Summer 7-14-2022

"SOMETIMES YOU JUST WANT TO BE ANOTHER PARENT AND ANOTHER KID AT THE PARTY": EXPLORING PARENTAL NARRATIVES SURROUNDING DISCLOSURE OF CHILD'S EPILEPSY

Lisa German
University of New Mexico - Main Campus

Recommended Citation

German, Lisa. ""SOMETIMES YOU JUST WANT TO BE ANOTHER PARENT AND ANOTHER KID AT THE PARTY": EXPLORING PARENTAL NARRATIVES SURROUNDING DISCLOSURE OF CHILD'S EPILEPSY." (2022). https://digitalrepository.unm.edu/cj_etds/149

Lisa M. H. German
Candidate

Communication and Journalism
Department

This dissertation is approved, and it is acceptable in quality and form for publication:

Approved by the Dissertation Committee:

Judith McIntosh White, PhD, Chairperson

David Weiss, PhD

Jaelyn deMaria, PhD

Paige Toller, PhD

"SOMETIMES YOU JUST WANT TO BE ANOTHER PARENT AND ANOTHER KID AT THE PARTY": EXPLORING PARENTAL NARRATIVES SURROUNDING DISCLOSURE OF CHILD'S EPILEPSY

by

LISA GERMAN

B.A. Speech Communication, University of Nebraska-Omaha, 1996
M.A. Communication Studies, University of Nebraska-Omaha, 2004

DISSERTATION

Submitted in Partial Fulfillment of the
Requirements for the Degree of

Doctor of Philosophy
Communication

The University of New Mexico
Albuquerque, New Mexico

August 2022

DEDICATION

I dedicate this dissertation to my husband, daughters, and parents, without whom none of this would be possible. While I spent hours studying and researching, my husband made sure my daughters were fed, well cared for, and entertained so I could maintain my focus on my dissertation. My parents both received many calls wanting to share ideas, talk through problems, and yes, a few panicky and teary calls as well.

I would be remiss if I didn't also express my deep thanks to the Moms who were so willing to share their deeply felt, lived experiences with me, a total stranger. I will be forever thankful for their generosity with their time, and openness with their thoughts and feelings.

ACKNOWLEDGMENTS

To Carlos: While I may have written this dissertation and conducted the research, we both continue to live with the uncertainty of having a child with epilepsy, and the challenges involved in deciding to conceal or reveal the diagnosis. I am so thankful for your support and the team we are. And yes, I am now done with school.

To my beautiful daughters, Isabela and Ciara: Thank you for trying your best to understand sometimes Mommy couldn't chat or watch TV with you while I was writing. I hope you remember for your own future that you can do anything you put your mind to, even if it takes longer than anticipated.

To my Parents: Thank you for always being there for me throughout my life, and understanding my drive and determination to keep achieving. You have been part of the epilepsy journey, as well as my doctoral journey, and I'm so thankful for you.

To my PhD cohort: I couldn't have asked for a better group of colleagues, friends, and family. Even now, with all of us spread out across the country, you are still my family and I treasure our group chats and monthly Zoom calls.

To Gabriela Morales and Emily Lilo: Little did I know upon meeting the two other health communication people in my cohort, that you would become the sisters I never had. Even when we can't talk for long periods of time, we still maintain contact via funny memes or short text messages. I know if I ever need anything, I can call you.

To Judith: While originally assigned to me as my "temporary" faculty advisor my first semester at UNM, I knew I wanted to continue working with you as soon as I met you. The entertainment education class you taught was my favorite class of my graduate career, and I hope to continue learning more in this subfield. Thank you for your support and guidance throughout my doctoral program.

To Paige: When I decided I wanted to write my dissertation on disclosure, I knew you were the person to talk to about possible theories and where to go from there. Thank you for your guidance, both theoretically and with regard to methods, as I designed and wrote my dissertation. Thank you for being a frequent sounding board as well.

To David: One of my first memories of you was when you came to speak to my graduate seminar. As a student who was teaching full-time while working on my PhD, some advice you shared that day about when you were working to complete your research and teaching was very helpful to me. I am thankful for your kindness, advice, and excellent editing suggestions.

To Jaelyn: I am so lucky to have taken the intercultural exchange program course when you were one of the faculty members. Your guidance regarding the importance of personal stories and narratives impacted me greatly, as did watching the ways you interacted with all the students from different walks of life who were taking the class. I truly appreciate your willingness to serve on my committee.

"SOMETIMES YOU JUST WANT TO BE ANOTHER PARENT AND ANOTHER KID AT THE PARTY": EXPLORING PARENTAL NARRATIVES SURROUNDING DISCLOSURE OF CHILD'S EPILEPSY

by

Lisa German

BACHELOR OF ARTS, SPEECH COMMUNICATION

MASTER OF ARTS, COMMUNICATION STUDIES

DOCTOR OF PHILOSOPHY, COMMUNICATION

ABSTRACT

Epilepsy is currently the fourth most common neurological disorder in the world (Epilepsy Foundation, 2022). However, it is largely misunderstood by both the public and those with epilepsy. In addition, epilepsy is still a stigmatized condition in most areas of the world.

In part due to the stigma, as well as the impact on quality of life factors, disclosure of an epilepsy diagnosis can be a struggle for those with epilepsy as well as their parents or caregivers. Therefore, this study explored disclosure challenges faced by parents of children with epilepsy, utilizing Communication Privacy Management theory and Stigma Management Communication theory to guide the research.

After interviewing 15 mothers of children with epilepsy, all of whom resided in the United States, seven primary themes emerged in relation to epilepsy disclosure and experiences. These seven themes were: a) everyone needs to know; b) "sometimes you just want to be another parent and another kid at the party"; c) positive social support; d) negative social support; e) providing support to others; f) quality of life; and g) stigma.

Given the prevalence of epilepsy, and the public misunderstanding of the condition, these findings could be used to continue helping educate the public about the condition. In addition, the findings could be helpful to parents of children newly diagnosed with epilepsy as they make decisions about disclosing the condition to others. The findings also add to the literature in CPM regarding disclosure and healthcare advocates. The disclosure practices described here also add to the literature on ways individuals determine stigma management strategies used.

TABLE OF CONTENTS

Chapter 1:
Introduction

In March of 2012, I was getting dressed for work when I heard an odd noise in my room. My three-year old daughter had climbed into our bed during the night, as was her habit, so I wondered what she was doing. When I peeked in the room, I saw her convulsing on the bed. Not knowing what was happening, I yelled for my husband and ran to her and picked her up. She was still seizing, her body was stiff at times, and her eyes were rolled back in her head. In a panic, I dialed 911 and began telling the operator what was happening. While on the phone with the operator, I passed out and fell straight forward on my face in a full-blown panic attack. I was afraid my daughter was going to die or end up brain dead.

When the emergency medical technicians (EMTs) arrived, my daughter was still barely awake and non-responsive. The EMTs immediately took my daughter down to the ambulance and started an IV, with no objections from her. This added to my concern as she allowed strangers to pick her up, take her into a vehicle, and start an IV with no apparent awareness of what was happening. One of the EMTs started explaining to me that she was in a postictal phase, and this was a normal response after a seizure. I had never heard the term and just stared blankly at him. Later, I found out that the postictal phase is the recovery phase after a seizure and common symptoms include feeling sleepy or confused, memory loss, and slow or lack of response (Epilepsy Foundation, 2022).

Upon arrival at the emergency room (ER), personnel immediately took her to a room and began checking vitals and asking us questions. We answered, no, she hadn’t been sick; no, she didn’t have a fever; and no, we didn’t have a family history of seizures.

My daughter came alert about an hour after arriving at the ER, and thought that the "owie" on her arm where the IV was inserted was why she was there. She had no memory of what had happened. We received very little information from the ER personnel other than she was now stable, blood tests were normal, and we should follow up with a neurologist.

Sadly, our story is more common than one might imagine. Many families report a lack of information from medical personnel and often feel lost and scared, wondering what is happening to their child. Even when meeting with a specialist, families often do not receive the information they need or want. In our case, when we met with the neurologist, we were told it wasn't uncommon for a child to have one seizure and never have another. However, he was ordering an MRI and EEG to aid in diagnosing any potential condition. Luckily, my mother worked in a medical field so I knew many medical terms and I had done some research on seizure disorders before our appointment. Otherwise, it would have been difficult to follow what was happening with the medical terms used and the constant worry about my daughter in the back of my mind. In some cases, simply hearing the medical jargon and tests that need to be run would be overwhelming for families.

After her MRI and EEG, the neurologist called to say her MRI was normal but that her EEG showed abnormal activity consistent with a person with epilepsy. He told me that they don't start medication when a child has only had one seizure, and to call him when she had another seizure. It wasn't until I hung up the phone that I realized he said "when" she has another seizure, not "if" she has another seizure. For the next three months we lived in a state of hypervigilance, with my daughter sleeping in our room since her seizure occurred when she was asleep. In June of 2012 she had another tonic-clonic seizure, previously referred to as a grand mal seizure. This is the type of seizure most people picture when they hear the word “seizure” where the entire body stiffens, and uncontrolled rhythmic jerking occurs. In the ER, again they checked her vitals, then called the neurologist. Our “official” diagnosis of epilepsy was when the nurse entered the room with medication and said the neurologist wanted her to start on an anti-seizure medication. Once again, our experience was not an unusual one…

After her diagnosis, we lived in a state of uncertainty, with many ups and downs. She would have a month or two where she was seizure free, then would start having seizures every three to seven days. All of the seizures occurred when she was asleep. We received little to no information from the medical professionals about epilepsy itself, possible effects on my daughter’s well-being from the diagnosis, or regarding support for my daughter and our family. The times we did receive any information was because I asked specific questions. Most of the information we learned about epilepsy was due to my research into the condition and possible effects of the condition itself and the medication.

In the ten years since her diagnosis, she has “failed” five medications. which means either the medication wasn’t working for her, or she had side effects that required a change in medication. We have also dealt with some learning delays and some behavioral issues, as well as continuing to live in a state of uncertainty about if or when another seizure will occur. Personally, I have since been diagnosed with anxiety and panic attacks, which, as I discovered through my research, is not unusual in parents of children with epilepsy (CWE). Looking back, I feel like for several of those years my family was living in a state of survival. All we could do was get through each day and keep moving forward. We didn't know where to look for support from others or what kind of support we might need, we had to find ways to explain to a young child what it meant to have epilepsy, and also consider how we would manage sharing her diagnosis with others.

Our first experience with disclosing her condition was when we went to take her back to daycare after her first seizure. I vividly remember the look on the daycare director's face when I disclosed that she had a seizure and might have epilepsy. Her eyes widened, her face showed an expression of shock or fear and she then whispered "she had a seizure?" Talking with her specific daycare teacher was similar, which led me to look for a new daycare. I checked several and chose one based primarily on their reaction to my disclosure about epilepsy. The director didn't even blink when told, she informed me what steps they would take to manage it, and then also let me know that their cook had a child with epilepsy, and they would call her (the cook) to help if my daughter had a seizure. The teachers in her room didn't express dismay either when told, and even made sure that her cot during nap-time was right next to them in case of a seizure.

Disclosure has continued to be a struggle for us. We have experienced positive reactions such as the reaction of the daycare director at the location we moved her to, neutral reactions such as a simple nod and saying "okay," and negative or fearful reactions such as that expressed by the first daycare director. Part of the struggle regarding disclosure has been that my daughter, who is now 13 years old, doesn't like us to talk to others about her epilepsy. She is a very private person in general, so it is hard to know if it is primarily because she is a private person or if it is related to stigma of the condition that she has picked up on. However, for her own safety it is imperative that we tell others about her condition, especially if they will be caring for her, such as daycare teachers, elementary school teachers, sports coaches, and other parents. In addition, by telling others about her condition, I have been able to share experiences with others who either have epilepsy or have a loved one with epilepsy.

Similar to my own experiences, the authors of a study based at two public hospitals in Athens, Greece, found that parents of CWE struggled with the disclosure of epilepsy and the lack of information about coping with the condition (Kampra, Tzerakis, Thomsen, Katsarou, Voudris, Mastroyianni, Mouskou, Drossou, Siatouni, & Gatzonis, 2017). Specifically, the authors interviewed 91 parents of CWE and identified two main themes: “The Disclosure of Epilepsy” and “Absence of Adequate Information About Coping with Epilepsy” (Kampra et al., 2017, pp. 96-100). As found in other studies, parents of CWE reported that the potential social consequences of the disorder were the main challenge, rather than the management of the medical disorder itself.

Parents indicated that after acceptance of the diagnosis, they felt they had adequate information to handle the medical issues such as medication and first aid (Kampra et al., 2017). However, they didn’t feel they had enough knowledge about the emotional and behavioral effects of the condition (Kampra et al., 2017). Interestingly, the authors also found a significant statistical relationship between disclosure of epilepsy and the level of parent education as well as the parent’s employment status. Parents with a college education talked with their child about epilepsy at a significantly higher rate than did parents with either a primary or secondary education (Kampra et al., 2017). In addition, “parents who were employed talked with their child about epilepsy at a higher rate (93.8%) than those who were unemployed (77.8%)” (Kampra et al., 2017, p. 97).

Three subthemes were included within the main theme of “Disclosure of Epilepsy”: (1) “How can I explain epilepsy to my child?”, (2) “Why should I inform school staff about my child’s epilepsy?”, and (3) “Why should I tell anyone about my child’s epilepsy?” (Kampra, et al., 2017, pp. 97-99). With regard to the second main theme, “Absence of Adequate Information About Coping with Epilepsy,” two subthemes emerged: (1) “Where should we seek help to cope with our child’s epilepsy after our visit to the doctor?” and (2) “No expert support in regular schools” (Kampra et al., 2017, pp. 99-100). Parents as a whole felt that while they received satisfactory information from the CWE’s doctor about medical treatment of the condition, they found an absence of experts to offer counseling about the psychosocial aspects of coping with the condition (Kampra et al., 2017). Parents expressed a need for help in terms of coping with everyday aspects of the condition as well as a need for social support, including both professional and peer emotional support (Kampra, et al., 2017). Overall findings indicate parents were especially concerned about disclosing the condition to their child, and the majority were hesitant to inform school personnel about their child’s epilepsy (Kampra, et al., 2017).

The following sections will provide more information about epilepsy overall, a discussion about epilepsy and disclosure, and the rationale for the present study.

Epilepsy

Epilepsy is a chronic neurological condition that poses unique challenges for people living with it, as well as for their families and caregivers. For most, “the impact of epilepsy goes well beyond the seizures” (England, Liverman, Schultz, & Strawbridge, 2012, p. 266). As Elliott and Shneker (2008) describe, patients with epilepsy live with uncertainty with regard to when they will experience another seizure and where it will occur. This is particularly stressful when considered in addition to the demands associated with any chronic condition such as diagnostic tests, doctor’s visits, and medications (Elliott & Shneker, 2008). At the same time, those living with epilepsy must also cope with the associated social stigma of the condition, public misunderstandings of the condition, and potential challenges in the workplace and educational institutions (Elliott & Shneker, 2008; England et al., 2012).

Due to the lack of public understanding of epilepsy, and associated stigmas, those with epilepsy and their families may experience a lack of social support, social isolation, and possibly discrimination (England et al., 2012). Personal experiences include reports of the condition being misunderstood, misinterpreted, and inappropriately handled (“Public education in epilepsy,” 2003). Due to many of these factors, individuals with epilepsy report lower quality of life; this is true for both children and their parents.

One study based in Taiwan interviewed 10 parents who had children between the ages of three and seven who had been diagnosed with epilepsy. The author first asked parents "What has this experience been like for you and your family in the first one and a half years after your child was found to have epilepsy?" (Mu, 2008, p. 546). The parents’ perceptions of ways this change to the family affected them fell into three overall themes: “Parental Psychological Reactions,” “Parental Coping Patterns,” and “Family Resources” (Mu, 2008, p. 546).

“Parental Psychological Reactions” included several sub-themes such as pain associated with the stigma of epilepsy, anxiety attacks and fear of impending loss, and psychological involvement in the child's condition (Mu, 2008). The author reported that "the essence of the parental psychological reactions was that of being emotionally traumatized and physically exhausted" (Mu, 2008, p. 546). Not only did parents report emotional pain related to stigmatization of the condition but also the stress due to the "loss" of a "healthy child" (Mu, 2008, p. 546).

"Parental Coping Patterns" also included several sub-themes including reframing parental roles, facing the social challenge, and assisting the child's social reintegration (Mu, 2008). The third major theme, "Family Resources," "reflected family resilience as the most important resource working at the individual, dyad, and family systems levels that helped them to cope with their stress and to maintain family functioning and integrity" (Mu, 2008, p. 548).

Epilepsy Disclosure

The stigma of epilepsy, social challenges associated with the condition, and concerns the child may have all affect the decision to disclose to others that a child has epilepsy. The authors of the "Future in Mind" report, commissioned by the International Bureau for Epilepsy (2006), conducted a survey of 214 children and teenagers from 13 different countries, finding that more than one-third of their respondents kept their epilepsy a secret at some time. Reasons included a fear of being treated differently and the belief that others shouldn't know. Parents and caregivers (N=516) from 15 different countries were also surveyed. Of these parents, 23% chose to keep their child's epilepsy a secret, in large part due to fear that people would treat their child differently (International Bureau for Epilepsy, 2006). In addition, 42% of parents reported witnessing different treatment for their child with epilepsy. The reports authors concluded that this “demonstrates that stigma still exists around epilepsy and this stigma has an impact on the perceptions and behaviour of children and teenagers with epilepsy and their families” (International Bureau for Epilepsy, 2006, p. 7).

A review of existing research on epilepsy disclosure and stigma by Lambert, Gallagher, O’Toole, and Benson (2014) explored the variety of factors that may prevent children and families from sharing a diagnosis of epilepsy with others. The authors report that, based on their review, children experience a great deal of apprehension, as well as other challenges, with regard to disclosing the condition to others such as family, friends, and teachers (Lambert et al., 2014). The children in the studies reviewed reported the possibility of being rejected, teased, bullied, and isolated if they were to disclose their epilepsy to others (Lambert et al., 2014). Given the fear of being ostracized by family, friends, and others, the authors maintain it isn’t surprising that many “children try to keep their condition a secret” (Lambert et al., 2014, p. 23). However, the authors also conclude that by keeping the condition a secret, children are at a greater risk of “experiencing higher perceived stigma and lower self-esteem, self-efficacy, and quality of life” (Lambert et al., 2014, p. 23).

Social Support

One reason children and parents may choose to disclose an epilepsy diagnosis is to receive support from others. According to Wright and Bell, “Decades of social support research have focused on the relationship between social support and health outcomes, and empirical findings indicate benefits to both mental and physical health” (2003, p. 40). Social support has been defined as “verbal and nonverbal communication between recipients and providers that reduces uncertainty about the situation, the self, the other, or the relationship and functions to enhance a perception of personal control in one's experience" (Albrech & Adelman, 1987, p. 19). Similarly, Albrecht, Burleson, and Goldsmith (1994) suggested that supportive communication includes both verbal and nonverbal behaviors, and is the primary way individuals interact in both support-seeking and support-giving situations.

Communication scholars have studied social support in relation to conditions such as cancer, HIV/AIDS, and depression, to name a few. For example, a study by Wright (2011) examining social support in an online cancer community suggested that both those with cancer and their family members may benefit from increased emotional support with regard to reduced stress. In a study looking at the relationship among communication competence, social support, and depression in college students, researchers found communication competence to be positively associated with social support in both face-to-face and online environments (Wright, Rosenberg, Egbert, Ploeger, Bernard, & King, 2012). In addition, those with more support networks experienced less depression; however, the effect was greater in face-to-face networks than in online networks (Wright et al., 2012).

Brashers, Neidig, and Goldsmith (2004) also found that social support is important in a variety of ways for people with HIV or AIDS. According to these authors,

> We found that support from others helps people with HIV or AIDS to manage uncertainty by (a) assisting with information seeking and avoiding, (b) providing instrumental support, (c) facilitating skill development, (d) giving acceptance or validation, (e) allowing ventilation, and (f) encouraging perspective shifts. (p. 305).

Findings from this research also supported previous research regarding "dilemmas of support, which arise "when the benefits of receiving support are accompanied by costs or complications" (Brashers et al., 2004, p. 307). In this particular study, two primary problems associated with receiving support for uncertainty management were identified: costs such as "negative outcomes or risks that accompanied the useful uncertainty management functions of social support," and complications including the "negative outcomes or risks of social support that created new forms of uncertainty or interfered with any assistance in uncertainty management that might be obtained by seeking support" (Brashers et al., 2004, p. 316).

Theoretical Basis

Clearly, risks are associated with disclosing a child's diagnosis of epilepsy to others. While possible outcomes of disclosing the condition include increased social support and associated potential reduction in stress, disclosing could also lead to negative outcomes such as social stigma and possible negative outcomes related to social support. In looking at disclosure of an epilepsy diagnosis to others, two theories seem appropriate. Communication Privacy Management (CPM) Theory and Stigma Management Communication (SMC) Theory both lend insight into studying parental disclosure of a child's epilepsy diagnosis.

CPM focuses on the ways individuals manage their private information. A major facet of the theory concerns the public-private dialectic, which refers to the conflicting feelings individuals may experience regarding sharing private information (Petronio & Durham, 2015). In the case of epilepsy, for example, sharing private information could result in finding support from others who also have epilepsy or a loved one with epilepsy.

On the other hand, withholding this information could limit stigmatizing reactions from others. The theory also contends that people believe they have the right to control information shared with others, and there can be breakdowns in the management of private information.

SMC is based on the assumption that stigma can relate to public perceptions, perception of self, and/or a combination of the two (Meisenbach, 2010). The theory is guided by three axioms: (1) stigma is discursively created based on perceptions of both non-stigmatized and stigmatized individuals, (2) stigmas shift and are shifted by discourses and material conditions, and (3) stigma varies in both breadth and depth (Meisenbach, 2010). Given the stigma associated with epilepsy, and the possible internalization of stigma, this theory is important when considering disclosure of an epilepsy diagnosis.

Rationale for the Present Study

The purpose of this study is not only to explore parental perceptions of disclosing a child’s epilepsy diagnosis, but also to potentially expand the use of both CPM and SMC theories. My experiences as both a mother of a CWE and a health communication researcher led me to believe it is important to explore ways parents of CWE manage disclosures of the condition. I want to help parents and children discover ways to reduce the stress involved in disclosure of epilepsy, especially given my personal experiences and research showing epilepsy is a stigmatized condition, as well as the challenges in making the decision to disclose the condition. My hope is that research on this topic will be especially helpful for parents and children who are newly diagnosed with epilepsy.

As shown, given the public misunderstanding and associated stigma, disclosure of epilepsy to others is a complex decision. On the one hand, disclosing the condition may be necessary in relation to the child’s safety, and could result in social support from others. On the other hand, disclosing the condition could lead to the child experiencing rejection from others due to the stigma of the condition and lower quality of life (QOL).

Finally, with regard to theory building, my study can advance both theories. CPM theory could be advanced by adding to the literature on disclosure of health conditions by healthcare advocates (parents). In addition, consideration of emotion and power come into play when deciding to disclose a child’s medical condition. SMC theory could be advanced, in part, because the theory has not been tested extensively in general, much less as related to a stigmatized health condition. The present study could aid in consideration of SMC strategies used, especially when the stigma applies to a child as opposed to oneself.

Researcher Positionality

As mentioned, I myself am a parent of a CWE. Given the scope of this study, it is important that I discuss my positionality as a researcher. As a parent of a CWE, I have experienced many of the same things reported by other parents in previous research studies. I have experienced anxiety and depression in relation to the diagnosis, living with constant uncertainty about when, where, and if another seizure will occur. I have also struggled with disclosing my child’s condition to others, and I continue to struggle with this today. These experiences not only shaped who I am as a researcher, they shaped who I am as an individual and parent. In fact, my experiences with my child’s diagnosis and my efforts to try to find information and support for my family led me to focus on health communication in my research.

However, as difficult as the experience has been for my family and me, I also recognize I am a person of privilege in many ways. As a highly educated, white woman from a middle-class background, I had multiple advantages while my family and I learned how to manage the condition. First, I have a high degree of health literacy, so when doctors started using terms like “EEG” and “left-temporal lobe,” I knew what they were talking about. On the few occasions when I wasn’t familiar with something, I had both the education and access to research the information on my own.

As a native English speaker, I also had the advantage of not needing a translator when speaking with doctors and other medical personnel. My family and I also have excellent medical insurance so we were not financially devastated by the repeated ER visits and medical tests. We never had to wonder if we could pay for my daughter’s medication. In addition, given my education and background, I had the skills and confidence to discuss my daughter’s condition with people like teachers and coaches. While it wasn’t easy for me for the reasons already shared, I didn’t have additional barriers like language or fear of speaking to those in authority.

Even with all these advantages, the diagnosis of epilepsy has still had a major impact on my family. We struggle frequently with the decision to disclose. For example, last week my daughter started gymnastics lessons. I didn’t have the opportunity to talk with her coach privately as all the other students and parents were standing there to send their children in. So, I didn’t disclose to her at that point that my daughter has epilepsy. Instead, I stayed for the hour-long practice and watched my daughter the entire time in case she needed me. I am still trying to decide how I can share her diagnosis privately with her coach, and am still worrying about how the coach may react. With the information I have gained through this study regarding ways parents manage disclosures of their child's epilepsy diagnosis, I plan to create educational materials to help parents of children who have just been diagnosed.

Outline of Study

In the current chapter, Chapter 1, I shared my own experiences as a parent of a child with epilepsy, provided information about epilepsy as a whole and about some of the particular struggles people with epilepsy and their families experience, discussed social support in relation to reasons individuals may choose to disclose an epilepsy diagnosis, and provided brief information about CPM and SMC theories.

In Chapter 2, I discuss prior research in the areas of epilepsy, stigma, and social support. I also provide further details about the theories of CPM and SMC. Chapter 3 provides a description of the research method I plan to use for the proposed study. In Chapter 4, I discuss the findings after reviewing interview transcripts, and in Chapter 5, I discuss implications of these findings. In addition, I discuss my philosophical assumptions that guide my methodological choices.

As a preview, the research questions guiding this study are:

RQ1: In which situations and with whom do parents disclose that their child has epilepsy?

RQ2: In which situations and with whom do parents conceal that their child has epilepsy?

RQ3: What types of support have parents received when they disclosed the epilepsy diagnosis to others?

Chapter 2:

Literature Review

In this section, first I provide an overview of epilepsy including the relationship between epilepsy and quality of life as well as the stigma associated with epilepsy. Next, I review existing literature on disclosure in general, and disclosure of concealable stigmatized conditions in particular. Finally, I discuss concepts and theories relevant to my study including social support, communication privacy management, and stigma communication management theory.

According to the Epilepsy Foundation, epilepsy is a spectrum condition with a wide range of seizure types and control options, which vary by the individual (2017). The Centers for Disease Control and Prevention (CDC) and The Epilepsy Foundation (2017) both indicate that over three million Americans currently experience active epilepsy, with 150,000 new cases diagnosed each year. In their “At a Glance 2015: Targeting Epilepsy” report, the CDC states that “a seizure happens when abnormal electrical activity in the brain causes an involuntary change in body movement or function, sensation, awareness or behavior” (2015, p. 1).

Epilepsy is a largely invisible, chronic neurological condition that affects both children and adults (Benson et al., 2015). Approximately 1 in 26 Americans will develop epilepsy at some point in their lives and 65 million people have epilepsy worldwide (CDC and Epilepsy Foundation, 2017). More prevalent than multiple sclerosis, Parkinson’s disease, and autism, epilepsy is still one of the least understood conditions by the public, doctors, and patients (Theodore, Spencer, Wiebe, Tangfitt, Ali, Shafer, Berg, & Vickrey, 2006).

In 2002, the CDC conducted a national survey titled “HealthStyles” that included nine epilepsy-related items (Kobau and Price, 2003). Results of this survey indicate that approximately only one-fourth of the American public believe themselves knowledgeable about epilepsy. Yet, about half of all Americans have witnessed a seizure firsthand, over half have witnessed one on television, and approximately 30% of adult Americans know someone with epilepsy (Kobau & Price, 2003). Several studies indicate that a lack of knowledge about epilepsy is also common among those who have epilepsy and their caregivers. For example, after completing the Epilepsy Knowledge Profile-General (or EKP-G, designed to assess general knowledge about epilepsy) and the Epilepsy Knowledge Profile-Personal (or EKP-P, designed to assess an individual’s knowledge about their condition), people with epilepsy showed no statistical difference in knowledge levels compared to people without (Elliott & Shneker, 2008). In fact, the report indicates, of those with epilepsy, “seventy percent did not know the name of their seizure type, 75% did not know the results of their EEG assessments, 65% did not know the results of their brain scans, and 25% gave incorrect dosages for all or some of their antiepileptic drugs (AEDs)” (Elliott & Shneker, 2008, p. 548).

Kobau and Price (2003) hypothesize that the lack of perceived knowledge about epilepsy, even among the respondents who knew someone with the condition, may be related to the general lack of education the public has about epilepsy. As stated in *Global Campaign Against Epilepsy*, a report sponsored by the International League Against Epilepsy (ILAE), World Health Organization (WHO), and the International Bureau for Epilepsy (IBE), epilepsy awareness is generally low across the world. “This can often lead to public discrimination and exclusion of people with epilepsy, as well as inappropriate treatment" (*Global Campaign Against Epilepsy*, 2003).

One study surveyed 165 patients treated for epilepsy regarding patients' thoughts and opinions on misperceptions about epilepsy (Paschal, Kore, Hawley, Sly, & Molgaard, 2006). Respondents completed a survey with questions pertaining to public misperceptions about epilepsy, patient misperceptions about epilepsy, and opinions on how these misperceptions could be addressed. Consistent with previous literature, the majority of respondents (65%) indicated that stress and problems in their lives could be alleviated by increased public education and awareness about epilepsy and seizures. The vast majority (90%) believed the general public lacked knowledge about epilepsy and that there is a strong need for public education to raise awareness about the condition (Paschal et al., 2006).

Epilepsy and Quality of Life

For those living with epilepsy, coping with the medical aspect of the condition is only one challenge. They also cope with stress related to the stigma of the condition, lack of public knowledge, and fear of having a seizure in public. In the case of children, the child or young person living with epilepsy and his/her parents face medical aspects related to the condition in addition to dealing "with the impact that the condition can have on psychosocial wellbeing." (Benson et al., 2015, p. 73). According to Lv et al. (2009):

> Seizures generally occur without warning, so they often bring a variety of potentially embarrassing and dangerous situations depending on the specific circumstances in which they occur. For those children with epilepsy and their families, epilepsy is not only a medical diagnosis but also a social label. Children with epilepsy are treated as less intelligent, less social than healthy children and

> tend to experience a limited school, professional career and marriage in the future. (p. 335)

Given the concerns about psychosocial wellbeing of children with epilepsy and their families, several studies have looked at quality of life of children with epilepsy. For example, Hoare, Mann, and Dunn (2000) conducted a study looking at QOL for children with epilepsy and children with diabetes, utilizing a newly designed illness-specific questionnaire. The questionnaire was completed by parents, thus is a study of parental perceptions of QOL. The questionnaire focused on the impact of the illness, impact on the child's development, impact on the parents, and impact on the family (Hoare, Mann, & Dunn, 2000). Aims of the study included determining if the questionnaire was useful when applied to children with epilepsy, as well as when applied to children with diabetes. In addition, the study sought to discover the association (if any) between QOL of children with epilepsy or diabetes and how well the illness is managed (Hoare et al., 2000).

The majority of children in both groups were well controlled, and epilepsy and diabetes seem to have similar effects on the family in regards to QOL. Factor analysis indicated that the impact of the child's health and development also affected QOL for those with epilepsy. The authors concluded their study as follows:

> For the majority of children with diabetes, the parents did not think that the illness had an adverse effect on their child's quality of life. By contrast, the parents of many children with epilepsy reported a major impact. In the epilepsy group, early onset, the presence of an additional disability, or poor current seizure control were the best predictors of a high score. (Hoare et al., 2000, p. 643)

Not only does epilepsy affect the QOL for children with epilepsy, several studies indicate it can also affect the QOL of the parents in a number of ways, including higher levels of psychological distress and increased risk of developing depression, as compared to parents of children without epilepsy (Lv et al., 2009; Shore et al., 2002; Taylor et al., 2011). As part of a larger study, Taylor et al. (2011) looked at surveys completed by children with newly diagnosed epilepsy and their parents. They found that, in comparison to healthy children, CWE reported lower overall QOL along with reduced QOL across multiple domains including physical, emotional, self-esteem, friends, and school. Scores were also compared to previous data from children with asthma, which is also a chronic, episodic condition with potential life-threatening attacks. When compared to children with asthma, the children with epilepsy reported lower QOL in relation to the physical, emotional, and friend domains. These newly diagnosed children also had negative attitudes towards epilepsy, which could in part be due to still adapting to the recent diagnosis. In addition, "parents' QOL was also affected by their child's health and behavior. Parents of younger children felt limited in the time for their own needs due to their child's health" (Taylor et al., 2011, p. 1496).

A previous study also found that parents of CWE reported lower QOL (Lv et al., 2009). In this study, parents of CWE were interviewed, and then just the mothers also filled out questionnaires. Parents were divided into groups based on time since diagnosis and whether the epilepsy was well-controlled. Study findings indicate that parents of CWE reported higher levels of anxiety and depression, and lower QOL, than parents of healthy children. In addition, parents of children whose epilepsy was poorly controlled had lower QOL, and higher levels of anxiety and depression, in comparison to parents of children whose epilepsy was well-controlled (Lv et al., 2009).

Epilepsy and Stigma

It could be argued that the stigma associated with epilepsy plays a role in the psychosocial wellbeing of CWE and their parents. Feelings towards seizures tend to be negative, in large part due to fear of seeing a seizure (CDC, 2017). Many types of seizures exist, some of which are not apparent to an observer and not likely to induce fear. As Kobau and Price (2003) state:

> Throughout history and in many cultures, however, the public has been exposed to epilepsy in a more frightening form through paintings, literature, and modern communication mediums such as television. These mediums typically display tonic-clonic seizures that result in distorted and stereotypical representations of epilepsy. (p. 1453)

Naturally, exaggerated representations as seen in media (including literature) affect cognitive responses, which then may affect social attitudes (Kobau & Price, 2003). This is concerning especially as some of the respondents who indicated they were somewhat knowledgeable about epilepsy based this on seeing a seizure on television, which may or may not have been an exaggerated representation (Kobau & Price, 2003).

As the aforementioned studies highlight, in addition to the lack of knowledge, epilepsy is still a stigmatized condition. Kobau and Price state:

> North Americans concurrently hold medical (i.e., neurological) and nonmedical (i.e., metaphysical) beliefs and attitudes about epilepsy. Such metaphysical beliefs (e.g., epilepsy is caused by good or evil supernatural spirits) have led to

> stigmatizing attitudes toward people with epilepsy in many societies throughout history. Although knowledge, attitudes, and beliefs about epilepsy have improved globally, misperceptions about the disorder still exist. (2013, p. 1449)

The CDC's "At a Glance 2015: Targeting Epilepsy" (2015) handout also reports that the lack of knowledge and understanding about epilepsy is related to negative attitudes and stigma in the workplace and in schools.

Some contend that the stigma associated with epilepsy is more difficult to manage than the clinical features of the condition itself (Fernandes, Snape, Beran, & Jacoby, 2011). Reducing stigma is a focus not only of various research studies, but also of epilepsy support groups globally. Studies have shown that there is a relationship between felt stigma in people with epilepsy, self-efficacy, social support, worry about seizures, depression, and QOL (Fernandes, et al., 2011). For example, one study about stigma and QOL found that higher levels of perceived stigma were a predictor of lower QOL (Whatley, DiIorio, & Yeager, 2010). Fernandes et al., similarly, note that:

> It is important to remember that the stigma associated with epilepsy is not just a personal matter for individuals with epilepsy, but has important public health implications, such that reducing both individual and societal burdens of epilepsy should be a major priority of governments and health care systems worldwide. (2011, p. 57).

Kilinc and Campbell (2009) explored the experience of stigma for adults with epilepsy. Using a phenomenological approach, 52 adults were interviewed using semi-structured interviews, with a second set of interviews with 32 of the original respondents conducted six months later. Once the interviews were analyzed, three themes emerged:

“Misconceptions versus Ownership of Epilepsy,” “Avoiding versus Sharing Epilepsy,” and “Embarrassment versus Normalizing Epilepsy” (Kilinc & Campbell, 2009, pp. 666-667).

The theme of “Misconceptions versus Ownership of Epilepsy” included the idea that participants felt the general public had many misconceptions about epilepsy, but so did patients when first diagnosed (Kilinc & Campbell, 2009). Interviewees felt that many of the misconceptions, such as people believing epilepsy is a mental illness or thinking someone is drunk when having a seizure, add to the stigma surrounding the condition. Participants also indicated that the more they learned about epilepsy and their own experiences of it, the more they accepted the condition and regained some sense of control (Kilinc & Campbell, 2009).

The invisible nature of epilepsy allows individuals to conceal the condition in many situations, which was one of the factors included in the “Avoiding versus Sharing Epilepsy” theme. The authors found that some participants “…contributed to the hidden nature of the condition” (Kilinc & Campbell, 2009, p. 668). The authors also found, within this theme, that for many, the process of disclosing evolved over time, with some participants indicating that disclosure had no limits while others only disclosed in certain situations or if the topic was raised (Kilinc & Campbell, 2009). In addition, findings indicated that concealment of the condition took a great deal of energy and effort and included the risk that others wouldn’t know what to do if a seizure occurred.

The final theme, “Embarrassment versus Normalizing Epilepsy,” was primarily about the ways that “an epilepsy diagnosis can challenge a person’s identity and sense of self, reducing their confidence and engagement in social interactions” (Kilinc &

Campbell, 2009, p. 669). The authors found that participants believed there is a need to improve awareness of the condition not only to normalize epilepsy, but also help minimize embarrassment those with the condition may feel.

Disclosure

As noted earlier, due to the stigma associated with epilepsy, many people choose to hide the condition. As epilepsy is largely invisible from the outside, it is considered a concealable stigmatized identity, defined as "…an identity that can be kept hidden from others but that carries with it social devaluation. Specifically, an identity is stigmatized if it is considered a mark of failure or shame, tainting the self in the eyes of others" (Quinn & Chaudoir, 2009, p. 635). A variety of identities would be considered concealable stigmatized identities under this definition including a history of mental illness, HIV/AIDS, epilepsy, and substance abuse.

In the first of two studies conducted by Quinn and Chaudoir (2009), the constructs of anticipated stigma, centrality of the concealed identity to self, and salience of the identity to self were measured within a sample of people living with a concealable stigmatized identity. In addition, psychological distress was measured. Based on their findings, Quinn and Chaudoir (2009) conclude:

> …the extent to which people anticipate social devaluation if the identity is revealed, the more central the identity is to the self, the more salient the identity is, and the extent to which the identity is considered culturally stigmatized each uniquely predicted variance in psychological distress in a sample of participants with a wide variety of concealable stigmatized identities. (p. 644)

These authors' second study extended the original by examining "a model in which anticipated stigma, centrality, salience, and cultural stigma predicted psychological distress and illness symptoms" (Quinn & Chaudoir, 2009, p. 645). Study two also indicated that anticipated stigma, centrality and salience predicted distress. "Interestingly, cultural stigma did not directly predict psychological distress but it did predict illness symptoms" (Quinn & Chaudoir, 2009, p. 647). Findings further indicated that distress was the strongest predictor of illness symptoms.

An individual with a concealable stigmatized identity often faces the decision of when, and to whom, to disclose the condition. "Because people with concealable stigmatized identities will likely face disclosure decisions for the rest of their lives, fear of disclosure could represent a chronic worry that could influence overall psychological well-being" (Chaudoir & Quinn, 2010, p. 573). Therefore, Chaudoir and Quinn (2010) posit, an individual's experience the first time they disclose is likely to affect their overall beliefs about disclosure.

In a study exploring how an individual's motivation for disclosing a concealable stigmatized condition for the first time affects the experience, and how the first experience affects current well-being, these same authors surveyed undergraduate students with self-reported concealable conditions. They found that an individual's motives for disclosure can impact the experience of disclosing to another; these experiences can then affect long-term well-being. Participants in the study who reported having an ecosystem motivation for disclosure reported greater first-disclosure positivity (Chaudoir & Quinn, 2010). The authors describe ecosystem motivation as follows:

> ecosystem motivations consider the well-being of others and place oneself as part of a larger structure of human interconnectedness. Ecosystem motivations for disclosure emphasize how disclosure might affect both the self and the disclosure confidant and could yield positive outcomes (e.g., strengthen personal relationships, educate others) and avoid undesirable outcomes (e.g., other people bearing their stigmatized identities alone) for both (p. 572).

In addition, when one receives support and positive feedback the first time they disclose a stigmatized identity, they might feel more trust towards others and comfort in disclosing information. Finally, the authors report, "one reason why first-disclosure positivity can continue to influence well-being years after the event has occurred is because it impacts people's chronic fear of disclosure" (Chaudoir & Quinn, 2010, p. 581).

Additional research has explored the concept of disclosure and concealable stigmatized identities. As shown in the previous study, depending on motivation and previous disclosure experiences, when individuals with a concealable stigmatized identity disclose this information, they may experience negative outcomes or become targets of prejudice. Thus, while some previous research has shown disclosure is an important part of social interaction and can lead to favorable outcomes such as developing a sense of self and building intimacy in personal relationships, in the case of individuals with a concealable stigmatized identity, disclosure is more complex. The decision to disclose a concealable stigmatized identity has the potential, then, to be harmful and/or beneficial.

With regard to epilepsy, visibility of the condition is contingent upon either: "(i) disclosure of the condition or (ii) the manifestation of symptoms (i.e., seizures) or cues that indicate the presence of the condition (i.e., medication taking) in a public setting"

(Benson et al., 2015, p. 74). Because of the associated stigma, as with other concealable stigmatized identities, some people living with epilepsy choose to conceal their condition from others. When individuals living with epilepsy do disclose, based on research examining adult populations, disclosure strategies include:

> (a) preventive disclosure (i.e., telling others prior to the occurrence of a seizure in order to avoid the inherent risk of detection and/or to forestall stigmatization); (b) selective disclosure (i.e., restricting to whom and/or what information about the diagnosis is disclosed); (c) voluntary disclosure (i.e., voluntarily disclosing epilepsy to others between seizures); and (d) social broadcasting (i.e., broadcasting the epilepsy diagnosis in an effort to educate others). (Benson et al., 2015, p. 74)

Others witnessing a seizure or others sharing the person’s diagnosis are considered cases of forced disclosure.

Parental Disclosure of Concealable Stigmatized Identities

While some research has explored disclosure of concealable stigmatized conditions in adult populations, including epilepsy, little research has looked at parental disclosure of stigmatized concealable identities. Of the research available, little to none looks at parental disclosure of epilepsy; however, two recent research studies explored parental disclosure of stigmatized concealable identities.

In the first such study reviewed, researchers interviewed 11 Australian biological mothers of children with a mental health problem including ADHD, an anxiety disorder, a mood disorder, and/or oppositional defiant disorder (Eaton, Ohan, Stritzke, Courtauld, and Corrigan, 2017). The questions asked were primarily designed to look at parental experiences of stigma and feelings of empowerment. Overall, four themes were found in relation to the mothers' disclosure decisions: "Using the Range of Disclosure," "Disclosing/Concealing in the Child's Best Interests," "Considering Others' Opinions," and "Experiences of Disclosure" (Eaton et al., 2017).

The first theme, "Using the Range of Disclosure," included the idea that disclosure "…was not an 'all or nothing' decision" (Eaton et al., 2017, p. 1631). Findings indicated the process guiding the decision to disclose was based on experience and considerations for "situation, context and individual(s) involved" (Eaton et al., 2017, p. 1631). The range of disclosure went from complete concealment to selective disclosure.

The second theme, "Disclosing and Concealing in the Best Interests of the Child," relates to the idea that the best interests of the child drove all reasoning and decision making in terms of disclosure (Eaton et al., 2017, p. 1631). As a whole, "mothers' decision-making processes were influenced by a desire to ensure that the child's best interests were met, and this meant not only protecting the child through concealment or selective disclosure but also advocating on their behalf" (Eaton et al., 2017, p. 1632).

"Considering Others' Opinions," the third theme, stemmed in large part from the mothers' anticipated reactions (such as stigma) from others when deciding to disclose or conceal (Eaton et al., 2017). Within this theme, considerations included choosing to disclose in order to defend against stigma and the right to privacy. Finally, the fourth theme, "Experiences of Disclosure," included situations the mothers shared in which their disclosure of the condition resulted in negative outcomes such as rejection and disappointment. However, "concealment also posed a significant disadvantage for mothers: the deleterious impact on their sense of social connectedness and the obtainment of social support" (Eaton et al., 2017, p. 1634).

The authors concluded it is beneficial for mothers to become more confident in their disclosures, especially for those in the early stages of getting help for their child or disclosing the disorder for the first time. The authors also concluded "learning how to best structure disclosures in a strategic and personally meaningful way may help to increase mothers' confidence with disclosure" (Eaton et al., 2017, p. 1636). Finally, the authors point out that research on mothers' disclosure decisions for their children is limited, even though these disclosure decisions may have serious implications for the child. "The process is complicated by the stigma associated with childhood mental health disorders and mothers' attempts to mitigate its effects on the child. Mothers are faced with unique and complex dialectics that create tension in the decision-making process" (Eaton et al., 2017, p. 1637).

Autism spectrum disorder (ASD) has also been explored in relation to parental disclosure of a concealable stigmatized identity; specifically, in two Canadian pediatric emergency departments. The authors of this study interviewed 31 parents and 22 health care providers (Muskat, Greenblatt, Nicholas, Ratnapalan, Cohen-Silver, Newton, Craig, Kilmer, & Zwaigenbaum, 2016). Once the interviews were coded, three themes emerged in terms of disclosure: "The Benefits and Risks of Disclosure", "Outcomes in Care Delivery Resulting from a Disclosure", and "Recommendations for Improving the Process of Disclosing and Communicating Information" (Muskat et al., 2016).

While in this situation, all parents in the study did disclose the child's ASD to the HCP(s), however some described considering potential risks and benefits in deciding to do so. In terms of outcomes, while some parents reported "…satisfactory accommodation following the disclosure of their child's ASD," others reported a lack of understanding of ASD following their disclosure (Muskat et al., 2016, p. 990). For example, one parent reported that the health care provider made an assumption regarding the child's communicative ability rather than looking into other medical reasons (Muskat et al., 2016). Finally, many participants recommended ways to improve communication in relation to their child and health care providers. For example, an alert in the child's file, which would also help "…alleviate the responsibility placed on them [parents] to disclose to multiple HCPs as well as reduce feelings of discomfort around public disclosure" (Muskat et al., 2016, p. 991).

The authors conclude, based on this study, that while disclosure assists HCPs in caring for a child with ASD in the Emergency Department, disclosure is a complex decision for families that is "both layered and purposeful" (Muskat et al., 2016, p. 992). The authors recommend not only a hospital tool aimed at communication between parents and HCPs, but also future research about disclosure that includes individuals who have chosen not to disclose.

Social Support

While people living with epilepsy and other concealable stigmatized conditions, as well as parents of children with concealable stigmatized conditions, struggle with the decision to disclose the condition for a variety of reasons listed above, one reason to disclose is to receive social support. Research over the past three decades has indicated the importance of the study of social support in relation to health outcomes, relational development, and quality of life. The concept of social support originally stems from epidemiological studies as they noticed the relationship between social ties and health and well-being (Burleson, Albrecht, & Goldsmith, 1994). Continued research has indicated a relationship between social support and both physical and psychological health outcomes. Early definitions (from the 1970s) indicated social support related to individual feelings of being cared for or supported by others and individuals feeling they were esteemed and valued by important others. For example, Cobb (1976) equated the term with being esteemed and valued, of belonging to a network of communication and mutual obligation (see also Burleson et al., 1994; Goldsmith & Albrecht, 2011).

Social support has been studied in multiple ways by multiple scholars. Such research can be classified into three successive categories: the sociological perspective or social network approach, the psychological or perceptual approach, and the communicative perspective or interactional approach (Burleson et al., 1994). Research from the sociological perspective looked at social support as related to social networks, which ties in with the early conceptualization of the relationship between supportive ties and health and well-being. Researchers tended to look at the number of social networks in relation to health and well-being, with the idea that the mere existence of social ties, or ties of a certain sort, resulted in improved or protected health. Some limitations to this perspective include the fact that more social networks does not necessarily mean better or more support, as not all social ties are health promotion-related, and the lack of a qualitative or subjective element to the perception of social support (Burleson et al., 1994).

Several studies concluded that health outcomes are best predicted by an individual’s perceptions of the quality and availability of support, not structural features of support networks. From this psychological perspective, social support is related to an individual sense of feeling supported with a focus on relationships with others (Burleson, et al., 1994). However, through research, the individual sense of feeling supported was eventually conceptualized as a personality characteristic related to attachment experiences when young. Thus, the feeling of being supported by others may not relate to actual degree or amount of support. Research did, however, suggest that this sense of feeling supported could have a buffering effect in relation to health outcomes (Burleson et. al, 1994). Limitations to this approach include the idea that relationships in and of themselves aren't necessarily directly supportive or unsupportive; instead, specific actions provide support, and more relationships may not equate with more support (Burleson et al., 1994).

The third approach in the progression of social support research is the communicative or interactional approach, which examines social support as interactions or exchanges that frequently occur in the context of enduring relationships (Burleson, et al., 1994). The focus is on communication between the support provider and the individual receiving support. Burleson and colleagues conclude that social support is best studied from a communicative perspective for multiple reasons, including the following: social networks are formed through communication with others, relationships are developed through communicative actions, messages sent and received are an important aspect of social support, emotional feelings are important in the study of social support and these are also studied through communication, and studying social support from this perspective could help provide future advice for support givers (1994).

Goldsmith and Albrecht (2011) claim that the phrase “social support” is an “umbrella term” for a variety of related concepts. Albrecht, Burleson, and Goldsmith (1994) suggested that supportive communication includes both verbal and nonverbal behaviors and is the primary way individuals interact in both support-seeking and support-giving situations. In addition, Goldsmith and Albrecht (2011) point out that major features of social support include supportive conversations and social networks. Supportive conversations relate to messages that indicate support and caring for others.

Supportive conversations help to build social networks. Members of such social networks can provide support through information on care taking and providers, emotional support, and performing care functions. “Study of supportive conversations focuses on the actions that relational partners (e.g., friends, family members, peers, neighbors, acquaintances and co-workers) undertake with the intention of helping one another cope” (Goldsmith & Albrecht, 2011, p. 337).

Thus, social support is important to the study of health communication as a whole, and in the study of disclosure of concealable stigmatized conditions specifically. Social support has an inherent communication aspect to it, as demonstrated by Burleson et al. (1994). The study of social support began with the field of health and has demonstrated effects on health and well-being. In addition, communication scholars have contributed greatly to the study of social support through research and conceptual constructs and/or models of the concept. Some specific contributions include comforting messages, person-centered messages, and the Optimal Matching Model of Social Support and Stress (which will be discussed later in this literature review).

Burleson (1994) contends that emotional support is a key type of social support.

Within emotional support, individuals send messages of comfort designed to show another that they care and the other is loved. Social science researchers tended to look at emotional support from an inductive viewpoint, clinicians and counselors from a deductive, and communication scholars created the interactional hierarchic perspective (Burleson, 1994).

The interactional hierarchical perspective looks specifically at messages within emotional support. The hierarchy consists of nine factors, three major levels and three minor supporting factors for each; messages can be categorized into the three major levels. Implicit or explicit disconfirming messages are categorized at the lowest level. These messages may deny feelings and experiences of others for example. Implicit supportive messages are categorized at the middle level and explicit supportive messages are categorized at the highest level. Messages categorized in the highest level seen as the most “sophisticated” type of messages (Burleson, 1994).

Sophisticated messages have been proven effective at showing emotional support and comfort (Burleson, 1994). Sophisticated messages are those that are listener- or person-centered, are non-evaluative, and express caring and positive regard (Burleson, 1994). Person-centered messages, also studied by communication scholars, are a type of sophisticated message.

Person-centered messages are explicitly related to the types of messages described by Burleson (1994) and coded in the hierarchy. As mentioned, person-centered messages focus on the listener or other person, rather than on an individual’s own needs and opinions. That is, messages provide efficacious support to the degree to that they reflect “an awareness of and adaptation to the affective, subjective, and relational aspects of communication contexts” (Burleson, 1987, p. 305). In addition, these types of messages are non-evaluative. As High & Dillard (2012) found through their meta-analysis of multiple studies on person-centered messages, verbal, person-centered messages are positively correlated with feelings of emotional support for the great majority of studies reviewed.

The Optimal Matching Model is an additional contribution by communication scholars to the study of social support (Cutrona & Russell, 1990). The authors posit that researchers agree on five major types of social support: informational, emotional, esteem, tangible, and network. Cutrona & Russell (1990) categorized these into two categories: action-facilitating and nurturant. Action-facilitating includes informational and tangible types of support; nurturant includes emotional and network types of support. Esteem could go into either category depending on the situation.

Informational support includes sharing knowledge about a condition or problem or helping an individual research the issue. Emotional support includes messages, such as comforting messages, that indicate love and caring for the other. Esteem support includes helping the other recognize they have the skills, motivation, and/or resolve to handle the problem or condition. Tangible support involves providing task or monetary types of support. Finally, network support relates to a group or network of individuals similar to the individual experiencing distress who they believe can relate to the situation (Cutrona & Russell, 1990).

The matching model argues, in part, that the type of support wanted or needed matches the type of support provided. So, for example, if a person is experiencing high degrees of stress while studying for major exams at the same time as working and caring for a family, they may be primarily in need of action-facilitating support such as tangible support. If the individual’s husband provides tangible support like making dinner and picking up children from activities, this is a match. On the other hand, if an individual needs emotional support for a distressing life event such as diagnosis of a chronic condition, and the other person provides unwanted advice, this is not a match. In addition, Cutrona & Russell (1990) theorize that when the stressor or condition is viewed as something an individual chose, or within their control, action-facilitating support is most appropriate. If the stressor or condition is viewed as outside the individual’s control, nurturant support is most appropriate.

Communication and Social Support

Communication scholars have studied social support through research related to a variety of health conditions such as cancer, HIV/AIDS, and depression. For example, a study of communication of social support in computer-mediated groups for people with disabilities looked at an online bulletin-board style support network and analyzed the messages posted (Braithwaite, Waldron, & Finn, 1999). Study findings supported the Optimal Matching Model in terms of types of support provided. The majority of support in this study was coded as emotional support. The original study by Cutrona & Russell (1990) reported that the majority of support shown was informational support. This also points to support for the Optimal Matching Model, as disabilities would be seen as a condition outside a person’s control, so emotional support is most frequently provided on the site (Braithwaite et al., 1999).

In addition, in this study, more network style support was provided than seen in the Cutrona & Russell (1990) study; again, this would make sense given those on the bulletin-board were seeking a network of similar individuals. New findings were that interactants on the bulletin board also showed support through the use of poetry and humor (Braithwaite et al., 1999). There could be many reasons for this, but among them could be that the anonymous nature of the site allowed for sharing of this type as well as the fact it is an asynchronous environment which allowed time to put thoughts into poems or humorous messages (Braithwaite et al., 1999).

Wright (2011) also looked at social support in an online environment. This study focused on an online cancer community which was a large-scale, funded site with 30 support networks included for a variety of types of cancer. Participants were both those with cancer and caregivers/family/relatives. All participants were asked to complete surveys regarding emotional support, perceptions of advantages and disadvantages, and motives for using the community. Findings indicated that both those with cancer and caregivers utilized the site for emotional support, and found such on the site.

In addition, results suggest that both people with cancer and family members may benefit from increased emotional support in terms of reduced stress (Wright, 2011). Those with cancer seemed to use the site more to develop interpersonal relationships than did caregivers; this could suggest that those with cancer were also in need of network support. Findings also indicated that those who stated the biggest disadvantage to an online support network was “not being able to hear tone of voice” experienced positive emotional support (Wright, 2011). Those who stated the biggest disadvantages were things like flaming and inappropriate comments or statements did not experience the same degree of emotional support.

Like cancer, HIV/AIDS is a chronic condition that has been studied frequently in relation to social support. One such study looked at both social support and the concept of social undermining in relation to health-related quality of life for people living with HIV/AIDS (Oetzel, Wilcox, Archiopoli, Avila, Hell, Hill, & Muhammad, 2014). Health-related quality of life (HRQOL) is an important concept as related to HIV/AIDS and has previously been found to be improved through social support. This study looks at not only social support from significant others and social networks, but also from health care providers as well as the impact of social undermining.

As discussed earlier, social support was viewed as including emotional, informational, tangible, network, and esteem types of support. For this study, the researchers looked primarily at emotional and instrumental support (instrumental includes informational and tangible) (Oetzel et al., 2014). Social undermining is a negative reaction in regards to support, and the researchers specifically looked at critical appraisals and isolation within this concept. Critical appraisals include things like making judgmental statements or inappropriate remarks, and not showing support.

Oetzel et al. (2014) found that while HRQOL was positively correlated with social support, it was more highly negatively correlated with social undermining. In addition, support from health care providers provided a buffering effect to the negative aspects of social undermining. This study indicates that avoiding negative interactions is more important to HRQOL than engaging in positive interactions. In addition, feeling a high degree of support from the health care provider can buffer some of the effects of the negative interactions for people living with HIV/AIDS.

Yet another chronic condition frequently studied on its own or in relation to other health conditions is depression. Wright et al. (2012) conducted a study looking at the relationship among communication competence, social support, and depression in college students. The researchers looked at these variables in relation to face-to-face and Facebook support network influence. The study began by looking at the 1988 Relational Health Communication Competence Model (RHCCM) by Kreps, which indicates that communication competence is at the center of the relationship between social support and health related outcomes such as depression (Wright et al., 2012).

The RHCCM posits that increased communication competence leads to "therapeutic communication, social support, satisfaction, information exchange, and cooperation" whereas decreased competence leads to "pathological communication, lack of social support, dissatisfaction, information barriers, and lack of cooperation" (Kreps, 1988, p. 354). Communication competence is the degree to which an individual's communication behaviors are both effective and appropriate in a variety of contexts; this concept includes knowing when to engage in certain behaviors. Findings indicated communication competence is positively associated with social support in both face-to-face and Facebook environments (Wright et al., 2012). As other research on social media has also found, amount of time spent on Facebook was positively correlated with depression. The authors hypothesize this could be related to which activities an individual engages in while on Facebook, which was not investigated in this study. While those with more face-to-face and Facebook support networks both experienced less depression, the effect was greater in face-to-face networks.

When developing a research study, it is important to consider potential theories related to the area of research. With regard to my proposed research on parental disclosure of a child’s epilepsy diagnosis, theories related to disclosure and stigma may be most appropriate. Given that multiple studies indicate epilepsy is still a stigmatized condition in multiple parts of the world, and that both those with epilepsy and their families cope with uncertainty almost daily, these topics are important considerations in relation to the decision to disclose. Therefore, I looked closely at the theories of Communication Privacy Management and Stigma Management Communication for this research.

Communication Privacy Management

Communication Privacy Management (CPM) theory is based on three guiding categories of maxims: assumption maxims that underlie CPM theory; axiomatic maxims that represent main principles of the theory; and interaction maxims (Petronio & Durham, 2015). The assumption maxim includes the ideas of public-privacy dialectic, privacy management, and boundary metaphors (Petronio & Durham, 2015).

First, the public-privacy dialectic refers to the push and pull individuals experience regarding sharing private information (Petronio & Durham, 2015). On the one hand, sharing private information could result in further connections with others and in relationship building. On the other hand, withholding private information could prevent rejection. Privacy management includes the assumptions that people believe they own their private information and have the right to control access to it (Petronio & Durham, 2015).

Second, because information is defined as private, with potential vulnerabilities, people believe they have the right to control its flow to others. Third, since we do not live in a perfect world, breakdowns can occur when managing private information (Petronio & Durham, 2015). Boundary metaphors refers to the idea that boundaries may be “thick” or “thin” (Petronio & Durham, 2015). A thick boundary is one where information is rarely shared with anyone. A thin boundary is one where information is fairly open and may be shared with many people.

The axiomatic maxim relates to the overall principles of the theory and includes the three areas of privacy ownership, privacy control, and privacy turbulence (Petronio & Durham, 2015). Each of these will be described in more depth within the discussion of the theory’s major constructs. The interaction maxim relates to the ways privacy management is an interactive process between “owners” and authorized “co-owners” and includes the ideas of shared privacy boundaries, coordinating boundaries and boundary turbulence (Petronio & Durham, 2015).

Shared boundary management occurs when an individual shares private information with another; as “co-owner,” this other person now shares in the management of boundaries with the original owner. This includes understanding the rules for maintaining privacy. Coordinating boundaries means the owner and co-owner(s) work together to determine when and if third parties have access to the information. These coordinated boundaries could be dyadic, group, family, or cultural, for example. Finally, boundary turbulence relates to the idea that when information is shared outside the rules of boundary management, this results in upset and possible conflict. In particular, privacy violations, dilemmas, and misconceptions about ownership contribute to boundary turbulence (Petronio & Durham, 2015)

Gossip is an example of boundary turbulence. However, boundary turbulence could also occur as a result of privacy rules not being explicitly stated or clarified (Petronio & Durham, 2015). Boundary turbulence often occurs due to differing expectations, misunderstandings about privacy expectations, or unclear guidelines with regard to handling private information (Petronio & Durham, 2015).

As mentioned, the three guiding principles of the theory include the principle of privacy ownership, the principle of privacy control, and the principle of privacy turbulence. The eight axioms of the theory relate to the various principles. Two axioms relate to the principle of privacy ownership. Axiom 1 is that people believe they own their private information (Petronio, 2013). Axiom 2 states when the "owner" of private information shares this information, the other person becomes an authorized "co-owner" with resulting responsibilities to guard private information (Petronio, 2013).

The principle of privacy control includes axioms three through seven. Specifically, Axiom 3 predicts that because people believe they own their private information, they also believe they have the right to control it. In relation, Axiom 4, then, predicts that controlling this information results in privacy rules (Petronio, 2013). These rules include both core and catalyst criteria (Petronio, 2013). Core criteria for privacy rules stem from factors such as family upbringing, gender, and culture. Core criteria tend to remain relatively stable, unless or until something happens to cause an individual to re-evaluate these criteria (Petronio, 2013). This occurrence is a catalyst that may result in changes to privacy rules. For example, an individual may feel that financial matters are a private matter to only be shared with his or her spouse. However, when both members of the couple retire, they may re-evaluate these rules and choose to share some financial information with others like financial planners and friends in order to obtain help in retirement planning (Petronio, 2013).

Because the information is now shared, Axiom 5 predicts that privacy rules are coordinated and managed with authorized co-owners (Petronio, 2013). The owners and co-owners of the information now create collective boundaries regarding the private information, as predicted by Axiom 6. Management of these collective boundaries is the prediction of Axiom 7 (Petronio, 2013). Finally, Axiom 8 is related to the third principle, that of privacy turbulence. Axiom 8 predicts that privacy management may be unstable and result in privacy turbulence (Petronio, 2013).

Stigma Management Communication Theory (SMC)

In addition to CPM, I also consider Stigma Management Communication Theory (SMC) to be appropriate when considering disclosure of a concealable stigmatized condition. SMC evolved from an interest in a communication focus on stigma management. According to Meisenbach (2010), most stigma research looks at three forms of stigma: physical, social, and moral. In addition, stigmatization is a part of human experience, creating groups considered “less than” in order to hold oneself up (Meisenbach, 2010). Stigmatization can result in feelings of worthlessness, isolation, and discrimination.

Meisenbach (2010) contends that stigma includes public perceptions, perceptions of the self, and the two combined. Three axioms were created to guide development of SMC: 1) stigma is discursively created based on perceptions of both non-stigmatized and stigmatized individuals, 2) stigmas shift and are shifted by discourses and material conditions, and 3) stigma varies in both breadth and depth.

Based on these assumptions, SMC as outlined by Meisenbach (2010) includes five propositions. Proposition 1 predicts that individuals choose a SMC strategy based on attitudes towards public perceptions of stigma and the applicability of the perceived stigma to them. Proposition 2 predicts that individuals who accept the stigma applies to them, and the public perceptions of said stigma, will respond with an attitude of acceptance and resulting strategies such as passive acceptance, isolation, and bonding. Proposition 3 predicts individuals who accept public perceptions of the stigma, but reject the idea the stigma applies to them, will respond with an attitude of avoidance and resulting strategies such as avoiding interaction or hiding the stigma. Proposition 4: Individuals who accept the stigma applies to them, but challenge the public perceptions of the stigma, will respond by evading or reshaping the meaning of the stigma. Finally, proposition 5 predicts individuals who challenge both the public perception of the stigma and that the stigma applies to them will respond with an attitude of denial and resulting strategies such as challenging meanings of the stigma, displaying stigma behaviors but reinterpreting meaning, and educating about the stigmatized condition or trait.

CPM, SMC and Epilepsy Disclosure

Having extensively read the scholarship on the aforementioned theories, I believe CPM and SMC are most applicable to my research on epilepsy disclosure. CPM strengths include large numbers of studies testing the theory in relation to stigmatized and chronic health conditions such as HIV/AIDS and cancer, as well as family communication, including a study on family and friends as healthcare advocates. For example, Smith &

Brunner (2015) utilized CPM theory as a basis to analyze an online health narrative (blog) about an individual’s experience with cancer. Their study found CPM applicable to disclosures in the online narrative as well as additional strategies (such as humor) used to disclose private information.

Beyond the strengths and relevancy of the theories, CPM and SMC complement each other theoretically. SMC looks at some of the underlying factors related to a decision to disclose a child’s epilepsy diagnosis while CPM considers the process of deciding to disclose and how to manage the private information.

Specifically, SMC considers how parents might view stigma related to epilepsy. If parents accept both the public perception of epilepsy as a stigmatized condition, and that the stigma applies to their children, they may choose to passively accept this perception and, when disclosing information about the diagnosis, not attempt to educate or change perceptions. They may also choose to isolate their child and not let them attend events such as birthday parties in order to avoid disclosing and/or could only disclose in situations such as a support group for those with epilepsy in order to allow the child to bond with those who share the condition. If they accept the public perception of stigma but reject the notion that it applies to them, the theory indicates that they might use avoidance strategies, such as hiding stigmatizing characteristics or otherwise choosing not to disclose. On the other hand, the other two attitudes described in SMC both focus on challenging public perception, whether parents believe the stigmatized perception applies to their child or not. Both of these attitudes could provide a push to disclose.

After considering SMC in relation to underlying considerations to disclose, I have found that CPM complements this theory because both the attitude towards the stigmatized condition as well as multiple uncertainties will go into the public-private dialectic. The combination of these two contribute to the push and pull of whether to disclose the condition. Also, if someone wants to challenge the stigma attached to epilepsy, more information might be disclosed and boundaries may be intentionally thin in order to change opinions and educate. If someone chooses to avoid the stigma, on the other hand, boundaries may be thick in order to protect private information. However, protecting the information in order to avoid stigma could put the child at risk, resulting in boundary turbulence.

Summary

In this chapter, I discussed the prevalence of epilepsy within the United States and the world as a whole. I also discussed ways an epilepsy diagnosis affects not only the person with epilepsy, but also the family including parents of children with epilepsy. One of the struggles a person with epilepsy faces is the stigma attached to the condition and ways they may be treated differently. This is a struggle for people with any concealable stigmatized condition, not only those living with epilepsy.

People with a concealable stigmatized condition cope with not only the stigma, but also when, where, and with whom to disclose this condition. As it is concealable, often others don’t know you have this condition (such as autism or epilepsy) until you disclose. Not only is this true for children with concealable conditions, this is also the case for parents as shown in the studies looking at parental disclosure of conditions such as mental illness or autism.

One reason individuals may choose to disclose a concealable stigmatized condition is to receive social support. Social support has been shown to be important in relation to health and emotional well-being. On the other hand, some types of social support are not appreciated or needed, adding to the complexity of the decision to disclose.

While the stigma of epilepsy has been researched, and some research has explored disclosure of epilepsy by adults as well as parental disclosure of other stigmatized conditions, little to no research exists regarding parental disclosure of a child's epilepsy diagnosis. In the present study, I fill this gap by looking at parental disclosure of a child's epilepsy diagnosis. With this goal, the theories of CPM and SMC were chosen as appropriate theories in the study of epilepsy disclosure. These theories are not only complementary in relation to the study of parental disclosure of a child's epilepsy diagnosis, but the study also helps advance CPM and SMC.

Chapter 3:

Method

Study Rationale

Given the lack of general knowledge the public has about epilepsy and the stigma of the condition, both of which affect quality of life (QOL) for children with epilepsy (CWE) and their parents, disclosure is a complex concern for such parents. While some literature exists examining disclosure of concealable stigmatized identities such as epilepsy, there is a lack of evidence-based material on disclosure experiences of CWE and parents. For example, researchers in a study reviewing available literature on epilepsy disclosure concluded that disclosure of an epilepsy diagnosis is a largely neglected topic, even though the limited evidence available indicates disclosure can be stressful and challenging for families living with epilepsy (Benson et al., 2015).

Research is clearly needed to identify patterns of disclosure and reasons for use of specific strategies. Therefore, the present study sought to uncover ways parents negotiate disclosing to others that their child has epilepsy by attempting to answer the following research questions:

RQ1: In which situations and with whom do parents disclose that their child has epilepsy?

RQ2: In which situations and with whom do parents conceal that their child has epilepsy?

RQ3: What types of support have parents received when they disclose the epilepsy diagnosis?

Philosophical Assumptions

When conducting research, it is important for the researcher to consider their own positionality and philosophical assumptions. Specifically, as researchers, our philosophical assumptions may differ with regard to our ontological, epistemological, and axiological assumptions (Tracy, 2013). Based on our individual positions in relation to these assumptions, we tend to position ourselves within a particular research paradigm, which then affects our methodological choices. According to Tracy (2013), our philosophical assumptions guide us into one of the four primary paradigmatic approaches: (post)-positivist, interpretive, critical, and postmodern/poststructural. Creswell (2013) includes a longer list of what he terms interpretive frameworks, including postpositivism, social constructivism, transformative frameworks, postmodern perspectives, pragmatism, feminist theories, critical theory and critical race theory, queer theory, and disability theories. Denzin and Lincoln (2011) include positivism, postpositivism, critical (to include feminism and race), constructivism (or interpretivist), and participatory (plus postmodern) as the inquiry paradigms they discuss.

In this section I discuss my own ontological, epistemological, and axiological assumptions. Overall, my philosophical assumptions position me in the constructivist or interpretivist inquiry paradigm. For the purposes of this dissertation, I will from this point forward use the term “constructivism” to refer to this paradigmatic approach. Researchers from a constructivist paradigm assume there are multiple realities and these realities are co-constructed (Denzin & Lincoln, 2011). Finally, I will explain how these assumptions guide my methodological choices for this research.

Ontological Assumptions

According to Creswell, “the ontological issue relates to the nature of reality and its characteristics,” (2013, p. 20). Similarly, Schwandt (2007) states that ontology comprises “the worldviews and assumptions in which researchers operate in their search for new knowledge” (p. 190). Denzin and Lincoln (2011) indicate that from a constructivist paradigm, a basic belief about ontology is that:

> we construct knowledge through our lived experiences and through our interactions with other members of society. As such, as researchers, we must participate in the research process with our subjects to ensure we are producing knowledge that is reflective of their reality (p. 103).

My ontological assumptions include my belief that the ways parents of a CWE manage decisions to disclose that the child has epilepsy are affected by both medical discourses and social norms surrounding what it means to have epilepsy. This includes ways social norms affect decisions regarding when private health information should or should not be shared. Through parental narratives, I intend to uncover the various considerations parents have with regard to making the choice to disclose and how much to share when doing so. As a parent of a CWE myself, I recognize that I am constantly learning how to navigate this openness-versus-privacy dialectical tension and it changes frequently through my experiences with others.

Epistemological Assumptions

Epistemology relates to the nature of knowledge, including what counts as knowledge (Creswell, 2013; Tracy, 2013). According to Anderson and Baym:

> Inseparable from our understandings of the real are the assumptions about knowledge that shape any effort to comprehend phenomena. Epistemology is the study of those assumptions: the inquiry into the character of knowledge, the nature of acceptable evidence, and the criterion of validity that enable one to distinguish the false from the true, the probable from the actual (2004, p. 603.)

From a constructivist perspective, “we are shaped by our lived experiences, and these will always come out in the knowledge we generate as researchers and in the data generated by our subjects,” (Denzin & Lincoln, 2011, p. 104).

As a mother of a child with epilepsy myself, as well as a health communication researcher, I approached the parental interviews I conducted within this study from a unique perspective. I recognize, through both personal experience and professional research, the struggles experienced by families of a CWE, often on a daily basis. I also recognize the ways in which children with epilepsy may be positioned differently in relation to other children in both academic and social settings. I have wrestled on many occasions with the decision about whether to disclose my child’s seizure disorder to others. For example, when taking my daughter to a birthday party, if the other parent asks if we can drop our child off and pick her up later, I have a more complex decision to make than other parents might. First, do I feel comfortable leaving my child there in general? Second, if I do leave my child, I need to disclose to the parent that she has epilepsy. If I disclose to the parent that she has epilepsy, will they feel comfortable with me leaving her? If I don’t disclose to the other parent that she has epilepsy, will she be safe? What if she has a seizure and they don’t know how to handle it? In the space of a second, I have to consider all of these things and make a decision. In addition, I need to consider how my daughter feels about the other child and the child’s parents knowing that she has epilepsy.

I believe this perspective allowed me to quickly establish rapport with the parents I interviewed for this study and guided my follow-up questions. In addition, the combination of my own experience and my familiarity with the literature on disclosing other conditions helped me create appropriate interview questions.

Axiological Assumptions

Axiological assumptions have to do with the role of values in research (Creswell, 2013). According to Anderson and Baym, axiology “considers the basis of ‘good’ choice and allows us to examine the rationales for actions” (2004, p. 608). From a constructivist or interpretivist point of view, values “are personally relative and need to be understood. [Values are] inseparable from the inquiry and outcomes” (Denzin & Lincoln, 2011, p. 109).

With regard to axiology, my values and feelings impact not only my research choices and questions, but also guide my feeling that the parents’ values and views are inherently important. My assumption is that each parent of a child with a chronic condition or disability has a unique voice and story to be told. I believe the lived experiences of the families of children with epilepsy are inherently valuable. The lived experiences of parents such as myself can provide rich insight into ways they cope with sharing their child’s diagnosis with others. In addition, I am aware of the ways that children with conditions such as epilepsy may be positioned differently in relation to other children. They may be treated poorly, shunned, or ostracized due to the current stigma associated with the condition. This understanding helped to guide my questions as well as my demeanor when interviewing the parents in this study.

Given these beliefs, I shared with my interviewees the fact that I myself have a daughter with epilepsy and that she was diagnosed five years ago at the age of three. This helped build rapport with parents and perhaps made them more comfortable sharing information with me. On the other hand, I was careful not to share my own ideas and feelings regarding disclosure practices as I wanted to be as open as possible to the experiences of the parents I interviewed. While it may not be possible to be completely objective, and is not necessarily required or encouraged when conducting interpretive research, it is, and was, important that I entered the interviews without preconceived notions of what the participants could, or should, share.

Based on my own philosophical assumptions, I employed a phenomenologically based interpretive approach within which I asked participants to explore their deeply felt, lived experiences, providing valuable insight into choices to disclose when a child has epilepsy. Overall, this study is based on a phenomenological research design which seeks to describe "the common meaning for several individuals of their lived experiences of a concept or phenomenon," (Creswell, 2013, p. 76). In this case, the phenomenon explored is that of disclosure of a child's epilepsy diagnosis. I sought to solicit narratives to build understanding of what parents of children with epilepsy experience in regard to coping with the diagnosis, and the pressures of balancing the need to disclose the diagnosis with the need to maintain privacy.

Research Site and Recruitment

For this study, parents were recruited from a variety of sites. Recruitment sites included common spaces at the University of New Mexico and Central New Mexico Community College, both located in Albuquerque, a local Albuquerque epilepsy support group's bulletin board, and online via Facebook. Facebook recruitment included my own network, sharing with friends' networks, and sharing to epilepsy support groups I am a member of.

In the end, 14 of the 15 participants were members of a Facebook support group for parents of children with epilepsy. One participant saw the recruitment on a friend's Facebook page and contacted me. Participants were located across the United States from California to New York State, therefore participants were given the option to meet with me either via telephone or a video platform such as Zoom. All participants chose to speak with me via the telephone.

Participants

In order to participate in the study, parents were limited to those over 18 years of age, whose child was diagnosed at least six months prior. The purpose of this limitation was to ensure that parents had experienced opportunities to disclose the child's condition to others, even if they hadn't actually disclosed it. Parents needed to have a child with epilepsy who was diagnosed between the ages of six months and 18 years of age. The rationale for this is that, by age 18, children are likely choosing when and if to disclose their condition on their own. My original goal was to interview at least 15 parents, or until no new themes appeared. Using a constant-comparative analysis format similar to Rafferty et al. (2019), theoretical saturation was reached at 11 interviews. The remaining four interviews were already scheduled, and were completed leading to the total of 15 interviews included in this study.

The interviewees were all mothers of children with epilepsy, who will hereafter be referred to as Moms. The interviewees were primarily (all but one) members of a Facebook support group for parents of children with epilepsy, and lived across the United States. All participants were female; 12 of the participants self- identified as white, two as Hispanic/Latino, and one as African American or Black. Ten of the participants indicated they are currently married, three were divorced, and two were never married. Figures 1-4 indicate additional demographic information for the Moms who participated in the study.

Figure 1

Participant Age

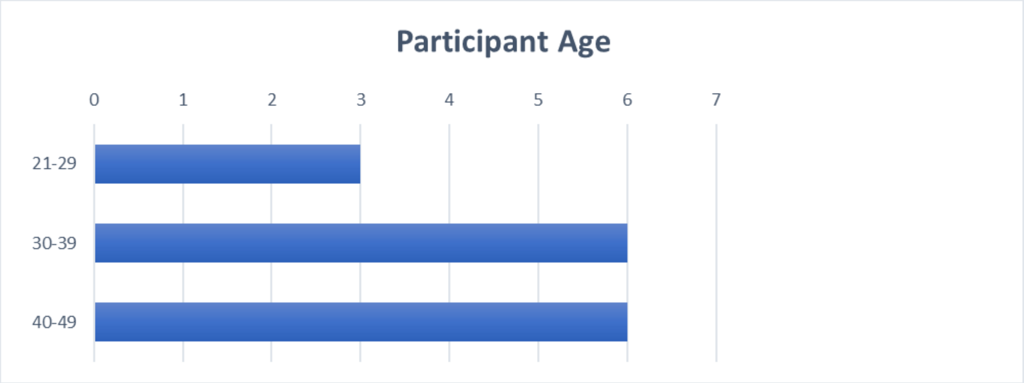


Figure 2

Education Level

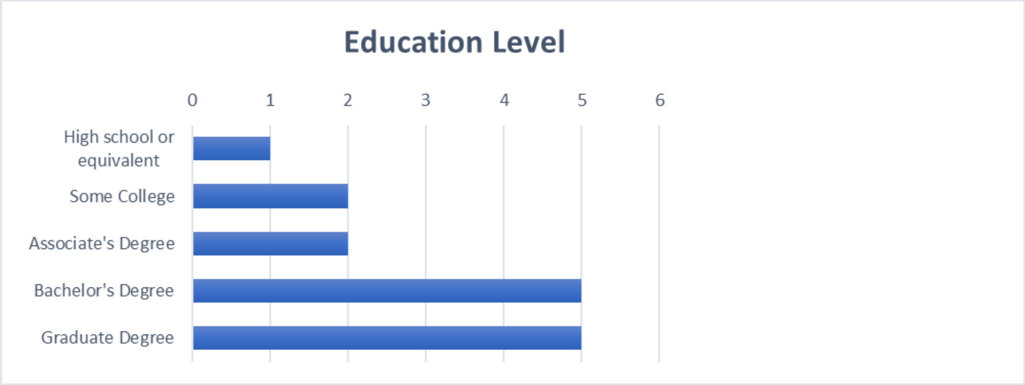


Figure 3

Annual Income

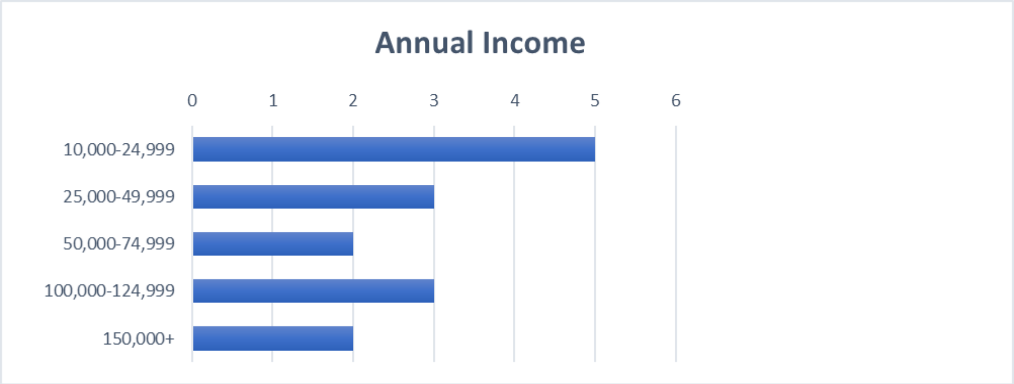
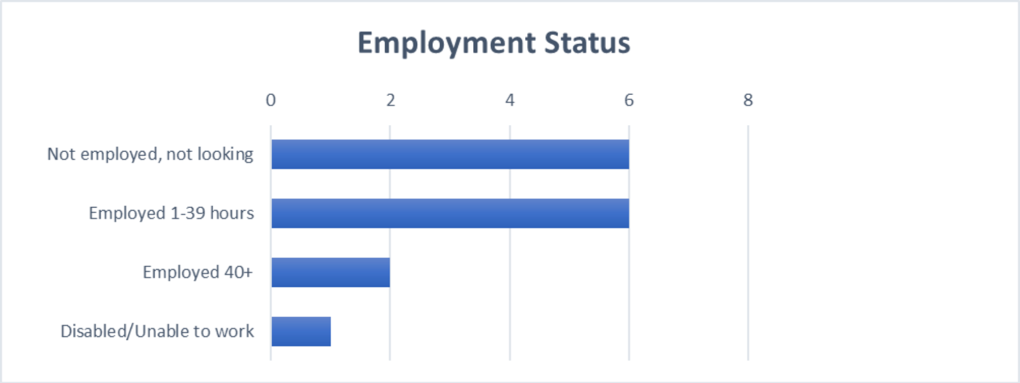


Figure 4

Employment Status



Procedure

Since this project explored concepts not previously covered in the literature, interview questions were open-ended, allowing for individual interpretation and levels of elaboration. Using a semi-structured interview guide (Figure 5), I interviewed each of the Moms at a time of their convenience. To allow room for interpretation, participants were allowed to elaborate as they felt inclined, and follow-up questions were asked to clarify the experience and process. In addition, participants were informed they could skip any questions or discontinue the interview at any point, consistent with interview research practices such as those used by Romo (2016) in a study on weight loss disclosure. All of the Moms chose to answer each of the questions, and completed the full interview.

Figure 5

Semi-Structured Interview Guide

Thank you for agreeing to meet with me. As you know, I am a parent of a child with epilepsy myself and am interested in learning your own and your family's experiences having a child with epilepsy, and how (or if) you choose to tell people about her/his diagnosis.

1. First, can you tell me how your child was diagnosed with epilepsy? (probe: how old was she/he, what led to the diagnosis).

2. Who in the family knows about the diagnosis (probe: Did you reveal the diagnosis of epilepsy to your child? If yes, how did you tell her, if no - why not? What factors influenced your decision to share the diagnosis with other members of your family?)

3. How have the other members of the family reacted to the child's epilepsy diagnosis?

4. Who else besides relatives have you told about your child's diagnosis? (probe: What methods did you use to share this diagnosis with others? In which situations did you share the diagnosis with others? How do other people react when you talk to them about your child's epilepsy?)

5. In what situations and with whom have you chosen to conceal your child's epilepsy? (probe: Does your child's teacher know?)

6. When you have revealed the diagnosis of epilepsy, have you received support from others? (probe: What type of support did you receive? Would you have liked more or less support from others?)

The study overview was submitted to the University of New Mexico's Institutional Review Board (IRB) for approval, and participants were informed of such approval. A document with the study overview was provided along with general consent information to all participants; I asked IRB, and received permission, for a waiver to signed consent forms as this helped to protect privacy as names are not collected on the documents. I also asked participants for their permission to audio-record the interviews; all participants agreed. Each study participants lived in a different state, so parents were given the option of a telephone or video-conference interview (using software such as Skype, FaceTime, Google Hangouts, or Zoom). All participants chose to speak on the telephone.

Participants were asked to create a pseudonym for themselves, and this pseudonym was used in the transcripts, data analysis, and reported results. Only the primary researcher has access to the full names associated with the pseudonyms to preserve privacy. Participant interviews, including names and pseudonyms, are kept on the primary researcher's private, password-protected laptop computer. Interview transcripts and related information will be destroyed three years after study completion.

Data Analysis

Audio recordings from the interviews were transcribed by me, the primary researcher, utilizing the INQScribe software. I first read the transcriptions line-by-line in order to become familiar with the data (Catona, Green, Magsamen-Conrad, & Carpenter, 2016).

The responses from the interviews were then coded for content and recurrent themes using inductive coding. An inductive approach to coding is one where the data are coded without trying to fit them into a pre-existing theory or model (Thompson-Janes, Brice, Mcelroy, Abbott, & Ball, 2016). Overall, in inductive coding, the themes are linked to the data themselves, not driven by the researcher's theoretical interest or frame (Braun & Clarke, 2014). At this stage in the coding process, both open coding and *in vivo* coding were conducted to form initial codes. As Creswell (2013) notes, "in the open coding phase, the researcher examines the text for salient categories of information supported by the text" (p. 195). Catona et al. (2016) also explain that open coding is "an interpretive process designed to examine, compare, and categorize qualitative data to develop thematic concepts" (p. 141). Further, as Lindlof and Taylor explain, "*in vivo* coding – coding the terms used by social actors to characterize their own scene (derived from interviews or ethnographic conversations) – is conducted at the same time as open coding" (2011, p. 251).

As part of this process, I created a codebook to keep track of definitions created, codes used for identifying categories, and specific examples for the category. After open coding to form initial codes, axial coding was conducted to integrate categories. "Axial coding involves searching for similar data sequences to foster connections between emerging thematic concepts" (Catona et al., 2016, p. 141). Lindlof and Taylor (2011) also indicate that the purpose of the codes created during the axial coding stage is to make connections between categories. At this same time, a second coder, who is well trained in qualitative research methods and health communication, read through all transcripts and independently coded each, following the same process.

When each coder felt a point was reached where the data could no longer be combined into new subgroups or thematic concepts, we shared the codes we had found and discussed points of agreement, points of concern, and areas we felt needed to be re-examined. At this stage, I (the primary researcher) went back and completed an additional round of open coding for all transcripts, this time using the Dedoose qualitative software package. Once I completed this round of coding, I again conferred with the second coder to develop final themes. To guide our discussion and final theme development, we followed Owen's (1984) guidelines ensuring that in order for the codes we found and combined to be considered a theme, they needed to meet the principles of recurrence, repetition, and forcefulness.

Part of the integration of categories during axial coding included considering the themes in relation to the research questions. For example, to answer RQ1, which asked in which situations and with whom do parents disclose that their child has epilepsy, codes were examined and combined into categories related to situations where parents disclose and to whom they disclose. To answer RQ2, which focuses on situations and people with which parents might choose to conceal the diagnosis, codes were examined and combined into thematic categories related to concealment. Codes that related to support received were analyzed and combined into themes to answer RQ3 as it focuses on types of support parents have received when revealing the diagnosis.

Finally, the initial researcher contacted eight of the participants, chosen randomly utilizing an Excel random number generator. Of the eight contacted, three responded and agreed to review themes to see if they concurred. One member did ask some questions about the theme of stigma, but agreed it was an aspect of coping with the condition from some perspectives, even as she felt stigma was not a factor. While each member had some questions about the wording of themes, after discussion each agreed the themes capture the overall experience of Moms of children with epilepsy as related to disclosure.

Chapter 4:

Findings

The goal of this study was to determine when parents choose to disclose to others that their child has epilepsy, and what factors might affect this decision. Given the impact a diagnosis of epilepsy has on both the child's and parents' quality of life, understanding these factors is important. In addition, this study sought to ascertain if parents were receiving support from others when they did choose to disclose.

Within this chapter, I will first discuss the seven themes and nine sub-themes that emerged, including relating five of the themes specifically to the research questions. The themes and sub-themes are all included in Figure 6, along with an overview of how they relate to the research questions.

Figure 6

Themes

THEMES	**SUB-THEMES**	**RELATED RESEARCH QUESTION**
Everyone Needs to Know	Safety of Child Parental Peace of Mind	**RQ1: In which situations and with whom do parents disclose that their child has epilepsy?**
"Sometimes You Just Want to be Another Kid and Another Parent at the Party"	I Don't Want Their Judgement Because They Don't Need to Know	**RQ2: In which situations and with whom do parents conceal that their child has epilepsy?**
Positive Social Support	Informational Support Tangible Support Emotional Support	**RQ3: What types of support have parents received when they disclose the epilepsy diagnosis?**
Negative Social Support		**RQ3: What types of support have parents received when they disclose the epilepsy diagnosis?**

Providing Support to Others		**RQ3: What types of support have parents received when they disclose the epilepsy diagnosis?**
Quality of Life	Fear and Grief Additional Challenges	
Stigma		

RQ1: In which situations and with whom do parents disclose that their child has epilepsy?

"Everyone Needs to Know"

When looking at situations and people with whom parents disclose a child's epilepsy diagnosis, one primary theme emerged. As several Moms responded, "everyone needs to know." In fact, this specific phrase was mentioned so often it became the name for this theme. This theme includes two sub-themes which will be discussed later within this section: a) "safety of child" and b) "parental peace of mind." This theme also ties into previous research on epilepsy disclosure from both Eaton et al. (2017) and from Benson et al. (2015). Specifically, Benson et al. (2015) describe the theme of preventative disclosure, which involves letting others now about the diagnosis prior to the possible occurrence of a seizure. Eaton et al. (2017) describe one theme titled "disclosing/ concealing in the child's best interests" as well. Both of these encapsulate much of the same idea as "everyone needs to know" and the sub-theme of safety of the child.

The vast majority of Moms in this study indicated they voluntarily disclose their child's epilepsy diagnosis to family members, friends, school personnel, and other people regularly in contact with the family because they believe everyone needs to know. As one mom, who used the pseudonym BALD, stated:

> Everyone knows in our family. We figure everyone that comes into contact with him should know. So, not only us, but everyone around him should keep a close eye on him… And we just need him not to get injured from them, so we need everyone to keep a close eye on him in case he were to drop or fall. So, we keep a close eye on him, so we figured it was good for everyone to know. So, you know they weren't freaked out when it happened or anything like that.

Several other Moms echoed these statements, whether asked about family or other people. One Mom specifically mentioned she doesn’t conceal the diagnosis from anyone, because she needs everyone to know for the child’s sake.

> I don't necessarily conceal it to anybody. I feel like, especially when it comes to school or his speech or OT, those are times that it can't be concealed. With everybody else, I feel like I need to tell them for Keenan's sake... Rather than wondering and assuming, I would rather people know what's going on with Keenan than assume. (Katie)

Other Moms brought up the need for sports coaches, school personnel, and even other children at school to know.

> Pretty much everybody else who knows us, he's active in sports so all of his sports teams, they know all. In fact, we've been, by some twist of fate, his head coach for his hockey team also has epilepsy. So, that I feel like has been neat for him to see an adult functioning and doing what he likes, and he has a family. Everybody in school knows, we go in, this is the second year, we've gone into the classroom and read books about epilepsy, explained it to the whole class. He's on the ketogenic diet so we've also explained that to the whole classroom, let the

> children ask questions, tell them they can ask him or ask questions about it anytime they want. (Lindsay)

As mentioned, the theme “everyone needs to know” was seen throughout all interviews, and also includes the sub-themes of “safety of child” and “parental peace of mind.” “Safety of child” as a theme, like the primary theme “everyone needs to know,” was mentioned in the majority of interviews. This theme relates to the need to make sure anyone who spends time with the child, takes care of them, or would be alone with them knows what to do if the child has a seizure. This supports previous findings by Petronio et al. (2004) where healthcare advocates used safety as a guiding factor when deciding to disclose. Tracey clearly expresses the concept of this theme in her statement “Safety, from a safety standpoint in case we aren’t there, it’s important for them to know how to handle it. So, nobody is surprised.” Many other Moms gave similar responses about the idea of safety – if the parents weren’t going to be with the child, other people around needed to know how to manage a seizure. This included recognizing the types of seizures, knowing the appropriate responses such as timing the seizure, knowing how and when to give rescue medications, and when to call emergency responders. As Katie expressed:

> I gave everybody (family) the heads up when he got diagnosed as a baby, because if in the event any of them wanted to watch him, I kind of pretty much bridged it to them: can you handle it. Because he has grand mals [type of seizure that includes stiffening of body and full body convulsions]. You have to know what to do and when to do it. You can't give him his rescue meds too soon or too late. Ya know, can you handle, you have to give him medication, it has to be on time, and

> can you handle that? … And so, as parents, we have to make sure you're confident in taking care of him in the event of a seizure.

The other aspect of safety for the child included keeping them safe in various activities such as school, a job, or sports such as swimming or hockey.

> I don't tell random people, unless I think it's a need for safety. For example, if he was going to camp for a day, and part of it was swimming, I would absolutely tell them. He's a good swimmer, but has to be observed or he can't do it. So, if it's a matter of safety, I definitely would tell. But, it doesn't come up in general conversation really often. (Rachel)

> The people that need to know, those are the ones that know. If it was up to my daughter, she would not have me tell anybody. But I feel like all of her teachers need to know, because they need to know how to react to it. And she, she has a job, her boss has to know about it because if something happens they have to be able to do something. (Michelle)

The sub-theme “parental peace of mind” was also a common thread among the Moms interviewed. “Parental peace of mind” included the idea that the Moms wanted to be sure anyone taking care of their child was comfortable, primarily so parents felt safe letting their child out of their sight. Virginia expressed this idea well when sharing her experience when her son started kindergarten:

> As soon as kindergarten orientation began, when I registered him, I told them he has epilepsy that isn’t controlled. I talked to the nurse, his teacher, the principal as I wanted them to take this into consideration when assigning classes. When diagnosed, he was still in daycare, so told all of them. Luckily, I worked in the

> same building which gave me peace of mind. I don’t know if I would have survived it otherwise.

Part of “parental peace of mind” also included feeling like others were prepared, or wouldn’t be scared or become upset if a seizure occurred or the child displayed unusual behaviors.

> Also, it’s better to know than just be startled – prepare people in case it happens. So they can understand that he’s going through things, rather than thinking he’s acting weird or different for no reason. Like he’s going through stuff with the different medications. (Tracy)
>
> I've become much more open about it, and I've had to become more open about it. For example, playdates. I don't feel comfortable sending him over to someone's house, even though he is controlled well right now. His seizure was the scariest thing I have ever seen. I can't imagine having a kid over for a playdate and seeing this kid seize if I hadn't been told this might possibly happen. So, I do tell playdates. I don't send rescue meds, I tell them to call 911. (Rachel)

RQ2: In which situations and with whom do parents conceal that their child has epilepsy?

“Sometimes You Just Want to Be Another Parent and Another Kid at the Party”

The second primary theme related to the question of whether there were situations parents would choose to conceal that their child has epilepsy. This theme includes two sub-themes as well: a) “I don’t want their judgment” and b) “because they don’t need to know.” While all the Moms interviewed disclosed in most situations, there were a few situations in which they chose to conceal. Most often, these were situations where the child and/or mom were with people they didn't see regularly or they wouldn't see again. Often this was a matter of convenience, or feeling other people didn't need to know or wouldn't understand. This theme especially supports previous research on Communication Privacy Management Theory, and considering control of the flow of private information. Virginia sums up the essence of this theme with her statement:

> If I'm with him somewhere like a birthday party or he's with friends, if I am there and not leaving him, I don't tell. I'm not leaving him, so I'm there to take care if anything happens. They don't need to know then. I don't know if he tells his friends, but I don't sit and talk about it or make a point to bring it up. A lot of people who come into causal contact don't realize so I don't always share in social situations as long as I am going to be there. Sometimes you just want to be another parent and another kid at the party.

Throughout the interviews, many of the Moms mentioned concerns about others judging their child because they didn't understand the condition, and they especially discussed this when asked if there were situations within which they could conceal the diagnosis. This concept led to the first subtheme of "I don't want their judgment." Specifically, this theme was related to not sharing information with some distant family members or those who weren't trusted.

> There have been situations [where I] chose to conceal. I'm just now starting to integrate her with children her age, able-bodied children her age. When I've taken her to Sunday school, I don't know the teacher personally, the first thing out of her mouth was "What's wrong with her?" She's in a wheelchair. I responded

> with, “well. let’s talk about what she can do.” I didn’t tell her she has epilepsy, just knowing she had cerebral palsy, if I had shared that also, I know she wouldn’t have let her stay. Luckily, her godmother volunteers back there so I knew she would keep an eye out. And so, I just didn’t tell this lady. (Nicole)

The judgments many Moms were concerned about were from family and friends, as well as strangers. As Rachel stated:

> We concealed, I don't know if we, I concealed from Facebook for two years. I just didn't want to put it out there. Finally, it was SUDEP [Sudden Unexplained Death In Epilepsy] awareness day and I thought screw it. I'm going to make a post about SUDEP and it was fine… The people that didn't know, they didn't react one way or another. We didn't tell my husband's sister, because we had no desire to tell his mother who is a nightmare of a woman. We've had no contact with her in, about five years, and she I'm sure as soon as she found out, made some lovely comment about I'm sure their children would be screwed up. We didn't even want to think about her reaction. I don't tell random people, unless I think it's a need for safety.

Along with avoiding anticipated judgments, many Moms expressed the second subtheme of “Because they don’t need to know.” Frequently, the decision to conceal the child’s epilepsy diagnosis came down to the moms’ feeling that in some situations, and with some people, there was no need for disclosure. They weren’t worried about safety, or if people might treat the child differently, or just felt the situation didn’t warrant a discussion. For example, Melissa stated:

> At times I haven’t told other parents or children, like if I was staying at the event or party or whatever. I haven’t told some friends. They just didn’t need to know, and she doesn’t like people to know.

Another Mom, BALD, added on to this idea by clarifying that a major deciding factor of who needs to know relates to proximity and frequency – if they don’t see certain people often, or are not close to the family, they don’t need to know.

> So, it's pretty much just everyone that we come in contact with, and like, say if we don't see them at least once a month they don't really know. They're not around him enough and not close enough to us to really know what's going on. (BALD)

One Mom, Marlynn, mentioned that she doesn’t believe she has ever concealed, but she could picture doing so mainly for convenience if she felt certain people didn’t need to know. Specifically, she stated:

> The only time I considered not writing it down was when I took him to the dentist. I know that's silly, but it's kind of a convenience thing, if I write it down, I've gotta worry, maybe they're gonna worry they have to get certain pads out, maybe... but I put it down and it was fine. But I probably wouldn't have checked it off if I had gone to a normal adult doctor, one who doesn't deal with special needs. Just convenience. And I know I'm gonna be there that whole time holding him anyway. And I know there are no medical risks to having dentistry to either of those things. So, I knew, I just didn't need to get that person in the nervous mode. They don't need to be nervous, he's fine, he's just a regular kid.

RQ3: What types of support have parents received when they disclose the epilepsy diagnosis?

"Positive Social Support"

The third RQ specifically asked about social support and the types of such support parents indicated receiving from others. Three major themes and three subthemes emerged to answer this question; the first major theme was that of "positive social support." The majority of Moms discussed a wide variety of ways in which they received positive social support from others after revealing the epilepsy diagnosis. The support came from a variety of people including family, friends, medical professionals, community groups, and online support groups. This was especially important since, as Sue stated, "epilepsy affects your whole family, it affects your whole family dynamic."

> Like our family is very supportive, our close friends. Like when we've been in the hospital, they will come visit. They go out of their way to be nice to my kids. Just supportive in like the general sense. I think support is sufficient, I think when I need more support I reach out and I can get it. I think it's self-dependent on what you're looking for in support. Like when I have to go in for like a five-day EEG. Friends will come and hang out with my other kid, and do things with my other kid, because I'm gone for x amount of days. Epilepsy affects your whole family, it affects your whole family dynamic. (Sue)

Within "positive social support," three subthemes were found: a) "informational support;" b) "tangible support;" and c) "emotional support." These terms were intentionally used for the sub-themes as these are terms used regularly in the social support literature. Informational support included sharing information about epilepsy with the families and/or directing parents to where they could find additional information. For example, Nicole stated “Her doctor sent us to epilepsy clinics for more knowledge, I’ve had friends and family send me articles they have found about different things with regard to epilepsy.”

“Informational support” also came from connections the Moms intentionally sought out. Rachel explained it well when she stated:

> Connections to other parents with epilepsy, connections to other parents with my kid’s type of epilepsy. I’ve got a good friend whose son also has epilepsy, she’s in another state now, I called her and she gave me so much information. Got me hooked up with different people, different resources…I receive that kind of connection, able to connect with so many parents who have been through the same thing and that has been absolutely invaluable.

“Tangible support” was another subtheme that emerged within positive social support. The majority of moms mentioned items related to tangible support when asked in what ways people reacted to the disclosure of epilepsy or if they received support from others. Often, types of tangible support included watching other children, taking them to doctor’s appointments, bringing meals, and more. As Tracy said:

> Friends brought us dinner to hospital… our family makes dinner for us. When he was home a lot from school, friends brought games and other items over for him while he was home. I feel like amount of support has been what we needed.

Eileen echoed the importance of tangible support when discussing how thankful she has been for the support her mother-in-law has provided.

> I have support, I mean my mother-in-law (MIL) has been amazing. She goes with me to every appointment, she's gone to every hospital, every time we've gone to the hospital she's been there… I know people have horror stories of MILs, and mine has been amazing through everything. She'll give her her meds if she has to, she went with me to the epilepsy foundation, so that we could learn how to use the Diastat.

In many cases, as seen in the quote above from Eileen, the tangible support was linked with the third subtheme, “emotional support.” Going to doctors’ appointments is in many ways tangible support, but also can provide emotional support. Other ways family and friends showed emotional support was through phone calls, emails, and listening to the moms. For example, Ellie also talked about support in a way that shows how often tangible and emotional support were connected:

> Yes, in that they would be concerned, they would call and find out how he is doing. Has he had any more episodes? Is there anything you need? I remember some of the neighbors, I'm going to the grocery store, do you need anything, so you don't have to go out? But no, we're fine. Does he need a ride?

Other times, emotional support was mentioned separately which made it an additional subtheme rather than a part of the tangible support subtheme. Virginia gives an example of this:

> School, doctors, family for the most part... very supportive. From family, listening a lot to the day-to-day struggles, from the school, the teacher has been very good. Like meeting for IEP and teacher, I got emotional and the teacher gave me a hug.

> They were very supportive emotionally. As well as not going crazy every time I check in.

Belle also described examples of emotional support that was particularly helpful when she stated:

> I think listening to me, and also the parents of the kids that my son hangs out with, going that extra step when my son is at their home, to message me and just let me know that they're playing fine and he is okay. Just that message to reassure me that he is okay not being home with me. I think that's a very big thing because when he is gone, I am on pins and needles wondering if I am going to have to go pick him up, and how is he doing, and so getting those text messages or pictures of them hanging out or playing outside, it's reassuring that he is okay.

“Negative Social Support”

While most of the support the moms discussed was positive, some was not as helpful or even desired, which falls into the second theme related to social support, that of “negative social support.” Negative social support includes unwanted or unwarranted advice, judgement, pity, and lack of understanding. Rachel described her reactions to some of the unwanted advice and lack of understanding as follows:

> Reactions vary when we tell…Other people, this was my mom, I know her intention was good, she responds with he'll grow out of it, and I know so many people who have managed it with medication. Her intent is to make me not worry; the result is to dismiss my feelings. Because I am worried about it. My half-sister died of SUDEP at age 30, which was 6 months before my son was diagnosed.

> Which is an additional level of concern for me since we have that biological connection.

Like Rachel, many Moms mentioned the lack of understanding, which therefore led to a lack of the type of support the families needed or wanted. Sometimes the lack of understanding resulted in unwanted advice, other times in judgement or pity. This was especially difficult when the moms believed they were making the best decisions they could for their family, as Katie and Lindsay both described:

> They wanna be there and support you, but it's like a pity party. And that's not what we're looking for. And, the ill-advised advice makes me want to beat my head up against a wall. It's more pity than support. Because, even right now, Keenan's almost three and nobody will take him overnight. Nobody will take Keenan for more than four hours because they’re not okay with it. And I appreciate that, I tell them okay at least I know. I want you to be secure in your decision in watching our child, but they all think they're seizure experts. That's where I kind of draw the line. I take their opinion, and I don't say much after. Because it's like a battle every day then. And I just don't have it in me to battle people every day about what's best for Keenan. I don't necessarily say I want more support from others, because if you don't have a kid with epilepsy there's no way you can support me in it. Because you don't understand it. (Katie)
>
> It depends, a lot of people are very supportive and encouraging. I think there are a few families that think it's not as serious as it is. Or, I know, because we're on the ketogenic diet, some people feel very strongly that it's torture for him. So, I hear more comments about the diet than epilepsy specifically. (Lindsay)

“Providing Support for Others”

The final theme relating to social support was that of “providing support for others.” Most of the Moms interviewed not only mentioned providing support for, and educating, other parents and families, but also discussed it as though they felt it was a moral imperative they do so. As an example, Nicole stated:

> We have started to use her epilepsy diagnosis as a platform to educate. She doesn’t display her seizure activity…people assume seizures is lying on the floor twitching, and hers don’t present like that. So, we like to use it as a way to educate other people.

Many other Moms mentioned using their situation to educate and provide support for other families. Rachel talked about how she tries to pass on the support she received by sharing information with other parents, “I will get Facebook messages or a phone call from a friend saying so-and-so’s son was diagnosed, would you mind talking to her?” Lindsay also discussed trying to educate others and provide support, stating:

> I think mostly, to kind of raise awareness about how common it is and reduce stigma… So, we've taken more of a proactive approach, we just get it out on the open so everybody's aware, and they can see that he looks just like any other normal child, he does anything anybody else does. We've also been able to that way, to connect with people we already know who have kids, or adults, who have seizures but they've been quiet about it and didn't feel like they could tell anybody.

Ellie also discussed helping others and sharing information when asked about support. She said:

> One of the teachers, one of our colleagues, at school because her daughter was having like those absence seizures. She wouldn't like seize, she would just fade out. I told her, maybe that's a seizure, maybe you should have her checked out. I told her Alonzo had epilepsy but would never phase out that we know of. He would have a full-blown seizure, especially after being tired or after band practice, he'd get home and lay on the couch. One time he was lying on the couch and sure enough he just started shaking. I had to quickly get up and hold him on the couch or he would have fallen off. So, I told her and sure enough her daughter did end up having epilepsy.

“Quality of Life”

While the Moms interviewed were not specifically asked questions related to quality of life, every one of them brought up issues and concerns specific to this concept. As a whole, the Moms reported experiencing fear and grief related to the epilepsy diagnosis and condition itself, as well as facing multiple additional challenges when raising a child with epilepsy. The theme “quality of life” (QOL) was prevalent among all interviews, and includes the subthemes of “fear and grief” and “additional challenges.” While this topic was not specifically explored in this study, every participant referred to QOL often several times, and it is clearly inherently linked to the experience of receiving and sharing a child’s diagnosis of epilepsy. In addition, QOL is frequently linked to the need to seek out social support from others. Eileen expressed ideas that many of the other moms described when she said:

> Yes, this is how I explain it to people, it's like you're standing on the edge of a cliff waiting for the cliff to drop out. That's how I feel every day. And you don't

> want to get too excited, because I was literally all excited, then the morning of my meeting, I woke up and she's having a grand mal, literally one of the worst she's ever had. I thought, this is exactly why I don't get excited about it. Everyone's like, she's gone a week seizure free, why aren't you excited about it? Because I'm afraid to be excited about it. When I get excited, that's when the shit hits the fan.

The subtheme of “fear and grief” was repeated throughout every interview, and with strong displays of emotion from many of the parents. The parents described not only the fear of seeing your child have a seizure, but also the fear of not knowing what was happening, not having a complete diagnosis, and not knowing what ramifications the seizures may have on the child’s well-being. As Sue said, “it's scary, so scary (that they are at night). All the medicine you have to take, and all the emergency medicine you have to take with you everywhere you go, it's a lot.”

Often, the discussion of fear was related to the first seizure the child had or the first one the Mom witnessed. Many of the Moms had a similar comment to that of Belle:

> He is my first born. And so, he went into a seizure, and during the seizure he stopped breathing and turned completely blue. The paramedics were able to revive him. It was a scary...it seemed like a lifetime but it was only about 5-6 minutes.

In addition to the fear of the first seizure, many of the Moms also discussed the ongoing fear of when another seizure might occur, and if the Mom would be with their child. Fears also related to the idea of SUDEP (sudden unexpected death in epilepsy) and the lack of discussion on the topic from doctors. Eileen’s comments about SUDEP summarize what many of the Moms described:

> … the doctors not wanting to talk to you about SUDEP. I had to bring it up, I found out about it. What do you mean she could die? So, she sleeps in our bed because I am petrified. I'm terrified, all the alarm systems she has are only for grand mals and she doesn't just have grand mals. So, I'm not going to spend thousands of dollars on something that doesn't work all the time. That's crazy. And, I actually had a doctor at the hospital tell me that epilepsy is harder to control and treat than cancer is.

An additional subtheme within “quality of life” is that of “additional challenges.” Fear for the child, and fear of having another seizure, affected quality of life, as did other daily challenges such as additional comorbidities, judgment of medical decisions by others, challenges at school, and not being able to find appropriate care for the child when the parent couldn’t be there. For example, many of the Moms discussed concerns regarding daycare, including BALD:

> The daycare owner is refusing to have his emergency medication on hand so we are actually getting ready to switch daycares. And they are willing to actually undergo extra training and have his medicine on hand at all times.

Not only was daycare a concern, but also at times the school the child attended added to the challenges that parents were facing. Sometimes the challenges were related to medication, as BALD experienced at daycare, but at times they were related to a lack of understanding on behalf of school staff. Virginia experienced this situation:

> Or if I get defensive about how he is treated since not everyone in school knows. For instance, one day we were late because he had some seizures in the morning and needed to rest. Secretary wouldn’t let me walk him to his classroom after that

> situation, so I asked for a teacher to come get him, and she said no also. I explained the special situation and didn’t want him walking by himself given the situation.

Challenges also arose for families when trying to make the best decisions for medication and other treatments for their children, especially given they often had multiple diagnoses to cope with. These challenges were exacerbated when they felt judged by others for the decisions they made. Overall, it was the norm rather than the rarity that parents had to make difficult decisions regarding medications and treatments. As Molly put it:

> [He had] two separate surgeries, but all within one hospital stay. After that one, I think that is a little harder to digest for people, like people who don't understand the situation. I kind of think that maybe they didn't think that was the best, so anyway, he's had another surgery since then. And we didn't tell a lot of people before that surgery. It was such a hard decision for us to make, it was just gut wrenching, and I just, I had told one friend that I thought we were very close, I thought she understood the situation, and she made the comment that well don't you love him just the way he is. As if we would be doing any of this if it wasn't truly necessary. The doctors are telling us that he needs this to have any chance of a normal life, because he was having such long episodes, and he had been having them since he was an infant, over and over, so they really thought he needed. Such a gut-wrenching decision, and to have somebody say that to me, we really felt like it wasn't an option.

Melissa summed up the wide variety of challenges the Moms described facing when she said:

> There are so many things none of the doctors or specialists tell you. Like my daughter has struggled to learn to read and receives additional learning support through the school for it. And no one can tell us why, she isn’t dyslexic, has a large vocabulary, no red flags. And now she doesn’t want to go to school for fear of having a seizure. And she has these violent tantrums out of nowhere that sometimes last an hour. And nothing we do gets through to her. And the doctors shrug and say “well, could be the epilepsy, could be the medicine.” And, we have no family in town, so we never get a break. No time to breathe or time for ourselves in all of this.

“Stigma”

Many of the Moms spoke to the concept of “stigma,” including avoiding or challenging stigma related to epilepsy. Stigma Management Communication Theory (SMC) addresses the idea of avoiding or challenging stigma, and therefore these findings support this portion of the theory. While not all of the Moms used the specific term “stigma,” they still referred to the overall concept. For example, Tracy stated when discussing disclosure, “So they can understand that he’s going through things, rather than thinking he’s acting weird or different for no reason. Like he’s going through stuff with the different medications.”

One of the aspects of stigma several parents discussed was the idea of voluntary or preventive disclosure to try to avoid any judgment or stigma with the child’s behavior or epilepsy. As Nicole stated:

> We were at the grocery store, and she was having cluster seizures (repeatedly). A very kind lady wanted to know what was wrong, so I explained to her what was going on. Another time, on a field trip with my older son, she had a seizure, and I had the looks of people who want to ask but don't know how. So, we shared, so there was no reason to be alarmed. We were okay and had it under control.

In addition, Moms often discussed concepts related to reshaping the conversation or denial of stigma associated. Frequently Moms would talk about disclosing their child's epilepsy diagnosis in part to reduce stigma, or make it clear there shouldn't be a stigma associated with the condition. Rachel said, "I struggled with being open initially, but I think not being open makes it shameful. And I don't want him to think we're not sharing this information with people because there's some kind of stigma to it."

Within this chapter, I discussed the seven themes that emerged through analysis of all interviews. This included description of all themes with representative quotes, as well as relating these themes to the study research questions. In addition, several sub-themes were discussed throughout to help further explain the various themes.

Chapter 5:

Discussion

In this final chapter, I first review the purpose of this research project and the overall objectives of the study. As part of this, I also provide a brief summary of the methods employed to reach the stated purpose and objectives. I them proceed to discuss relationships among the themes found and guiding theories as well as contributions to the field. Finally, I share study limitations and possible implications for future research.

Purpose

Epilepsy is a complex condition, generally misunderstood by both the public and those coping with a diagnosis of same. As epilepsy is a concealable, often stigmatized identity, those with the condition may face an internal tension when deciding whether to disclose it to others. In the case of children with epilepsy (CWE), parents are often the ones faced with the decision to disclose, while simultaneously coping with other factors affecting their children’s as well as other family members’ and their own quality of life (QOL) . When making a decision to disclose, parents need to consider reasons for sharing private health information about their child with others, and possible reactions to the disclosure.

Previous research has examined epilepsy disclosure as a small portion of a larger study, but none have focused specifically on parental narratives surrounding disclosure. In addition, some research within the CPM literature has looked at caregivers and disclosure, but not specifically at parents of CWE. Stigma Management Communication theory (SMC) has not been extensively researched within the health communication field, therefore this research helps build this body of knowledge. This study adds to the existing literature by exploring parental perceptions of disclosing a child’s epilepsy diagnosis, utilizing both CPM and SMC theories.

Objectives

This study was designed specifically to explore the challenges parents face when deciding to disclose or conceal that their child has epilepsy. Given the uncertainty of the condition itself, the stigma attached, and ways quality of life is affected by the diagnosis, the decision to disclose or conceal is a complex one that parents face on a regular basis. As shown in previous literature (Brashers et al., 2004; Canary, 2008; Wright et al., 2012), the need for social support when coping with a variety of health conditions is clear, yet disclosure is required in order to obtain support from others.

Previous research has looked at parental disclosure of a variety of chronic conditions such as mental health and autism, but not specifically disclosure of epilepsy as the focus of the study (Eaton et al., 2017; Hays & Butauski, 2018; Rafferty et al., 2019). Therefore, this study sought to explore parental disclosure of their child’s epilepsy through the lens of both CPM and SMC theories. In addition, within this study I wanted to look at ways quality of life and need for social support might impact these decisions. In order to examine these relationships, I posited the following Research Questions:

RQ1: In which situations and with whom do parents disclose that their child has epilepsy?

RQ2: In which situations and with whom do parents conceal that their child has epilepsy?

RQ3: What types of support have parents received when they disclose the epilepsy diagnosis?

Summary of Methods

To meet the objectives of the study, I interviewed 15 Moms of children with epilepsy. While the study was open to any parent, only Moms responded. Interestingly, not only were Moms the only respondents, almost all who responded were members of a Facebook support group specifically for parents of children with epilepsy; this will be further discussed in limitations. All interviews were conducted via telephone, based on interviewee preference, and then transcribed verbatim by me, the primary researcher.

Once all interviews were transcribed, all transcripts were individually coded by the secondary researcher and me, and then member checks were conducted with four of the original participants. Once themes were agreed upon between both coders, and checked with four participants, we determined how the themes answered the research questions posited for the study. Finally, within the findings, thick description utilizing direct participant quotes was included to validate findings.

Contributions to the Field

In some ways, epilepsy is similar to other concealable stigmatized conditions with regard to its effects on quality of life and stigma. However, one way that epilepsy differs in relation to parental disclosure of the condition is the inherent safety risk for the child in case of a seizure. This is an important consideration when looking at disclosure, and the push and pull parents might experience when deciding to disclose.

Within this study, Communication Privacy Management (CPM) and Stigma Management Communication (SMC) theories were utilized as the theoretical underpinnings for exploring parental disclosures of a child's epilepsy diagnosis. To briefly recap, CPM theory posits that individuals believe they own their private information and therefore decide who is allowed to share in this private information. Once the information is shared, the other person(s) becomes co-owner(s) of the private information and is subject to privacy rules surrounding the sharing of this information with anyone else (Petronio & Durham, 2015). These rules may be explicitly stated or assumed to be “understood” by both parties, and are subject to ongoing boundary coordination and negotiation. If the boundaries are not respected, this can lead to boundary turbulence and disruptions in the relationship.

SMC theorists looked at existing stigma-related literature and theories in order to develop a new theory focused on the communicative aspect of stigma and stigma management. Specifically, SMC theory states that individuals will make decisions about stigma management strategies based on their perception of whether the stigma applies to them and on their own attitude about challenging or maintaining public perceptions of the stigma. The theory then goes on to predict specific stigma management communication strategies individuals will use within these two continuums. For example, if one accepts that a public stigma is attached to a given condition or characteristic, but do not accept that it applies to them, the individual is most likely to utilize avoiding strategies such as distancing oneself from a situation (Meisenbach, 2010).

When considering disclosure of epilepsy, this study was guided by the insight that these theories may be complementary because the attitude towards the stigmatized condition will likely impact the public-private dialectical tension, contributing to the push and pull of whether to disclose the condition. Parents’ attitudes towards the stigma, including public perceptions and whether they feel it applies to their child, are likely to affect not only the decision to disclose but also how they disclose and the types of information they share. Also, if someone wanted to challenge the stigma attached to epilepsy, more information might be disclosed, and boundaries may be intentionally thin in order to change opinions and educate. If, on the other hand, someone chooses to avoid the stigma, boundaries may be thick to protect private information. As posited within CPM theory, thin boundaries are ones where less control is exerted over keeping information private, and thick boundaries are ones where private information is closely held and controlled. However, protecting the information to avoid stigma could put the child at risk, resulting in boundary turbulence. Figure 7 visually highlights the themes and related theories below.

Figure 7

Themes and Theories

THEMES	**SUB-THEMES**	**RELATED RESEARCH QUESTION**	**RELATED THEORY/CONCEPTS**
Everyone Needs to Know	Safety of Child Parental Peace of Mind	**RQ1: In which situations and with whom do parents disclose that their child has epilepsy?**	Communication Privacy Management
“Sometimes You Just Want to be Another Kid and Another Parent at the Party”	I Don’t Want Their Judgement Because They Don’t Need to Know	**RQ2: In which situations and with whom do parents conceal that their child has epilepsy?**	Communication Privacy Management
Positive Social Support	Informational Support Tangible Support Emotional Support	**RQ3: What types of support have parents received when they disclose the epilepsy diagnosis?**	Social Support

Negative Social Support		**RQ3: What types of support have parents received when they disclose the epilepsy diagnosis?**	Social Support
Providing Support to Others		**RQ3: What types of support have parents received when they disclose the epilepsy diagnosis?**	Social Support
Quality of Life	Fear and Grief Additional Challenges		Social Support Stigma Management Communication
Stigma			Stigma Management Communication

Everyone Needs to Know

While most parents acknowledged there might be times they have concealed or hypothetically would conceal the diagnosis, as a whole the Moms in this study agreed that everyone the child comes into contact with needs to know of the diagnosis. With regard to CPM, this would indicate overall thin privacy boundaries on behalf of the Moms in this study. Not only did they feel everyone needed to know, they also didn’t talk about any restrictions on others to keep the information private once shared. This indicates either the Moms didn’t have any major rules for co-ownership of this shared private information, or they didn’t feel the rules needed to be communicated explicitly.

The reasons the Moms in this study felt everyone needed to know fell into two overall categories which became the two sub-themes of safety of child and parental peace of mind. By far, safety of the child was the primary concern most Moms expressed when considering whether to share the diagnosis, whether this was with family, friends, school personnel, or others. This supports the findings by Petronio et al. (2004) that healthcare advocates (or guardians or parents) were more likely to disclose private health information if they felt it related to the safety, health, and/or well-being of the friend or family member. In relation to the present study, due to safety of the child in case of a seizure, there is a push to disclose the condition to anyone (even a relative stranger such as a sports coach) who may have contact with the child.

Parental peace of mind seemed to be primarily related to reducing some of the Moms' uncertainty about leaving the child in the care of others, either family members or other caretakers such as teachers. As parents of CWE, the Moms live with the reality that, in general, uncertainty about when and if their child will have a seizure can only be reduced to a certain degree. Given this, they must manage this uncertainty, and one way to do so may include disclosing to others that their child has epilepsy, simply because they can't be certain the child won't have a seizure while they aren't there. In addition, parents cope with uncertainty as to how another individual will handle a seizure if one occurs. Disclosure allows for easing this in some ways by gathering information about what the other person knows about seizure management.

"Sometimes You Just Want to be Another Parent and Another Kid at the Party"

All of the Moms indicated that, in general, they subscribe to the "everyone needs to know" philosophy and therefore that there would be only rare instances when they would choose to conceal the diagnosis. The sub-themes of "I don't want their judgment" or "because they don't need to know" help to understand this theme by clarifying the thoughts or feelings the Moms might have when deciding not to disclose. Primarily, this concealment occurred in situations where the Moms knew they were going to be there in case of a seizure, and so then they were able to consider other factors of disclosure rather than safety of the child. This led to the name of this primary theme, when one Mom put it well by discussing how sometimes you don't want to go through the explanations, and possible judgment, and you just want to be another person at the party.

Social Support

Three main themes were related to social support: positive social support, negative social support, and providing support to others. Most of the Moms reported receiving adequate support from others after they revealed the diagnosis of epilepsy, and some described examples of informational, tangible, and emotional support. However, some of the Moms didn't elaborate on the concept of support, perhaps due to the phrasing of the question or because it was asked at the very end of the interview when they may have been emotionally or physically ready to stop talking about the topic. The ones who did elaborate discussed how helpful and important informational, tangible, and emotional support all were to them and the family while dealing with the child's epilepsy.

Some of the Moms also discussed the negative side of social support; in particular, unwanted advice and information. For example, this at times included questioning a parent's decisions about treatment options or medications. Negative social support also included expressions of pity, which most of the Moms rejected. While others might have felt they were providing support, pity was not something the Moms wanted or accepted.

The final theme within social support included providing support to others. This was prevalent among most of the Moms, and was a primary factor in why they chose to publicly share the epilepsy diagnosis. Some of the Moms talked about trying to help parents of children who were newly diagnosed by providing information, while others talked about participating in advocacy events with their children. The Moms not only were providing support to others, they felt it was incumbent upon them to do so.

Quality of Life

Quality of life (QOL) is a frequently discussed concept within epilepsy research and health communication as whole. While not a focus of the present study, the theme emerged as a major factor in the lives of the Moms interviewed. In particular, the fear and grief experienced by parents of CWE, and the ways their lives are affected by the condition, were mentioned multiple times by the majority of Moms interviewed. Not only did the parents experience fear and grief the first time their child had a seizure, but they also discussed the ongoing worry of future seizures and ways their child would be impacted by the condition. Whether it was a year prior to the interview, or several, the Moms were able to vividly recall the first time their child had a seizure, often with clear indications of emotion while describing the experience, including tears and tremors in their voices.

The life of the entire family, not just the child with epilepsy, is impacted by the diagnosis. Moms described the need for new daycares, multiple doctors and appointments, medication management, learning challenges at school, and lack of care providers, to name a few. It is highly possible that this major impact on the life of the entire family contributed to the push most Moms felt to share the diagnosis with others.

Stigma

Participants were not directly asked about epilepsy-related stigma, yet many of the parents discussed it, whether they used the word “stigma” or some other term. Primarily, the Moms in this study challenged the idea of stigma as a whole, both in relation to their child and regarding public perceptions of stigma. Indeed, many of the Moms were advocates for epilepsy awareness in their communities, and indicated they felt the need to educate others about the condition even if the others are strangers.

Theme Relationships

The seven primary themes, and theories of CPM and SMC, can all be considered together when looking at parental disclosure of epilepsy. Specifically, SMC considers how parents might view stigma related to epilepsy. For example, if parents accept both (a) the public perception of epilepsy as a stigmatized condition and (b) that the stigma applies to their children, they may choose to avoid gatherings like birthday parties to protect the child and reduce the need to disclose. In the present study, the Moms who discussed stigma appear to fall into the category of challenging both the public perception of epilepsy-related stigma and the idea the stigma applies to their child. They do this by making statements such as “I don’t want my child to feel there is something to be ashamed of” and by using their voices to advocate for awareness and education.

One possible interpretation of the ways the themes all fit together is that the Moms in this study challenge the idea that epilepsy is a stigmatized condition; are seeking positive social support given the fear, grief, and additional challenges they experience as parents of CWE;, and place a priority on the safety of the child. For all these reasons, they (as a whole) believe everyone needs to know about the child’s epilepsy diagnosis. The only times they would be comfortable not disclosing are those times they feel the child's safety isn't at risk.

Finally, this study adds to the literature on both CPM and SMC, and contributes to the theories. In the case of CPM theory, the majority of existing research has focused on individuals who own their private information; this study, therefore, adds to the literature on disclosure of health conditions by healthcare advocates (parents). In addition, the findings highlight the ways healthcare advocates primarily consider safety when deciding to disclose, consistent with prior findings (Petronio et al., 2004) As SMC theory has not been tested extensively in general, much less as related to a stigmatized health condition, the present study could aid in consideration of SMC strategies used, especially when the stigma applies to a child as opposed to oneself.

The findings from this study could be utilized to develop further research regarding CPM and "rules" specific to parents of children with epilepsy and similar conditions. It is possible that their rules for disclosure differ from those of individuals and parents of neurotypical individuals, due to the inherent safety risk to the epileptic child. In addition, SMC could be further developed by asking specific questions about stigma and its application to epilepsy and children with the condition. This could help strengthen the propositions of the present study when considering how people approach stigma and the management strategies they use.

Limitations and Implications for Future Research

As is the case with the majority of research projects, this study has several limitations that need to be addressed. First, 14 of the 15 participants were members of a Facebook support group for parents of children with epilepsy. Not only does this limit generalizability of the findings (in addition to the small sample size), but it is also possible that the participants may have been more inclined to disclose the child's epilepsy diagnosis to others as they had already done so simply by choosing to be members of the group. Future research should attempt to include a broader sample to include those who may be more hesitant to disclose the diagnosis.

In addition to all being members of a Facebook group for parents of children with epilepsy, the participants were all women, and all resided within the United States. Experiences with stigma, social support, and disclosure may be different for men and/or those living in other countries. Since this is the case, the findings of this study would apply to a much smaller portion of the studied population. Also, while all members resided in the United States, the demographics gathered didn't include whether individuals lived in rural or urban areas which could play a role in experiences accessing care and finding social support.

While this study asked participants if they received support from others after disclosing an epilepsy diagnosis, this wasn't the primary focus of the interview questions. Yet, many of the Moms discussed ways people supported and helped them and the family once they disclosed. This leads to the idea that support is an important feature for families of CWE. Consequently, future research should look more closely at social support as a whole, and more specifically in online groups, since all participants self-selected into an online support group.

None of the research questions specifically mentioned the word *stigma*, which was an intentional choice on my part as I didn't want to influence the participants' opinions about whether there is a stigma attached to a diagnosis of epilepsy. However, this led to less discussion or responses about stigma as might have occurred if participants been explicitly asked about it. Some did mention issues related to stigma when asked about reasons to not disclose, but since all of the parents had already disclosed the condition to most people, some of them didn't provide much detail during this portion of the interviews. Stigma should be more explicitly queried in future research in order to obtain more detail about parental concerns around the subject.

Quality of life is frequently discussed in the literature on epilepsy and families, particularly in studies focusing on individuals' epilepsy and/or their parents. Future research on epilepsy, social support, and disclosure should include the concept of quality of life. In addition, this concept should be broadened to consider the impact on the entire family, not just the individual or parents.

Finally, uncertainty appears to play a large role in decisions about whether to disclose, as shown within the sub-theme of parental peace of mind, which falls under the main theme of "everyone needs to know." One major reason that parents felt everyone needed to know was for their own peace of mind; that is, they needed to feel certain that their child would be taken care of in the event of a seizure. For parents of CWE, when and if another seizure will occur is a constant uncertainty, one that most likely plays a role in decisions to disclose. Future research might carefully consider the role this plays in the decision to disclose, and include theories such as Uncertainty Management Theory (author, year) within the study rationale and design.

Conclusions

The findings of this study appear to indicate that child safety may trump other factors that go into the decision to disclose a child's epilepsy diagnosis to others. On the one hand, the Moms in this study resoundingly felt everyone needed to know about the diagnosis, primarily for the safety of the child. Therefore, they disclosed the condition to family, friends, coworkers, school personnel, coaches, and others on a regular basis. The only time the Moms in this study did not disclose (or considered not disclosing) were those times they didn’t seem to feel the child’s safety was at risk. When the safety factor was removed, the Moms appeared to consider other factors related to disclosure such as stigma, as shown in the sub-theme of “I don’t want their judgment” when considering times they would conceal.

Social support continues to be an important aspect in the lives of individuals coping with a chronic condition as well as the lives of their parents. This was highlighted by the clear descriptions of how important informational, tangible, and emotional support were to the Moms in this study as they coped with their child’s diagnosis. This study also highlights the need to avoid negative social support displays such as pity or unwanted advice when responding to a disclosure of a chronic condition such as epilepsy.

Finally, based on the responses within this study, lowered quality of life and uncertainty are a constant in the lives of parents of CWE,. Greater support systems need to be in place to help families navigate the challenges they face when a child is diagnosed with epilepsy. For example, hospitals and clinics would do well to employ therapists to work with parents of CWE to help them cope with the fear and grief associated with watching one’s child have a seizure.

References

Albrecht, T. L. & Adelman, M. B. (1987). *Communicating social support*. Sage.

Benson, A., O'Toole, S., Lambert, V., Gallagher, P., Shahwan, A., & Austin, J. K. (2015). To tell or not to tell: A systematic review of the disclosure practices of children living with epilepsy and their parents. *Epilepsy & Behavior*, *51*, 73–95. http://doi.org/10.1016/j.yebeh.2015.07.013

Braithwaite, D. O., Waldron, V. R., & Finn, J. (1999). Communication of social support in computer-mediated groups for people with disabilities. *Health Communication, 11*, 123– 151

Brashers, D. E., Neidig, J. L., & Goldsmith, D. J. (2004). Social support and the management of uncertainty for people living with HIV or AIDS. *Health Communication, 16*(3), 305-331. http://dx.doi.org/10.1207/S15327027HC1603_3

Burleson, B. R. (1994). Comforting messages: Significance, approaches, and effects. In B. R. Burleson, T. L. Albrecht & I. G. Sarason (Eds.), *Communication of social support: Messages, interactions, relationships, and community* (pp. 3–28). Sage.

Burleson, B. R. (2003). Emotional support skill. In J. O. Greene & B. R. Burleson (Eds.), *Handbook of communication and social interaction skills* (pp. 551–594). Lawrence Erlbaum.

Burleson, B. R., Albrecht, T. L., Goldsmith, D. J., & Sarason, I. G. (1994). Introduction: The communication of social support. In B. R. Burleson, T. L. Albrecht & I. G. Sarason (Eds.), *Communication of social support* (pp. xi-xxx). Sage.

Burleson, B. R., & Goldsmith, D. J. (1998). How the comforting process works: Alleviating emotional distress through conversationally induced reappraisals. In P. A. Andersen & L. K. Guerrero (Eds.), *Handbook of communication and emotion: Research, theory, applications and contexts* (pp. 245–280). Academic Press.

Burleson, B. R., & MacGeorge, E. L. (2002). Supportive communication. In M. L. Knapp & J. A. Daly (Eds.), *Handbook of interpersonal communication* (3rd ed., pp. 374–424). Sage.

Bute, J. J., Petronio, S., & Torke, A. M. (2015). Surrogate decision makers and proxy ownership: Challenges of privacy management in health care decision making. *Health Communication*, *30*, 799–809. http://doi.org/10.1080/10410236.2014.900528

Brule, N. J., & Eckstein, J. J. (2016). “Am I really a bad parent?”: Adolescent-to-parent abuse (AtPA) identity and the stigma management communication (SMC) model. *Journal of Family Communication*, *16*(3), 198–215. http://doi.org/10.1080/15267431.2016.1160908

Canary, H.E. (2008). Creating supportive connections: A decade of research on support for families of children with disabilities. *Health Communication, 23*, 413-426. DOI: 10.1080/10410230802342085

Centers for Disease Control and Prevention. (2015). *At a glance 2015 targeting epilepsy: Improving the lives of people with one of the nation’s most common neurological conditions*. Retrieved from http://www.cdc.gov

Centers for Disease Control and Prevention. (2017). http://www.cdc.gov

Chaudoir, S. R., & Quinn, D. M. (2010). Revealing concealable stigmatized identities: The impact of disclosure motivations and positive first-disclosure experiences on fear of disclosure and well-being. *Journal of Social Issues*, *66*(3), 570–584. http://doi.org/10.1111/j.1540-4560.2010.01663.x

Eaton, K., Ohan, J. L., Stritzke, W. G. K., Courtauld, H. M., & Corrigan, P. W. (2017). Mothers' decisions to disclose or conceal their child's mental health disorder. *Qualitative Health Research*, *27*(11), 1628–1639. https://doi.org/10.1177/1049732317697096

Elliott, J., & Shneker, B. (2008). Patient, caregiver, and health care practitioner knowledge of, beliefs about, and attitudes toward epilepsy. *Epilepsy & Behavior*.

England, M. J., Liverman, C., Schultz, A., & Strawbridge, L. (2012). Epilepsy across the spectrum: Promoting health and understanding. A summary of the Institute of Medicine report. *Epilepsy & Behavior*.

Epilepsy foundation. Epilepsy Foundation. (2022, May 22). Retrieved May 14, 2022, from https://www.epilepsy.com/

Fernandes, P. T., Snape, D. A., Beran, R. G., & Jacoby, A. (2011). Epilepsy stigma: what do we know and where next? *Epilepsy & Behavior : E&B*, *22*(1), 55–62. http://doi.org/10.1016/j.yebeh.2011.02.014

Hays, A. & Butauski, M. (2018) Privacy, disability, and family: Exploring the privacy management behaviors of parents with a child with Autism. *Western Journal of Communication*, *82*(3), 376-391. doi: 10.1080/10570314.2017.1398834

Hoare, P., Mann, H., & Dunn, S. (2000). Parental perception of the quality of life among children with epilepsy or diabetes with a new assessment questionnaire. *Quality of Life Research : An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, *9*(6), 637–644.

Kampra, M., Tzerakis, N., Thomsen, L.L.H., Katsarou, E., Voudris, K., Mastroyianni,S.D., Mouskou, S., Drossou, K.S., Siatouni, A., & Gatzonis, S. (2017). The challenges that parents of children with epilepsy face. *Epilepsy & Behavior*, *71,* 94-103.

Kilinc, S. & Campbell, C. (2009). “It shouldn’t be something that’s evil, it should be talked about”: A phenomenological approach to epilepsy and stigma. *Seizure*, *18,* 665-671.

Kobau, R., & Price, P. (2003). Knowledge of epilepsy and familiarity with This disorder in the U.S. population: Results from the 2002 HealthStyles survey. *Epilepsia (Series 4)*, *44*(11), 1449.

Kreps, G.L. (1988). Relational communication in health care. *Southern Speech Communication Journal, 53,* 344-359.

Kreps, G.L., Barnes, M.D., Seiger, B.L., & Thackeray, R. (2009). Health communication. In R.J. Bensley & J. Brookins-Fisher (Eds.), Community health education methods: A practical guide, 3rd edition. (pp. 73-102). Jones and Bartlett

Lambert, V., Gallagher, P., O’Toole, S., Benson, A. (2014). Stigmatising feelings and disclosure apprehension among children with epilepsy. *Nursing Children and Young People, 26*(6*)*, 22-27.

Lv, R., Wu, L., Jin, L., Lu, Q., Wang, M., Qu, Y., & Liu, H. (2009). Depression, anxiety and quality of life in parents of children with epilepsy. *Acta Neurologica Scandinavica*, *120*(5), 335–41. http://doi.org/10.1111/j.1600-0404.2009.01184.x

Meisenbach, R.J. (2010). Stigma management communication: A theory and agenda for applied research on how individuals manage moments of stigmatized identity. *Journal of Applied Communication Research*, *38*(3), 268-292. http://dx.doi.org/10.1080/00909882.2010.490841

Morgan, D.L. (2008). Paradigms lost and pragmatism regained. In V.L. Plano Clark & J.W. Creswell (Eds.), The mixed methods reader. (pp. 29-65). Thousand Oaks, CA: Sage Publications, Inc.

Morse, J.M. (2008). Approaches to qualitative-quantitative methodological triangulation. In V.L. Plano Clark & J.W. Creswell (Eds.), The mixed methods reader. (pp. 151-158). Thousand Oaks, CA: Sage Publications, Inc.

Mu, P. (2008). Transition experiences of parents caring for children with epilepsy: A phenomenological study. *International Journal of Nursing Studies*, *45*, 543-551.

Muskat, B., Greenblatt, A., Nicholas, D.B., Ratnapalan, S., Cohen-Silver, J., Newton, A.S., Craig, W.R., Kilmer, C., and Zwaigenbaum, L. (2016). Parent and health care provider perspectives related to disclosure of autism spectrum disorder in the pediatric emergency departments. *Autism, 20*(8*)*, 986-994.

Owen, W. F. (1984). Interpretive themes in relational communication. Quarterly Journal of Speech, 70, 274–287. doi:10.1080/00335638409383697

Paschal, A.M., Kore, L., Hawley, S. R., Sly, J., & Molgaard, C.A. (2006). Overcoming stigma through education and awareness: Using a community participatory approach with epilepsy patients. *Epilepsia (Series 4), 47*, 128-129.

Petronio, S. (2013). Brief status report on communication privacy management theory. *Journal of Family Communication*, *13*, 6-14. http://doi.org/10.1080/15267431.2013.743426

Petronio, S. (2004). Road to developing communication privacy management theory: Narrative in progress, please stand by. *The Journal of Family Communication*, *4*(3&4), 193-207.

Petronio, S. (2007). Translational Research Endeavors and the Practices of Communication Privacy Management. *Journal of Applied Communication Research*, *35*(3), 218–222. http://doi.org/10.1080/00909880701422443

Petronio, S. (2010). Communication privacy management theory: What do we know about family privacy regulation? *Journal of Family Theory and Review*, *2*, 175–196.

Petronio, S., Sargent, J., Andrea, L., Reganis, P., & Cichocki (2004). Family and friends as healthcare advocates: Dilemmas of confidentiality and privacy. *Journal of Social and Personal Relationships, 21*(1), 33-52. http://doi.org/10.1177/0265407504039838

Petronio, S. & Durham, W.T. (2015). Communication privacy management theory: Significance for interpersonal communication. In Braithwaite, D.O & Schrodt, P. (Eds.), *Engaging Theories in Interpersonal Communication: Multiple Perspectives, 2nd edition*. (pp. 335-348). SAGE.

Public Education in Epilepsy. (2003). *Epilepsia (Series 4)*, *44*, 64-65. doi:10.1046/j.1528-1157.44.s6.27.x

Quinn, D. M., & Chaudoir, S. R. (2009). Living with a concealable stigmatized identity: The impact of anticipated stigma, centrality, salience, and cultural stigma on psychological distress and health. *Journal of Personality and Social Psychology*, *97*(4), 634–651. http://doi.org/10.1037/a0015815

Rafferty, K.A., Hutton, K., & Heller, S. (2019). “I will communicate with you, but let me be in control”: Understanding how parents manage private information about their chronically ill children. *Health Communication*, *34*(1), 100-109, doi: 10.1080/10410236.2017.1384432

Roy, R. (2011). *Social support, health, and illness : A complicated relationship*. Toronto [Ont.]: University of Toronto Press, Scholarly Publishing Division.

Smith, S.A. & Brunner, S.R.. (2015). The great whoosh: Connecting an online personal health narrative and communication privacy management. *Health Communication*, *31*, 12-21. http://dx.doi.org/10.1080/10410236.2014.930551

Taylor, J., Jacoby, A., Baker, G. A., & Marson, A. G. (2011). Self-reported and parent-reported quality of life of children and adolescents with new-onset epilepsy. *Epilepsia*, *52*(8), 1489–1498. http://doi.org/10.1111/j.1528-1167.2011.03094.x

Theodore, W. H., Spencer, S. S., Wiebe, S., Langfitt, J. T., Ali, A., Shafer, P. O., & Vickrey, B. G. (2006). Epilepsy in North America: A report prepared under the auspices of the Global Campaign against Epilepsy, the International Bureau for Epilepsy, the International League Against Epilepsy, and the World Health Organization. *Epilepsia (Series 4)*, *47*(10), 1700-1722.

Whatley, a D., DiIorio, C. K., & Yeager, K. (2010). Examining the relationships of depressive symptoms, stigma, social support and regimen-specific support on quality of life in adult patients with epilepsy. *Health Education Research*, *25*(4), 575–84. http://doi.org/10.1093/her/cyq001

Wright, K. B., Rosenberg, J., Egbert, N., Ploeger, N. a., Bernard, D. R., & King, S. (2012). Communication competence, social support, and depression among college students: A model of facebook and face-to-face support network influence. *Journal of Health Communication*, *730*(July 2015), 1–17. http://doi.org/10.1080/10810730.2012.688250