugh, play, and live.

Chapter 5 will provide interpretations of the findings, limitations of the study, recommendations, and implications. More specifically, after summarizing the key findings, the research results for this project will be compared to the literature review in Chapter 2. The conceptual and theoretical framework will be revisited, and the limitations of the study will then be discussed. Finally, I will explore and recommend what future research should focus on due to the strengths and limitations of this study. Implications will revisit the positive social change proposed before data collection, analysis, and the results of this study, which is followed by a conclusion.

Chapter 5: Discussion, Conclusions, and Recommendations

In this chapter, the key findings will be further explored. With the use of interviews and journal responses, in-depth descriptions were provided to help understand the different ways that using cannabidiol to treat your epileptic child can influence a sense of hope. As previously mentioned in the Results section in Chapter 4, six different themes emerged. Those themes will be further explored in the upcoming section titled interpretation of findings. Limitations of the study will also be discussed in addition to recommendations for future research. Finally, implications and the conclusion will complete Chapter 5.

Although there has been research conducted to explore the stress, low quality of life, and feelings of hopelessness for parents who have a child with epilepsy, there remains a gap in literature that explores how the use of cannabidiol can affect a sense of hopefulness and quality of life for families who have a child with epilepsy. The purpose of this qualitative study was to explore a sense of hopefulness as described by the parents who have a child with epilepsy and have/are treating their child cannabidiol. In addition, quality of life was explored through the parents' descriptions, which helped answer how a sense of hopefulness was experienced and how using cannabidiol to treat epileptic symptoms also affected their family and child's quality of life.

Interpretation of the Findings

A descriptive qualitative design was used to obtain rich data that could answer the research questions in detail while capturing personal experience with a sense of hopefulness. With the use of interview and journal responses, interpretations were

accomplished with the intention to provide how a sense of hopefulness and quality of life was influenced by using cannabidiol or medical marijuana to treat epileptic symptoms. Six themes emerged as data analysis was completed, and those six themes not only helped answer the research questions, but also brought light to different aspects of how epilepsy negatively affects the quality of life, and how the use of cannabidiol improved, relieved, and alleviated most of those factors. The following section will explore each theme, how each theme confirms the knowledge discussed in the literature review in Chapter 2, while contextually exploring the theoretical and conceptual framework of the study.

Experiences With AEDs

This first theme illustrated the negative experiences with AEDs due to side effects. Parents described how their negative experiences and research encouraged them to look for alternative treatments. Parents mainly reported negative side effects such as fatigue, being in a fog, anger, and personality changes. Similar to the literature review results from this study support the previous study results that indicate negative experiences with AEDs (M. Anderson et al., 2015). Furthermore, within this theme, a sense of hopelessness was described during the use and research of AEDs and was a challenge that all of the participants experienced. Essentially, because of the negative side effects, parents described not experiencing a sense of hopefulness and a lower quality of life due to the debilitating side effects, which also supports results from the literature review stating that side effects, ineffectiveness, and the inability to control seizures often lead to strain, distress, and anxiety (Mendes et al., 2017). Finally, within this theme,

participants demonstrated how the theoretical framework can provide more personal insight with a sense of hopefulness being affected by AEDs. Specifically illustrating the real-life sense of hopelessness when using AEDs and a described sense of hopefulness when using cannabidiol, thereby supporting the conceptual framework of Hope Theory, and literature results demonstrating how feeling hopeless leads to cannabidiol treatments (Leo et al., 2016).

The participants' responses illustrated that they did not experience hopeful thinking when using AEDs and were motivated by the possibility that alternative treatments could provide a better quality of life for them and their child. All participants described a sense of hopefulness as they were able to do things as a family, experience fewer side effects, and see more seizure control. As hope theory postulates, with a sense of hope, individuals can find solutions, options, answers and live for what they want; not give up. This theme firmly indicates that a sense of hopefulness encouraged the parents to find alternative treatments for their child and live for more than what they experienced with AED treatments.

Frequency of Seizures

The most prominent symptom of epilepsy is seizures. Parents from this project reported seizure frequencies that ranged from 1-88 a day before cannabidiol treatment. This theme illustrated how the frequency of seizures was described by all participants as unpredictable, and debilitating. Some participants described how their family life revolved around the unpredictable nature of epilepsy, and how it affected their ability to do normal family things, such as go for a walk, go to the beach, even use the restroom

without worrying about their child having a seizure. All participants in this project reported how the reduction in seizure frequency also influenced their sense of hopefulness. More specifically, before cannabidiol treatment, all participants reported higher seizure frequency, which prevented family interaction, sleep, cognition, and time to heal. This is similar to previous literature reviewed discussing AED inefficiency and experience with epileptic symptoms (Leo et al., 2016).

The findings for this theme imply that cannabidiol treatment reduced seizure frequency, often significantly, which gave parents a sense of hopefulness. Parents described seeing their child endure less physical pain, needing less recovery time from the seizures, and being able to leave their child in a room knowing they would be safe from a seizure. Parents also communicated a sense of relief that there could be more enjoyable moments. As few as they may come, many of these parents illustrated an appreciation for a small break from seizures. Because seizures can be painful, parents described that they felt the seizure frequency reduction improved quality of life because it allowed their child to be pain-free; it also allowed the family to operate and interact more positively together instead of just focusing on seizure prevention or relief.

This information is significant, for it answers the research questions by illustrating a major change in symptom reduction. Seeing their child experience less seizures was encouraging for parents and gave them an opportunity to experience hope that their child would not be in constant pain. With continued research, medical professionals can start providing alternative options to treat epilepsy. Collaboration is key, and parental involvement during treatment planning should be preferred, for it encourages inclusivity,

and other factors that parents witness first-hand such as cognitive delays, personality changes and emotional distress.

Independence

Parents are the main caretakers of a child with epilepsy. Epileptic symptoms require constant supervision and maintenance, and study results indicated that parents often reported the inability to aid with managing the condition and disruption with cognitive and behavioral development (Porter & Jacobson, 2014). Parallel to previous studies, the results from this study suggest that parents felt hopeless and confused when they could not support their child in alleviating the epileptic symptoms, which often lead to more stress and depression (Jones & Reilly, 2016). The results of using cannabidiol to treat epileptic symptoms as reported by the participants of this study illustrated how independence became a leading theme in a sense of hopefulness.

The participants' responses demonstrated how they experienced a sense of hopefulness when they noticed that their child was able to do things on their own. Some participants discussed the ability to sit up and show their emotions, whereas others described their child's ability to do schoolwork, communicate their needs and thoughts. Another participant also discussed their child's ability to play on their own. The participants discussed how this sense of hopefulness helped them envision a better future for their child. Essentially, seeing some forms of independence promoted the idea that epilepsy did not control every part of their child, that their child had a chance to be free from it, even it was temporary, their child was more independent than they were before using cannabidiol. Furthermore, with the added change in independence, participants also

indicated that quality of life was improved, for it alleviated stress, guilt, and depression for the parents while improving their child's ability to independently interact with the world around them.

A whole-person approach incorporates mental, physiological, emotional, spiritual, social, and existential needs (Polley et al., 2016). This kind of approach explores the lack of support or unmet needs with conditions such as cancer or long-term diseases (Polley et al., 2016). Seeing their child demonstrate forms of independence was a psychological and emotional concern that was described by many of the participants in this study. Essentially, expanding treatment options such as cannabidiol, services and resources can provide support for these situations, which could help obtain a sense of hopefulness that will positively affect quality of life. Families will be able to overcome challenges together, feel less isolated and help their child do things for themselves.

Advocacy

Previous literature illustrated how parents frequently reported challenges and difficulty navigating the healthcare system, which lead them to feel unsupported, isolated, and stressed (Mula & Sander, 2016; Steiger & Jokeit, 2017). I found that advocacy was an underlying reason parents held onto when seeking cannabidiol treatment. As previously mentioned, several factors contributed to cannabidiol treatment: negative side effects from AEDs, seizure control, and independence. The parents from this study suggested that they were willing to do what they felt necessary to do to make sure that their child could experience a better quality of life. Parents consistently described a need

to advocate for their child's needs, their well-being, and their chance to live without the burdens and pains of epilepsy.

After personal research and an initial cannabidiol treatment, parents described observed positive changes not only with seizure frequency but cognition, interaction, independence in addition to seeing a genuine personality. Not only did this lead to a sense of hopefulness as described by the participants of this study, but it also encouraged them to advocate for their child because they felt that it would provide a better quality of life for themselves and their child. They no longer felt as hopeless as they did before cannabidiol treatment, they had a direction and motivation to move forward. Essentially, parents experienced a sense of hopefulness and need to help their child live a fuller life.

A sense of hope encourages motivation, ability, and positive self-reflection (Hullmann et al., 2014). Parents wanted to exhaust all options to provide a better quality of life. Study results signify that a sense of hopefulness directly affected parents' ability to perceive the ability to obtain alternative resources and support. Instead of being complacent with the continued symptoms of epilepsy and the side effects from AEDs, parents adopted a different path where their child could be resilient, and their family could do things as a family. A more hopeful family can overcome challenges together and develop coping strategies to manage the long-term consequences of a diagnosis (Santos et al., 2015). To reduce family stress, anxiety, and strain, parents should have the option to collaborate with medical professionals and discuss their fears openly. Rather than treating the symptom, a whole-person approach can help improve the quality of life by incorporating the themes discussed in Chapter 4.

Implementing a whole-person approach can be advantageous for families who have a child with epilepsy, for it treats the social, mental, emotional, and physical consequences of the condition, not just epileptic seizures. As seen in Chapter 4, parents often described their experience with AEDs as an attempt to reduce seizures and nothing else. It would be valuable and strategic for a treatment plan that addressed the mental and emotional needs that are affected by the condition, not only for the child but for the parents as well.

Genuine Personality

In this theme, parents described seeing different parts of their child that they did not see before. Parents recognized that with more cognitions, they were seeing their child react and interact with their environment, the family, and even their peers. Some participants described seeing their child voice their thoughts and opinions more freely. Study results suggested that observing a genuine personality helped the participants experience a sense of hopefulness because their child was given a chance to voice who they were, be who they were, and interact with others as other kids could. Furthermore, participants would compare their child's behavior from when they were on AEDs and many described positive changes such as less anger, more eye contact, and communication.

I found that parents from this study were more willing to stand behind cannabidiol treatment because they witnessed their child outside of the AED fog and were able to see more emotions and behaviors that were age-appropriate, such as boldness, and being opinionated. For these parents, this was their chance to help their child experience a

higher quality of life because it improved alertness with fewer side effects, which aligns with previously discussed literature (Cilio et al., 2014; Hess et al., 2016). Study results also added onto the literature by illustrating changes in parental interaction and stress, indicating that stress was lowered, and positive interactions were more frequent due to the change with cannabidiol treatment. This implies that quality of life can be positively affected when using cannabidiol to treat epileptic symptoms.

The ability to support families who have a child with a medical or mental health condition is vital parents, community, teachers, and providers (Vasilopoulou & Nisbet, 2015). Focusing on recognizing and improving strengths can encourage individual potential and self-worth not only for the children but for the parents as well (Bekenkamp et al., 2014). Without a sense of hopefulness, parents were discouraged; they felt incompetent, guilty, and depressed. Seeing a genuine personality come through increased their sense of hopefulness and motivated the parents to move forward and exasperate options. Rather than reacting to a helpless situation and treating symptoms, proactive solutions can alter these circumstances by focusing on what can promote a life with dignity.

Hopeful Future

For the parents in this study, a hopeful future meant that their child had a chance to live without frequent, painful seizures. It meant not living with negative side effects that kept their child from interacting with family members and peers, being cognitively aware, not having diarrhea, sleeping regularly. A hopeful future meant that their child would get to have chances to do things with dignity, gain independence, demonstrate

their abilities while developing their genuine personality and sharing it with others and the world. Essentially, this theme of a hopeful future is a combination of the other themes coming to fruition due to the sense of hopefulness achieved with the use of cannabidiol treatment. The parents described a change not only in a sense of hopefulness but a change in quality of life because a positive change in the listed themes basically meant the ability to perceive a better life for their family. These findings correspond to past study results illustrating the positive influence cannabidiol treatment could have on relief and child development and the future not only for the child but for the parents as well (Leo et al., 2016; Rosenberg et al., 2017).

Similar to results from previous studies (Fayed et al., 2015; Wu et al., 2014), the parents in this study also consistently reported experiencing stress and helplessness. For these parents, the stress and helplessness motivated them to explore different answers and possibilities, which lead to cannabidiol treatment. Gaining a sense for a hopeful future was a prominent response because before cannabidiol treatment, these parents described watching their child every minute of the day without a break and purchasing helmets and wheelchairs for permanent use. Although epileptic symptoms are problematic and may never go away, parents in this study illustrated that a sense of hopefulness helped them acknowledge that a better quality of life was more attainable for their present and future lives. This is significant in human services because it provides an understanding of what affects the ability to move forward, to be resilient, to believe in their community and themselves. Knowing that there is a hopeful future is indicative of possibilities.

Limitations of the Study

Limitations in this study include only gathering information from parents who use the internet and social media. The recruitment process was completed through a social media platform, so only those who use this platform were included in the study. Thusly, parents who do not use this social media platform were not part of the data collecting process. In addition, all participants happened to women. Although many of the participants were married or in a relationship, all descriptions were provided by women who had a child with epilepsy, not men. It would be crucial to include the descriptions from male parents as well, for it could provide a different perspective and experience when having a child with epilepsy. Although participants were from different parts of the country, another limitation would be the inability to generalize the findings. With a criterion sample, the population followed specific parameters. Furthermore, all the participants in this study reported positive experiences with cannabidiol treatment. It would be necessary to conduct similar studies to explore possible negative experiences, the addition of male participants, and participants who do not use social media to confirm generalization.

Recommendations

The findings from this study indicate that a sense of hopefulness was experienced when using cannabidiol to treat an epileptic child. This sense of hopefulness also fueled the ability for parents to provide their child and family with a better quality of life. The sense of hopefulness as described by the participants of this study seemed to have directly related to a better quality of life, not only through the themes discussed in Chapter 4 but

because it encouraged parents to move forward. However, as previously mentioned, there were some limitations to the study. This section will discuss recommendations for future research.

The first recommendation is to explore this topic while integrating more male parents to obtain a more generalized idea and collect descriptions from male parents and learn their experience with a sense of hopefulness as well. Although study results demonstrate that the participants experienced a sense of hopefulness and aligned with previous studies, it is not inclusive of all parents. A sense of hopefulness must be explored by all caretakers, to inform any family care and medical centers. As recommended by other studies, parents and their experience with having an epileptic child should be further research to alleviate stress, anxiety, depression confusion, and enhance the quality of life (Jones & Reilly, 2016; Wu et al., 2014).

The second recommendation is to utilize different platforms and ways to recruit participants. The study results only include parents who used Facebook and were part of a closed group of parents or guardians interested or use cannabidiol or medical marijuana to treat their epileptic child. Future research should recruit participants from medical clinics, support groups, and other outlets that are not social media. With no cure for epilepsy, future families and children may experience the same stigma, pain, side effects, and stress. Epilepsy diagnosis and the symptoms are highly dysregulating, and parents are confined to specific resources and solutions. With future research exploring the broader population, parents can help provide a better quality of life for their child and family.

Instead of experiencing stigma, stress, and a sense of hopelessness, parents can utilize resources that facilitate inclusion, connection, and healing.

Future research should also include other medical conditions. There are other medical or health conditions that could be treated with cannabidiol. The parents of these children should also be included in research to broaden the experience with a sense of hopefulness and how it affects the quality of life. This would help provide generalizability and understanding of how parents and their children experience and manage onset diagnosis, symptoms, and possible changes in family dynamics and interactions. Finally, a sense of hopefulness can positively affect the quality of life. Parents, in general, can be challenged with a multitude of stressful situations such as illness, mental health, schooling, work, societal expectations, peer pressures, interactions and even quarantine as Covid-19 affected the world ways never expected. Future research on a sense of hopefulness in different circumstances can provide understanding and support for parents, individuals, children and how they all interact with one another. It promotes the ability to live with dignity, thrive and experience happiness.

Implications

The results from this study could help inform medical professionals, family care providers, resource centers, and the community living with epilepsy. With these findings and future research, resources, support, and potential treatment plans can be implemented to increase a sense of hopefulness and better quality of life for those experiencing the same struggles. The results of this study indicate that cannabidiol treatment for children with epilepsy has a positive effect on family dynamics, interactions, and the symptoms of

those diagnosed. Study results also suggest that a sense of hopefulness as described in Hope Theory was experienced by all participants in the study, for it positively influenced self-reflection, ability, potential, and perseverance (Chang et al., 2016).

Quality of life considers psychological, physical, social, and emotional needs (Polley et al., 2016). In order to provide a better quality of life, a whole-person approach should be considered when treating long-term conditions such as epilepsy. Treatment should be more than symptom control, treatment should place value on the person, what they are experiencing and who they can be. Study results illustrated the importance of a sense of hopefulness and how a myriad of factors can affect feeling hopeless. Epilepsy along with any long-term condition should be addressed contextually, with collaboration from parents, families and place a priority on the human experience. Many of the participants described feeling isolated and judged for using cannabidiol to treat their child's condition. Training and a fuller range of interventions should be implemented by the medical and mental health community to encourage a sense of hopefulness to enable a better quality of life.

If the medical community and family care programs would take into consideration the positive experiences with cannabidiol and how it provides a sense of hopefulness and better quality of life, parents would be less likely to experience anxiety, stress, and depression that comes with finding the right treatment. Study results show that stigma is still experienced by parents of epileptic children, not only for the condition but for their decision to treat their child with cannabidiol as well. With continued research, community support can be developed to help these parents find resources, feel less

isolated and be part of a community that listens and learns from their voice. As the participants in this study suggested, being part of that closed Facebook group helped them research, learn and feel a sense of community that made them feel less alone. Educating medical and mental health professionals should create a sense of inclusivity, and help the professionals understand that experience, the condition, and the consequences of it. This should lessen the stigma and empower those who already face challenges daily because of epilepsy. Overall, with more information, parents will feel supported enough to provide a better quality of life for their child and themselves.

Conclusion

A sense of hopefulness can alter a situation; it can provide motivation, alleviate stress, promote positive thinking, interaction, and self-reflection (Smedema et al., 2014). A sense of hopefulness can also support a better quality of life (Pompili et al., 2014). With hope, individuals can overcome obstacles, feel capable, see their potential, and move forward (Smedema et al., 2014). Being able to move forward is a major result of experiencing a sense of hope; it encouraged parents to uphold standards that fostered positive interactions and a positive future.

The purpose of this study was to explore a sense of hopefulness as described by parents who have or are treating their child with cannabidiol. That sense of hopefulness was then further examined to describe how it also affected the quality of life. A component of this study was developed with social constructivism, to give the parents a voice, to shed light on their experiences, and explore a challenging situation from those who live it. Their experience with hopefulness illustrated their desire to continue

cannabidiol treatment, while also having more faith in their abilities as parents. This sense of hopefulness encouraged participants to explore more homeopathic remedies and cannabidiol instead of the usual AED treatment. Seeing their child thrive in different ways fostered a sense of hopefulness and encouraged parents to believe that a better quality of life could be achieved.

Study results indicate that parents were/are willing to do whatever it takes to ensure that their child is living their best life, by their standards and on their own terms. Epilepsy is a debilitating condition that affects the diagnosed and their family, it is a condition that forces a standard of living that the participants of this study refused to accept. With a sense of hopefulness, parents from this study were able to contend with the challenges of epilepsy, explore possible solutions, and achieve a sense of peace. Using cannabidiol to treat their epileptic child encouraged parents to trust themselves, trust that their child could experience a better life, and trust that their child could experience life with dignity and value.

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Appendix: Semi-structured Interview Guide

Interview Questions for Semi-structured Interviews:

1. How would you describe a sense of hope?
2. How would you describe quality of life?
3. How would you describe a good quality of life?
4. Did you decide to use Cannabidiol in hopes of changing the quality of life for you and your family?
5. Has using/used Cannabidiol to treat the symptoms of epileptic seizures influenced a sense of hope for you?
6. Has using/used Cannabidiol to treat the symptoms of epileptic seizures influenced the quality of life for you and your family?
7. Would you describe any differences in your sense of hope before using Cannabidiol and after using Cannabidiol to treat your child's epileptic symptoms?
8. Would you describe any differences in your quality of life before using Cannabidiol and after using Cannabidiol to treat your child's epileptic symptoms?
9. Due to your experiences with Cannabidiol and how it has affected your sense of hope, would you recommend it to others, and why or why not?
10. What factors in using Cannabidiol has affected your sense of hope?
11. What factors in using Cannabidiol has affected the quality of life in your household?
12. What kind of future do you see for your child, and family?